

# LIVING WELL WITH HEART FAILURE

 **PumpingMarvellous**  
The heart failure charity



# FOREWORD AND INTRODUCTION



Part of our mission at Pumping Marvellous Foundation is to raise the profile of Heart Failure, which we have always felt, doesn't get the coverage it should. As a result, it has a lower profile than other conditions with similar or lesser levels of incidence,

both amongst the public and policy makers. Working with our colleagues from the University of Lancaster has confirmed that to be the case, and it leads to an obvious next question; what are we going to do about it?

This report is part of the answer to that question. It is a step along the path to raising the profile of Heart Failure. We want to use data and academic studies; we want to tell real stories from our amazing and committed Pumping Marvellous Heart Failure patient and family community; and we want to continue to work with our world leading team of clinical advisers, to improve people's lives.

This report lays bare the difficulty we have talking about Heart Failure, both in terms of how seldom it is spoken about, and the context it is used in. As you will see, it has negative associations, different from those of other conditions and this must have an impact on the way it is viewed. We want to begin to alter that perception by highlighting the problems, and also pointing out the success stories. We are under no illusion that a diagnosis of Heart Failure is a major shock to people, but we want to make clear that it is treatable, manageable, and that people can – and are – living well with their diagnosis of Heart Failure.

This report won't alter those perceptions by itself, and it won't be achieved quickly, but we are determined that it will happen. By raising the profile of the condition, we hope to be able to drive continuing improvements in the diagnosis, treatment and care of people with Heart Failure. We want to give as many people as possible the best chance to live well with Heart Failure.

**Nick Hartshorne-Evans, CEO,  
Pumping Marvellous**

**HEART FAILURE IS NOW THE ONLY CARDIOVASCULAR DISEASE INCREASING IN PREVALENCE<sup>1</sup>**

**IN THE UNITED KINGDOM, HEART FAILURE AFFECTS ABOUT 920,000<sup>2</sup> PEOPLE WITH 200,000 NEW CASES ANNUALLY<sup>3</sup>**

1. End of life care in heart failure A framework for implementation (2014, updated 2016) - NHS Improving Quality found at <https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/heart-failure.pdf>

2. Conrad, N; Judge, A, Tran, J et al. Temporal trends and patterns in heart failure incidence: a population-based study of 4 million individuals, The Lancet, 2018; 391, 10120

3. British Heart Foundation, Heart failure: A blueprint for change, Available online <https://www.bHeartFailure.org.uk/what-we-do/policy-and-public-affairs/transforming-healthcare/heart-failure-report>

# METHODOLOGY

To produce this report Pumping Marvellous have drawn on multiple sources of information. Firstly, we held a clinical advisory board which included Heart Failure patients, Cardiologists, Heart Failure Specialist Nurses and General Practitioners with interest and specialism in the field. The aim of this advisory board was to discuss Heart Failure's impact on patients, how all parties had been affected by the coronavirus pandemic, and what is needed to improve the quality of life of patients.

We have drawn on the work completed by Professor Elena Semino and Dr Jane Demmen who looked at the language used to discuss and describe heart failure, and its prevalence in the media, fiction and UK parliament.

We surveyed our community of patients and family members, asking questions about the effects of living with Heart Failure and how it had changed their lives. This survey received a total of 508 responses. Lastly, we conducted in depth interviews with five patients, and these conversations form the basis of the patient testimonials used in this report.



# HOW WE (DON'T) TALK ABOUT HEART FAILURE

Heart Failure isn't spoken about as much as cancer and on the occasion it is, it's often in a negative context. 'Heart Failure' is most associated with the word 'died', but rarely with any elaboration, explanation or context. This contributes to a simplistic and stark association between 'heart failure' and death.

**72% OF PATIENTS THINK THERE IS A NEGATIVE ASSOCIATION WITH HEART FAILURE AS A CONDITION**

This is among the findings of research carried out on behalf of Pumping Marvellous Foundation by Professor Elena Semino and Dr Jane Demmen from the University of Lancaster. They analysed a dataset compiled by the Oxford University Press of more than 2 billion words from web-based materials, as well as the Hansard record of proceedings in the UK parliament from 1945 to the current day.<sup>4</sup>

This context is very different to the discourse around cancer for example, which is far more likely to centre people's experiences of the illness, or around dementia which emphasises the suffering of both patients and carers.<sup>4</sup> The fact that both cancer and dementia are discussed in more people-focused ways than Heart Failure could contribute to wider awareness and understanding of these conditions. The conversation around cancer also highlights 'fight' against it and celebrating those individuals who 'beat' it, unlike Heart Failure. As the authors note in the report:

"'Heart Failure' was also more typically mentioned in the context of death, whereas cancer was more typically mentioned in the context of incidence, diagnosis, cure or awareness - in many ways an opposite framing."<sup>4</sup>

**"I GOOGLED IT AND IT TOLD ME I HAD FIVE YEARS TO LIVE. I THOUGHT WHAT WAS THE POINT OF SAVING ME IF THAT'S ALL THE TIME I HAD LEFT ANYWAY."**



4. Demmen, J., Hartshorne-Evans, N., Semino, E. and Sankaranarayanan, R., 2022. Language Matters -Representations of 'heart failure' in English discourse: a large-scale linguistic study.

# UK PARLIAMMENTARY LANGUAGE

It is noticeable that in the UK parliament, there has been far less discussion of 'Heart Failure' than either cancer or dementia. 'Heart Failure' has only been referenced around five debates that took place in 1995, 2005, 2007, 2020 and 2021.<sup>ibid</sup>

More encouragingly, the recurring themes of many of the debates saw parliamentarians focusing on personal and/or constituent experience, including the benefits of specialist care in a local setting. The most recent 2021 debate also included more mentions of 'Heart Failure' than in any of the previous debates analysed, with 'quality of life' also featuring. Some of the challenges faced by people living with Heart Failure, such as lack of resources and treatment strategies, were also raised in parliament.<sup>ibid</sup>

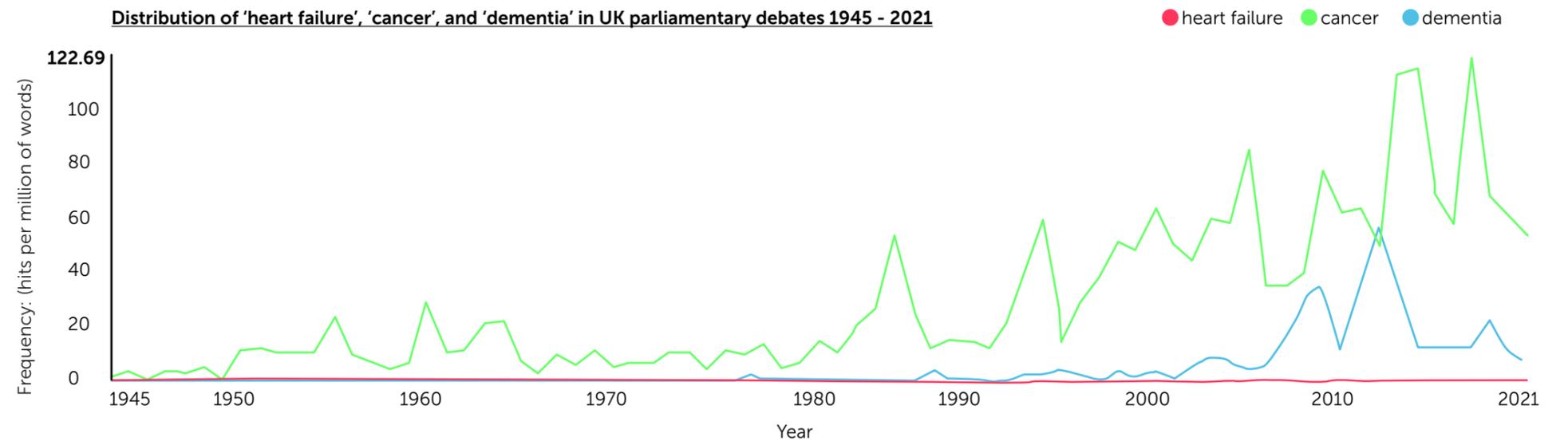
This shows there is much more work to be done to raise the profile of Heart Failure in both the eyes of the public and policymakers.

As a result, we have produced this report, which aims to look at the effect Heart Failure has on patients, and the impacts of COVID-19, but also to provide stories and examples of how the right support and specialist treatment can truly change people's lives.

Simply put, Heart Failure remains a condition which has a disproportionately low profile given its incidence; and as this analysis illustrates, much of that profile serves only to reinforce the negative – and incorrect – perceptions that Heart Failure is associated solely with death, rather than the active, brave and brilliant people who live, and live well, with the condition every day.



Distribution of 'heart failure', 'cancer', and 'dementia' in UK parliamentary debates 1945 - 2021



# FIRST REACTIONS TO RECEIVING A HEART FAILURE DIAGNOSIS

"It wasn't until my second admission to hospital, that somebody started to mention the term 'failure.' Mentally, it was a word that I thought they had got wrong. I think that's the first reaction of a patient. You think, well I know my body and I'm sure I'd know if my heart wasn't working properly because I'd be dead." Dave



"I had an echocardiogram and I remember all of these cardiologists suddenly appeared around my bed and told me I had Heart Failure. I didn't know what to think really. The first question I asked was, am I going to die? They wouldn't really answer that." Clare

## **"I'd never heard of Heart Failure.**

Growing up in and out of hospital with my pacemaker, I'd still never heard the words Heart Failure. It just came out of the blue. I was a rabbit in headlights. You automatically hear the words Heart Failure and think you're going to die. The doctor did say, 'I'm really sorry for doubting you, you did think there was something wrong. We're going to put you on some medication and come back in six months.' I remember leaving the doctor and bursting into tears in the waiting room. I told my mum and dad that I'm going to die." Donna

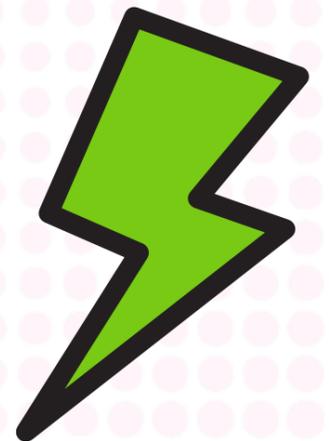
# FROM FEAR TO POSITIVE THINKING

**"My first reaction was: I need to live;** I've got a 14-year-old daughter, she was ten at the time. I'd been married a year and I was frightened that I was going to die. Then I Googled everything I could find out. So, I'm lying-in hospital, reading all these American websites telling me I'm going to be dead in five years. I was quite frightened, but my cardiologist was brilliant. I asked her lots of questions and she answered. The one that people wouldn't answer was, 'how long am I going to live?' Then I started to try and turn it around. I know I'm going to live, but what have I got to do to make myself live a really good, happy and long life?" Clare



"I had a down spell after my diagnosis. But once I understood more, I became more positive. I quit drinking, and I won't go back to alcohol. I keep a diary, so I remember what I eat and drink, and I have a much healthier diet. I didn't go back to work, as I couldn't physically do a manual job, but I exercise daily. Life isn't really much different than before, and I have a nice life." Jay

"I thought 'right, well I'm not going to give up'. Having a strong partner helped me digest Heart Failure and come to terms with the fact life will be different - but it could be a good different. That's the important element. It has to be a good different." Dave

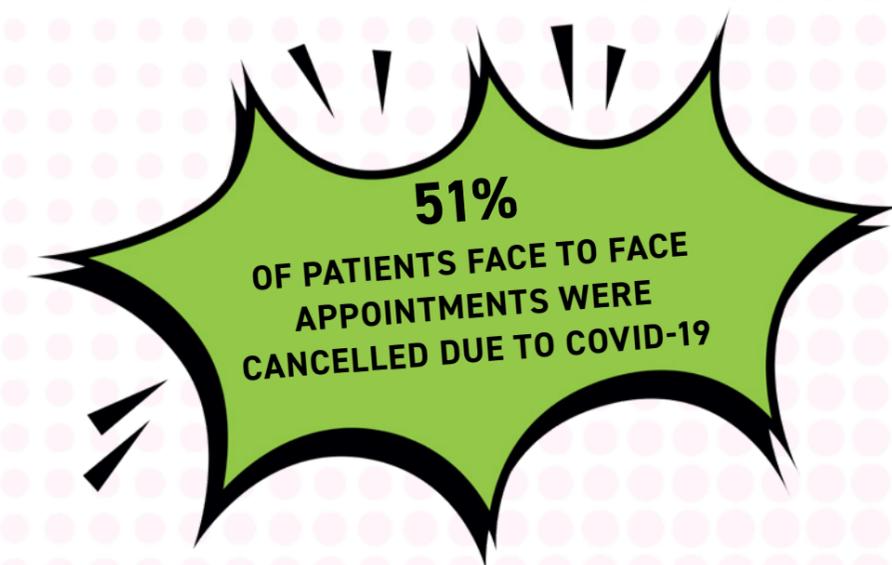


# IMPACT OF COVID-19 ON PATIENTS

The effect of the pandemic on patients has differed based on how far along in their diagnosis they are. For those who had been diagnosed long before the pandemic, they were able to manage their symptoms remotely with the support of their specialist Heart Failure teams. Patients found that though their face-to-face appointments were cancelled, they were still receiving the support they needed either through video, telephone, or text consultations. This was in part because many were already aware of how to manage and track changes to their symptoms, and because they had good relationships with their clinical teams.

Patients diagnosed during the pandemic found it more difficult. During the first wave of the pandemic, there were large numbers of patients with concerns ranging from fear around their condition and what it meant for their future, fear of seeing their clinical team while shielding, and a lack of knowledge about symptom management. There was an understanding that they were not receiving the level of care and treatment they would have pre-pandemic – a gap which the Pumping Marvellous Foundation patient support community helped to fill.

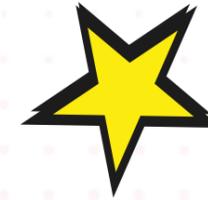
Though many patients' clinical treatment and care has almost gone back to normal, many feel as if their behaviour has changed for the long-term. While they were not classed as clinically extremely vulnerable by the government during the pandemic, many had been shielding and continue to avoid large crowds such as sports gatherings or public transport due to ongoing fear of catching coronavirus and are likely to do so for the foreseeable future.





## CLARE'S STORY

"I was diagnosed in July 2018. By the time COVID happened, I had been diagnosed for nearly two years. I was a member of Pumping Marvellous by then too, so I knew I could access lots of things online. I have 'a phone number' for my Heart Failure team. It doesn't matter if it's the most trivial thing in the world: I ring, leave a message and they will get back to me. I did access that a lot during the lockdown. I was shielding in the lockdown, which was quite hard, but I knew I had to do it. I knew my health was in quite a good place. I was able to call the Heart Failure team and say, 'if I promise to be really sensible will you let me go back to work?' They checked with the cardiologist and let me go back. That's my experience, I don't think that's happened for everybody." Clare



**The support from Pumping Marvellous over the pandemic was amazing.**

I felt very low for a few months, but the network, and the peer support and positive examples from within the community made me realise that there were people living positive lives." Jay



"I didn't know anything about Heart Failure. It's something my nan had so I had heard of it, but I had no idea what it meant, or what the symptoms were."

**41%**

**OF PATIENTS REGULAR CHECK-UPS AND BLOOD TESTS WERE DISRUPTED DUE TO COVID-19**

**60%**

**OF PATIENTS SAID THEY HAD BEEN ABLE TO SUCCESSFULLY MONITOR THEIR CONDITION DURING THE PANDEMIC WITH THE SUPPORT OF SPECIALIST HEART FAILURE TEAMS**

# IMPACT OF COVID-19 ON CLINICAL TEAMS

Clinicians made the transition to digital and telephone communications rapidly during the pandemic, but the success has been dependent on the individual patient situations. Some clinical teams have also used methods such as texting to stay in touch with patients. It is likely a hybrid approach to managing and keeping in touch with patients will become the norm, a situation that many within clinical teams are comfortable with, depending on the category a patient falls into.

In secondary care settings, many nurses and cardiologists were redeployed during the pandemic. As a result, it had been difficult to keep clinical teams intact to ensure Heart Failure patients were taken care of appropriately.

There is concern amongst clinical teams that many people have not been identified as suspected Heart Failure patients and are therefore not receiving treatment and support. However, where patients have been diagnosed, teams have set up rapid access Heart Failure clinics, redeployment of nurses has not occurred, and there has been open access between general practice and cardiology teams. For example, in Glasgow, a Heart Failure diagnostic hub was set up in one of the unused Nightingale hospitals, which managed to see over 900 people, contributing to a streamlined Heart Failure diagnosis pathway. In Northern Ireland, a rapid access Heart Failure clinic was set-up so they could keep diagnosing people appropriately. They set up replacement blood services and remote monitoring of blood pressure, heart rate, and other vitals.

"I did go to A&E once in COVID when I had chest pains that I could explain. I can't fault the NHS to be honest. I think they're a fabulous service that is so undervalued in terms of what they get in resources as well." - Dave



**54%**

**OF PATIENTS FOUND AN INCREASED  
USE OF DIGITAL OR TELEPHONE  
APPOINTMENTS DUE TO COVID-19**

# HEART FAILURE SUCCESS

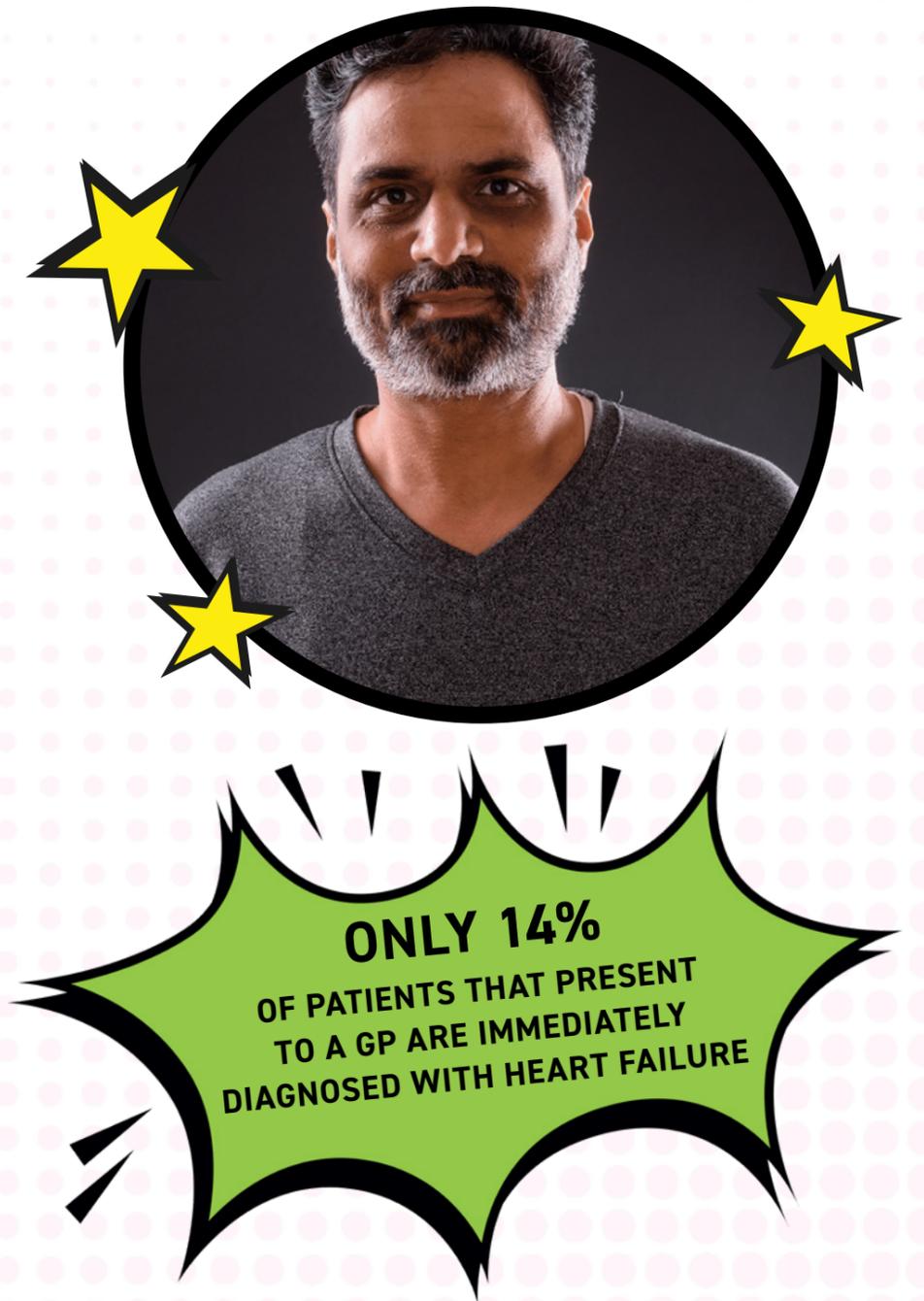
## EMERGENCY DIAGNOSIS TO TURNING MY LIFE AROUND

"I was diagnosed after a large heart event in August 2020. I went to work after two weeks off on holiday. Half an hour after I got in, I had a cardiac arrest. I was worked on by my colleagues who managed to get me going again. Paramedics were called, but I was down for about 26 minutes. I was blue lighted to hospital, where I was put in an induced coma for eight days. My family were told to expect the worst. Luckily, I managed to make it out of the coma, and stayed in hospital for three weeks.

When they told me what happened, the first thing I said was 'don't be daft'.

My mum told me on the way home, I just was shocked. I just thought old people got Heart Failure. The first thing I did was the worst thing anyone can do and that was Google 'how long do you live with Heart Failure?'. Which turns out to be about five years. I had a mini meltdown and thought, 'what's the point being saved if I'm just going to die within five years.' I got quite down about it.

Luckily, I had a really good Heart Failure nurse and she said you should check out Pumping Marvellous as younger people also use it. Although I'm about 49 years old I still feel like I'm about 20, so I looked up the Facebook group and joined nearly a year after my diagnosis. I thought I could cope with it on my own, but I needed more information and support. I joined the Facebook group and that turned out to be an absolute lifeline to me and my partner. We've learned a lot, gained massive support, and made a lot of friends in the group." Jay





# HEART FAILURE SUCCESS

## I CAN RUN A MARATHON!

"I've made a lot of changes to my lifestyle. I used to drink heavily, I was a smoker, and I never did any exercise. Literally no exercise at all as I had a sedentary job in IT and have worked from home in front of the computer for years. I would work and then go to the pub. That definitely had an impact on me getting Heart Failure, there's no point pretending otherwise.

When you're in hospital lying in bed, you start re-evaluating your life and how you're living it. I did that and made the very conscious decision things needed to change quite seriously. The smoking and drinking went. The one other thing I needed to do was exercise, which I had never done, and I'd never enjoyed it even as a child.

I was watching the park run on TV and I thought, 'how about trying to work myself up to do a 5k park run?' I mentioned it to my wife, and she looked at me like I was mad. I did my first one as a fundraiser for Pumping Marvellous. I thought that would be it and I might do a few more – but it wouldn't amount to anything else.

However, I was told by another patient's family member that I needed to do a 10k run. I thought, 'I don't know about that' but, sure enough, I started training for it and did a fundraiser for the 10k. I've done various 10k runs since then.

Then it went even further – I was asked 'how about a half marathon?' Nick, the CEO of Pumping Marvellous Foundation, asked what I thought about doing the Great North run! I said go on then. Then I got asked, 'do you cycle Rich?'. So, Ride London came into it, and I bought a bike.

Eventually I was sat at a barbeque with friends and Nick rang me up and said, 'have you ever thought about doing the London Marathon?'. Hang on a minute, a marathon?! That's a really long way. Nick signed my brother and I up for it and we completed it in October 2021. It was amazing, such an experience. Just thinking that I would ever run a marathon was so far beyond me, just unbelievable.

My friend was training for a triathlon, and I thought how about trying that because I already run and cycle? Now I need to learn to swim, so I literally had my first swimming lesson the other week. I have a long way to go but I'll get there, and it just doesn't worry me anymore. I suppose after the triathlon I'll ask, 'what next?'" Rich

# IMPORTANCE OF EDUCATION, DIAGNOSIS AND SPECIALIST CARE

Heart Failure patients would like there to be increased awareness around the condition, so both the public and non-specialist clinical teams, for example in general practice, can recognise symptoms more quickly. Across NHS GP surgeries, a simple blood test – NT-proBNP exists that can help identify potential clinical signs of Heart Failure. To improve diagnosis, people should be correctly identified for referral wherever they are presenting, for example in diabetic clinics, pharmacies or in primary care. However, this would require education aimed at all healthcare professionals.

**23%**

**OF PATIENTS ARE DIAGNOSED WITH HEART FAILURE AS A RESULT OF AN EMERGENCY HOSPITAL ADMISSION**

Clinicians have noted that exhibiting Heart Failure signs and symptoms in generalist care over the long-term is detrimental for patients. Receiving a Heart Failure diagnosis sooner means patients are able to access specialist care – and the correct treatment - from the right teams, at the right times which gives people a far greater chance to successfully manage their condition, and live well with Heart Failure.

A whole pathway approach is required, meaning that people with Heart Failure can be identified and referred to specialist treatment at any stage of their patient journey. It also requires systems to be in place for treatment and care delivery to help people manage their condition. Patients need to be empowered to do this, and it requires a strong relationship and sharing of knowledge between the clinical team and patient. This is vital as patients are not with clinicians most of the time, and so need to be able to recognise when they are well, when they need additional support, and when they are experiencing an emergency. This open communication should work both ways, where patients and clinicians can ask questions, learn from each other, and provide individualised care. This pushes past the commonly used phrase of “shared decision making” - it is more than that.

**87% OF PATIENTS DID NOT KNOW THE SYMPTOMS OF HEART FAILURE BEFORE DIAGNOSIS, AND 63% OF PATIENTS DO NOT KNOW WHAT THE B.E.A.T METHOD IS TO RECOGNISE THE SYMPTOMS OF HEART FAILURE.**

# B.E.A.T

**BREATHLESS**

**EXHAUSTED**

**ANKLE SWELLING**

**TIME FOR A SIMPLE BLOOD TEST**



# HEART FAILURE SUCCESS

## I CAN COOK AND GARDEN!

"Last year, I decided to start growing some fruit and veg. I asked for some advice on the Pumping Marvellous Community page, we've got a few gardeners on there. I planted carrots and ended up with over 200!

I mean they were baby carrots, they were tiny, but they grew. I grew some runner beans, lettuce, and different herbs. I never ever thought I could do that.

Every year with Pumping Marvellous, we have a sunflower growing challenge which is brilliant. It's a competition and everybody gets involved and it's fun. It's brilliant and you get a really good laugh seeing everybody taking part, it just makes you smile. I think it makes people forget they have Heart Failure.

Before, I could never cook. I was always known as 'can't cook won't cook'. But again, down to Pumping Marvellous, I learned a lot of cooking. We have a food page called Hearty Meal Share where we can share different recipes. It's really good, and it really got me cooking, although it does take me a while, as I have to take my time. I learned how to make homemade pizza, so much so, I was gifted a pizza stone which is absolutely fantastic!

I feel quite proud of myself because I wouldn't have pushed myself to do these things before. I found as a family, we became closer, and it got us into the kitchen, helping each other cook and my nephew helps me grow my fruit and veg. So, I do associate a lot of positivity with Heart Failure." Donna





# HEART FAILURE SUCCESS

## I CAN INSPIRE OTHERS TO GET UP AND TRY!

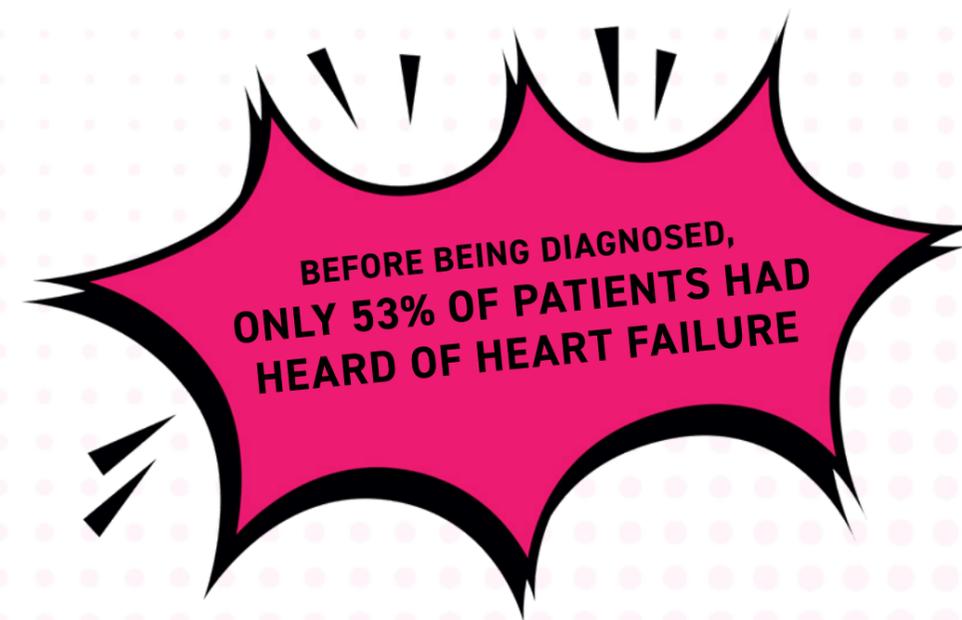
"I was referred by my GP to a gym for a period after my diagnosis, as part of cardiac rehabilitation, and then I carried on my gym membership. As we all know, we've had the pandemic, so gyms closed. It was a case of what do I do now?"



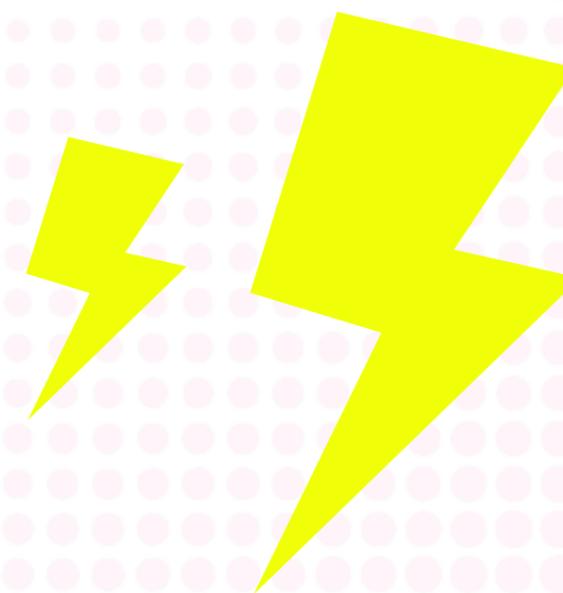
I would get my trainers on and go for a run occasionally. I took my distance from 1km right the way through to 10km. I'm not a small guy - I'm about 20 stone so for me to be able to do that was incredible.

I think it's massively important to understand that in the past 20 years I've been learning to help people. I like people to be inspired by something I say or do. During the pandemic I thought I could turn this into a positive and talk to the Pumping Marvellous community and say, 'hey guys, I've been out and had a run today. It was hard. I achieved a slightly better time'. It started off as just words on a post, and it was hard to put real emotion into it. Eventually, I just filmed my end of run cool down and shared that with the group and the response has just been incredible from people saying, 'you're inspiring me to simply do something'. I don't do it for the number of likes and comments and reactions. I do it because I just want to inspire people. And the comments that I get are incredible and I think 'wow, that has touched somebody.'

You can live and manage your Heart Failure. I don't claim to be a fitness expert. I don't claim to be the best at managing Heart Failure, but I have a bloody good go and I do try to help others to get up, put a pair of shoes on, and go for a walk - because it's so worth it." Dave



**BEFORE BEING DIAGNOSED,  
ONLY 53% OF PATIENTS HAD  
HEARD OF HEART FAILURE**



# RECOMMENDATIONS

There is a lot of work to be done in Heart Failure, that much is clear. However, there is a great deal of positive work going on among the clinical teams, who are incredibly dedicated and committed to their specialism. And of course, from patients, who through the Pumping Marvellous community, can support and inspire one another to face their diagnosis with fighting spirit and a positive mindset that is not reflected in the negative language so often associated with the condition.

**"Life is important to us all isn't it.**

We don't want it to be shortened, we want to fight back. All life events shape the person you are. And Heart Failure has to shape the person you become but it doesn't mean you can't still have a great life".



# RECOMMENDATIONS

Our recommendations for improving the care of people living with heart failure, and giving them a better quality of life are:



## • Increase awareness of symptoms of Heart Failure using B.E.A.T.

Increasing awareness of symptoms will help people recognise the need to go to their health services as soon as possible, helping them to be diagnosed and treated more quickly. People already living with Heart Failure would also benefit from B.E.A.T to better manage their Heart Failure.

Additionally, increasing awareness amongst all healthcare professionals across different settings will support recognition and diagnosis. This is especially important in primary care where there is universal access to a simple blood test called the NT-proBNP test to help diagnose Heart Failure.

B.E.A.T however has pushed past the acronym, it is now a talisman of BEATing Heart Failure.

## • Ensure patients receive specialist care as soon as possible after diagnosis

Once patients have been diagnosed with Heart Failure, they should be referred to a specialist multi-disciplinary team as soon as possible. This gives people a better chance to improve their quality of life, ensuring they live well with Heart Failure.

## • Improving communication between patients and their clinical team

People should already be part of the decision-making around their care and treatment, but there needs to be an active culture of discussion, education and learning from each other to provide the best, individualised care for each patient. The NICE Chronic Heart Failure Guidelines for Adults 2018, indicate that patients should have access to an understandable care plan, which can be used as a discussion and knowledge tool for the clinical team as well as by patients and their loved ones.

## • Let people know that you can live well with Heart Failure

There is a lot of fear when people are diagnosed with Heart Failure, but it does not have to be an automatic death sentence. Many patients live long and well with Heart Failure, and this needs to be widely recognised to give patients hope, and show they are part of a wider community. Peer to peer support groups are incredibly valuable to people living with Heart Failure, where sharing self-care knowledge and techniques can build a person's understanding - and with it, their confidence of Heart Failure.

*LET'S*

**B.E.A.T**

*HEART FAILURE*

*TOGETHER*