

# **Cardiomyopathy Patients' Experiences of Cardiac Care Services**

**Findings from a patient-led qualitative study**

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## Abstract

This report examines the experiences of 21 people affected by cardiomyopathy who have journeyed through the cardiac care services in the northern region of England. The research is patient-led, based on in-depth interviews and has as its focus respondents' experiences of the health care system and their experiences of adjusting to and living with a diagnosis of cardiomyopathy. The experience of carers, as well as patients, has been captured.

There is a need for information and support at key times on the journey through cardiomyopathy - at diagnosis, on discharge from hospital, when dealing with a device, when issues around family screening arise or when the condition 'changes' in some way. Respondents have experienced a paucity of information and support at these times. They would have liked 'someone' to go to with their unanswered questions and concerns. The idea of a 'specialist nurse for cardiomyopathy' was suggested to help guide respondents 'through the maze'.

Respondents' experiences of medical care were mixed across all elements of the health care system (consultant cardiologists, GPs, specialist nurses, secondary and tertiary hospitals). Confidence in tertiary hospitals and specialist nurses was evident and examples of 'good practice' emerged.

Psychological support was often lacking at diagnosis and as people continued to live with cardiomyopathy, emotional issues arose such as fear for the future and the impact of the condition on family members. Practical concerns also arose for both patients and carers around exercise, work and social activities.

The overall picture which emerged from this research was of a group of people deeply affected by a diagnosis of cardiomyopathy who had experienced both positive and negative aspects of a health care system that does not appear to fully understand cardiomyopathy or the impact it has on the lives of patients and carers.



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Acknowledgements

## **Introduction, Background and Methodology**

This report was undertaken by three members of the North East Cardiomyopathy Support Group (Cathy Stark, Ian Mackersie & Vera Mackersie), supported by Julie Goodfellow, BHF Cardiac Genetics Nurse.

### **Where did the research idea come from?**

In April 2015, Ian Mackersie was diagnosed with Hypertrophic Cardiomyopathy and had an ICD inserted. During this time, he met Julie Goodfellow, BHF Genetics Nurse based at the Freeman Hospital, Newcastle, for a meeting about family implications. Julie sees many patients and families with cardiomyopathy to discuss genetic implications of the condition. She also informs the families that she sees about the North East Cardiomyopathy Support Group. We know from our support group members, that Julie also provides newly diagnosed patients with much needed information and support.

Ian expressed concern to Julie that no one had really told him what to expect after getting his device fitted. He had not expected to experience further 'funny turns' but these had continued. Vera, Ian's wife, was also worried about what 'getting back to normal' might look like – should she encourage Ian to exercise, push him or wrap him up in cotton wool? Ian and Vera's concerns resonated with Julie and for some time she had wanted to explore patients' experiences of cardiac care services in the Northern Region. She contacted the support group leaders with the following email:

"I want to know what patients want from health staff when they are diagnosed, going through a crisis. What they get. What is done well? What could be done better? I need their experiences." [Email from Julie Goodfellow, 18/06/2015]

While running the North East support group, the group leaders had noticed how members reported very different experiences; some described themselves as having been well supported, while others were reeling from their diagnosis and felt disorientated and cut adrift. Support group leader, Dr Cathy Stark, who has cardiomyopathy and a background in academic, health-related research, was keen to look more systematically at the range of experiences that members reported.

When Ian, Vera, Julie and Cathy got together, the research project took off.

### **Setting up the project**

After an initial meeting, it was agreed that the project should be patient-led as in today's climate, feedback from patients is on the agenda and considered valuable when looking at improving services. Also, as a medical professional, Julie did not want to get involved in the

research process as she did not want to influence the research in anyway. Therefore, it was set up as, and has remained, a patient-led research project, with Julie offering as much support as possible but remaining one step removed from the data gathering process.

## **Our Aim**

Our aim was to gain an understanding of cardiomyopathy patients' experiences of cardiac care services in the region – from diagnosis, throughout their journey up to present day.

We wanted to find out:

- what parts of the service worked well, and what didn't work so well
- what patients found helpful on their journey and where and when the holes in provision appeared
- what patients thought would improve their experience of the care services

## **Our Methodology**

In order to capture these ideas, a semi-structured questionnaire was constructed which used more open-ended questions than a 'tick box' approach. We knew what we wanted to find out but in no way wanted to restrict respondents to just these topics. At the same time as finding out what we wanted to know, respondents had the opportunity to tell us whatever was important to them about their experience of the condition and their journey through the cardiac care services. The result was a meaningful interview, rich in data, which elicited both what we need to know and what has been important to respondents during their journey with cardiomyopathy.

## **Piloting**

We then tested the questionnaire through the piloting process which allows questions to be refined and reworded. After each pilot interview, the data collected was examined and the interview schedule amended as necessary. By the end of the piloting process we were confident that the questionnaire would elicit the information we wanted. Cathy is an experienced research interviewer, so the piloting process enabled Ian and Vera to gain feedback on interview technique.

## **Recruitment**

We spoke to the support group about the proposed project during one of our meetings in July 2015, supported by Julie. We invited people to take part and provided a consent form and also emailed invitations to the whole group after the meeting to ensure that everyone had the opportunity to participate. At this point, carers/supporters from the group also volunteered to take part and, although we had not initially set out to collect carers'

experiences, we welcomed this as an ideal opportunity to begin to find out how cardiomyopathy affects the wider family. A 'carers' questionnaire was designed and piloted.

In total, 21 people agreed to speak to us about their experiences (16 people with cardiomyopathy and 5 carers).

## **The Interview Process**

Interviews took place at the Freeman Hospital on consecutive Saturdays in August and September 2015. Each participant was interviewed separately, the interviews lasted between 30 and 75 minutes and all interviews were recorded. Cathy and Ian, who both have cardiomyopathy, interviewed patients and Vera, who supports Ian, interviewed the carers. Julie did not undertake any interviews to ensure that the process was entirely patient-led, but she came to each interview session at the hospital so she was on hand to offer support, information and advice to all the interviewees should this be needed. Telephone interviews were undertaken with three respondents who were unable to travel to the Freeman Hospital during the interview period, and one further interviewee was interviewed at home.

## **Anonymising the transcripts**

All the interviews were fully transcribed and then anonymised. Names of patients, family members, and clinicians were removed. The names of hospitals were also removed. We have been asked why we anonymised the data and the following example may help to explain this. If a consultant is deemed excellent, we want to know what makes them excellent – not who they are. We want to know what patients value about them and their practice. And the same goes for a consultant considered unsatisfactory – what makes them appear this way? This allows us to pull together what makes a good consultation and what does not. It is not about naming and shaming, it is about unpicking good practice so we can say what works well and what patients value. This makes the data more generalisable to any cardiac consultation.

We have anonymised hospitals up to the point where we know whether they are tertiary care hospitals (specialist centres) or secondary care hospitals. We wanted to be able to explore the different experiences of care across tertiary and secondary hospitals in order to identify good and bad practice.

Everyone who took part was known only by a code number and in the report they are further anonymised and presented only as male or female with their condition e.g. Male, HCM or Female, DCM etc.. However, there are some things that will identify a person to those who know them – for example, if we refer to someone who has had a heart transplant, most of our group members might know who this is. However, people outside of the group will not be able to identify this person. Also, before our final report was sent to Cardiomyopathy UK or to any other interested party, every respondent who took part was

sent a complete copy of the report and asked for their comments. This gave participants the chance to inform us if there was anything that they wanted to amend.

## **Coding Process**

Transcription of the interviews produced 21 transcripts which then needed to be analysed. This type of 'qualitative data' needs to be broken down into categories and then into codes and the codes then form the basis of the analysis. A code is a word or phrase that captures what the data is telling you. The transcripts were read and reread by Cathy, Ian, Vera and Julie and a coding frame was devised. The codes were refined until they captured the essence of the data. Once transcripts were coded, analysis was possible.

## **The Report**

The report consists of 11 chapters. Each chapter can be read as a stand-alone report. It was written in this way to enable readers to focus on the chapters that are of particular interest, without having to read the whole report. To ensure that the chapters can be read individually, some findings are repeated in different chapters.

A summary of each chapter is also provided for those who wish to gain an overview of findings.

The report is based on the experiences of members of the North East support group, but we very much believe that these will resonate with, and be generalisable to, many more people with cardiomyopathy across the country.

We hope that you find the report interesting and informative. Thank you for reading and we welcome your comments

**Cathy Stark, Ian Mackersie, Vera Mackersie & Julie Goodfellow**

**April 2017**

## Key Findings

- Cardiomyopathy impacted on the lives of respondents, carers and their families. Information and support were needed throughout the patient journey.
- When asked how to improve care services for people with cardiomyopathy, the suggestion of a 'specialist nurse for cardiomyopathy' or a 'MacMillan nurse for cardiomyopathy' loomed large.
- The value of having a 'someone' to go to with questions and concerns, for carers as well as patients, was highlighted. The vast majority who had access to a specialist nurse placed great value on this service. However, not all patients were allocated a specialist nurse.
- Respondents wanted information about their condition: what a diagnosis of cardiomyopathy meant; what they could expect and what might happen in the future. Such questions arose around diagnosis and often remained unanswered.
- Other times on a patient's journey when both information and support were needed included: discharge from hospital; when there was a change or deterioration in the condition; having a device fitted or an ICD firing; and when family screening was raised.
- None of the respondents had heard of an ICD prior to having one fitted. Understanding of the need for a device varied; it was not always fully explained by medics or understood by respondents. Experience of the process of having a device fitted varied with respondents recounting both positive and negative experiences.
- Information about the device and how it worked was not always given. Having a device implanted could be alarming and was a time when information and support were needed. Most respondents appeared to adapt over time.
- Respondents became aware of genetics and inheritance of cardiomyopathy through a variety of routes, including medical staff, specialist nurses, support group and literature. There were a myriad of emotions associated with knowledge of inheritance, including: worry and fear for relatives, guilt and fear for themselves and impact on families.
- Families reacted to knowledge of inheritance in different ways, including: a reluctance to be screened, acceptance of advice and many reported how this had a massive impact on lives. Family screening advice given to patients and families varied hugely. When information was given by a specialist genetics nurse, respondents said it resulted in a greater understanding, leading to a much more positive experience.
- Respondents also indicated a need for information around practical aspects of living with cardiomyopathy (e.g. diet, driving, medication). Exercise was an important topic for respondents and one where information was often lacking or ambiguous. Access to rehab appeared ad hoc.



- Patients may be too poorly or overwhelmed to take in information at the time it is given. Patients may not initially know what questions to ask or questions may arise over time. Respondents valued having family members present when being given information and valued having them involved in discussions. Carers appreciated being involved in discussions about their loved ones.
- The manner in which information is imparted by medics impacts on how well it is received and understood. Timely and accurate information imparted sensitively in lay person's terms helps patients manage expectations. Examples of good sources of information included specialist nurses, some cardiologists, some members of the Rhythm Management Team and staff at the Institute of Transplantation.
- Cardiomyopathy UK and the local support group were identified as valuable source of information and support for respondents and for carers. The potential role patients could play as information-givers was raised.
- A lack of information, conflicting or partial information caused increased anxiety for patients. Some medics (for example some A&E and ward staff & some GPs) appeared to lack an understanding of cardiomyopathy.
- A diagnosis of cardiomyopathy can bring a sense of loss. Adjusting to the diagnosis involved re-managing expectations. Over time, the condition impacted on physical activities, working life and social life. Giving up roles and activities that were previously enjoyed and valued could cause low mood. A diagnosis of cardiomyopathy appeared especially devastating for those who described themselves as being very physically fit and active.
- Respondents identified a need for psychological support around the time of diagnosis - but this was often lacking. Very few respondents had accessed psychological support; those who had found it helpful. Respondents were often unaware of the availability of psychological support services or 'put off' by long GP referral times.
- Respondents had a wide experience of hospital care across secondary and tertiary hospitals on different occasions and also simultaneously as "cross care". Communication between hospitals did not always work well. Positive and negative examples of care across both secondary and tertiary hospitals were documented but patient confidence in tertiary hospitals was evident.
- Hospital care was perceived as good when it was delivered by knowledgeable professionals, who communicated effectively, when treated as an individual and when time is given. Hospital care was perceived as poor when communication was lacking, when staff did not give clear explanations, or when staff seemed to lack knowledge, as well as when staff lacked pastoral care and empathy.
- Suggestions to improve hospital care centred around improving communication (especially between hospitals) and providing better information and support to patients.

- Respondents voiced both positive and negative experiences of their consultant cardiologists in both secondary and tertiary hospitals – but in general experiences were described as more positive than negative.
- When a patient-consultant relationship worked well it was valued by respondents as an expert source of information and support. Respondents particularly valued consultants who: took their time; provided jargon free, clear explanations; were contactable by email between consultations; answered questions and took concerns seriously.
- A patient-consultant relationship worked less well when: a patient felt rushed; the consultant lacked bedside manner; concerns were not taken seriously. Overall, the 15 minute consultation was felt to be too short. The time between consultations was sometimes considered too long and patients could be left with unanswered questions.
- Family members and carers are affected by a patient's cardiomyopathy All carers were heavily involved at every stage of their partner's diagnosis and treatment. The condition impacted on them as they took on more duties, curtailed previous activities, experienced the stress of the caring role, and attempted to balance work and care.
- Carers have their own psychological support needs too – fear for the future, guilt and concerns for children and wider family members. Carers sometimes felt their needs were overlooked. Carers appreciated someone to talk to and valued the support group whilst acknowledging it wasn't specifically for them.
- Carers specifically suggested that they would value the opportunity to speak to medical staff on their own, away from the patient.
- The Institute of Transplantation was described as a model of good practice where both information and support were given, and both physical and emotional needs were met.

# 1

## **The Impact of Cardiomyopathy on the Lives of Patients and Carers**

Cathy Stark

### **Background to study**

Three members of the North East England Cardiomyopathy Support Group<sup>1</sup>, supported by Julie Goodfellow<sup>2</sup>, BHF Cardiac Genetics Nurse, have undertaken research to examine patients' experiences of cardiac care services in the North East region. Twenty-one members of the local Cardiomyopathy Support Group (16 patients and 5 carers) were interviewed in September 2015, using a semi structured interview schedule and the interviews were transcribed and analysed thematically.

### **Introduction**

This report examines the impact that cardiomyopathy has on a person's life. The research has identified diagnosis as a time when both information and support are crucial for patients. Whilst looking back to their time of diagnosis, some respondents identified a need for psychological support around this time. Once diagnosed with cardiomyopathy, a patient's journey is not over but rather cardiomyopathy continues to impact on a patient's life and that of their family in a number of ways. It may be that extra support would be helpful for some people at certain times on this journey as they confront the changing ramifications of cardiomyopathy on daily life.

The report is divided into 6 sections:

1. Feelings around the time of diagnosis
2. The impact of cardiomyopathy on daily life

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<sup>1</sup> Ian Mackersie, Vera Mackersie & Cathy Stark

<sup>2</sup> Julie Goodfellow, BHF Cardiac Genetics Nurse, Freeman Hospital, Newcastle-upon-Tyne

3. The impact of cardiomyopathy on the lives of family members
4. Managing change
5. Experience of psychological support services
6. Carers' perspectives

## **Section 1 Feelings around the time of diagnosis**

Interviewees were asked how they felt after receiving a diagnosis of cardiomyopathy. Two respondents had been diagnosed with cardiomyopathy less than a year; 5 had been diagnosed between 1 and 3 years prior to the interview; and nine respondents had lived with cardiomyopathy for 8 years or more, with 3 of these having the condition for over 20 years. The year of diagnosis is given in brackets after the quotation to give it context. When reflecting on how they felt at diagnosis, respondents described a range of emotions from 'relieved' to 'bereaved'.

Feelings of relief were described by interviewees once they had an explanation for what they had been experiencing.

When I came to the cardiomyopathy clinic a lot of people said you're newly diagnosed you'll still be in shock. And I kept thinking in a way I was relieved that they'd found what was the matter. I was relieved I had a diagnosis and they could do something about it. (Female, DCM, diagnosed 2013)

Well better because I knew what it was....It settled me down. You know what I mean, because I couldn't find out what it was. (Male, HCM, diagnosed 2003)

I think I was relieved to know what it was (Male, HCM, diagnosed 2015)

In contrast, others described how the diagnosis had a dramatic effect on their sense of self. One respondent described his diagnosis and the resultant loss of his working life as an "intense bereavement" (Male DCM, diagnosed 2014). Indeed, the commonly recognised 'stages of bereavement'<sup>3</sup> – denial, anger, bargaining, depression and acceptance – have been identified in patients' journeys.

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<sup>3</sup> Kubler-Ross, E. (1969) *On Death and Dying*, New York: Macmillan

I was told I had this thing my dad died of when I was 13. Looking back I was probably in denial and it was a surprise to me (Female, HCM, diagnosed 2012)

Being diagnosed with a heart condition was a blow to the following respondent. His lack of understanding about cardiomyopathy at the time of diagnosis led him to wonder whether he was somehow to blame. He felt that his lifestyle was not the cause and therefore was left with unanswered questions.

Drained. I didn't understand it because I didn't know what cardiomyopathy was....I have always been a hardened worker, working on a farm. I played rugby until I was 37.... I never smoked. I hardly drink. Why me? That was the first question I asked myself. Why is this happening to me? That's as much as I can say. (Male, DCM, diagnosed 2001)

The following respondent described himself as very physically fit prior to diagnosis and therefore the diagnosis came as a blow to his sense of self.

That was a big hit for me as a man who is a marathon runner. I was a very fit guy. I mean I had coped with this fast heart beat all my life and being short of breath, I've always coped well with it because you force yourself to. So I left there feeling in a mess to be honest and I didn't know where I was. Then you start to feel pretty alone with things, and think who do I turn to here?... Ruined my self-confidence. It took everything away from me to be honest. I had always been quite a confident guy, quite a fit guy and to be told to stop today and you can only walk twenty minutes was just like – 'oh my god'. (Male, HCM, diagnosed 2013)

Other interviewees described their feelings at being diagnosed with a condition that already existed in their family.

Not surprised but not happy (Male, DCM, diagnosed 2008)

I was told that I could drop down dead at any time ... It floored me actually, when he told me what it was and what it could potentially do. Especially with what's happened in the past with my family (Male, HCM, diagnosed 2012)

Finally, over 17 years since his diagnosis, the following respondent appears to have 'accepted' his cardiomyopathy.

Well I wasn't too happy, put it that way, but after a while you just say 'Well if you've got it, you've got it'. (Male, HCM, diagnosed 1998)

Whilst looking back to the time of their diagnosis and reflecting on this during the interviews, some respondents identified a need for psychological support at that time to assist with the adjustment process.

In the following quote, the respondent was fitted with an ICD within 2 weeks of his diagnosis of cardiomyopathy.

You've got an ICD in now, you'll be fine and they didn't really explain what cardiomyopathy meant and also they didn't address the psychological effects which were devastating really. So that was very difficult.....I don't think it's because I've forgotten, I don't think there was that pastoral support, it was all very technical, the need to get it sorted. (Male, DCM, diagnosed 2014)

....I tell you what I think was lacking and is still lacking is when you get a diagnosis of whatever disease....there was never any kind of counselling, never anybody around you could just offload a bit. So at the time of diagnosis, I've always been a very positive person very happy go lucky, but I've got to be honest, then you start questioning your future, have you got one? How much of a future have you got? (Male, HCM, diagnosed 2012)

The following respondent had not been offered any psychological support around the time of diagnosis and only found out about its availability when offered it for her children at a later date.

We have been offered support for them [children] which has made me realise that there is adult support as well. I don't think I need it now, I think I've got myself there. I'm getting there by other means but it should have been offered at the time because I think it's such a humungous thing... I wasn't offered it when I was diagnosed or I would have taken it. It's such a massive thing and I think I was probably quite depressed for quite a few months and it's just now that I was getting back to normal. (Female, HCM, diagnosed 2012)

## **Section 2 The impact of cardiomyopathy on daily life**

As a patient journeys past diagnosis, cardiomyopathy continues to impact on a person's life. After the initial flurry of activity around diagnosis, there may be a realisation that they will not 'get better' but rather have to adjust to living with a chronic condition. This process involves re-managing expectations. The following two respondents recognised the need for psychological support to help them do this.

I think that was one of the things that happened when I was so upset, because I kept thinking I will get better ...That was another thing. I didn't know there was counselling. I was ill for over a year and had depression because I think I always had it in my mind that I would get better. Then I didn't and it really sort of hit me... and I actually had counselling through

work because I work for the NHS. They have their own but I think a lot of people would have gone to the doctor or just struggled on. (Female, DCM, diagnosed 2012)

It's like any sort of bereavement really, you get loads of care in the initial stage and then sometimes 12 months later people crash. I'm aware of that possibility, I mean I'm dealing with it myself, I've got a counsellor... (Male, DCM, diagnosed 2014)

### **Impact on sense of self**

Before a diagnosis of cardiomyopathy, respondents saw themselves in certain ways and defined themselves through what they did – their role within their family, their jobs, their hobbies. As cardiomyopathy disrupts the ability to carry on with what they did before, people can feel disorientated. Charmaz<sup>4</sup> (1986) described this “loss of self” as a “fundamental form of suffering” amongst chronically ill people “who observe their former self-images crumbling away without the simultaneous development of equally valued new ones”.

In the following two quotations, feelings of loss of identity are apparent.

Now I'm not saying I was superman, but I was a pretty fit guy and I was head of the family and did everything for the family, as you do. Then suddenly I wasn't superman anymore and I might be dead tomorrow, so there was an effect....(Male, HCM, diagnosed 2013)

I do see a counsellor occasionally, about every 6 weeks, that's more to do with, it's a consequence of what's happened in terms of role, identity, all those things - a bereavement of sorts. I talk to her and that's on a general on-going basis. You know, where are you up to, I'm still not sure what I'm going to do, it's about who I am now, you know. (Male, DCM, diagnosed 2014)

Cardiomyopathy can cause people to make changes to their working lives. In the following quotation, a respondent described how a diagnosis of cardiomyopathy in 2001 led to the eventual loss of both his job and his home.

I worked on a big farming estate, I was the farm manager, eventually the guy I worked for said we cannot keep you living in a house and doing no work, type of thing...a tied house, a

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<sup>4</sup> Charmaz, K. (1983) 'Loss of self: a fundamental form of suffering in the chronically ill' *Sociology of Health & Illness*, Volume 5, Issue 2, pp.168-195

tied cottage... He was brilliant he looked after us for like two and half years. He paid my full wages and let us live in the house. Eventually I kept going back to work and ending up in hospital ... eventually having to give up the job I'd loved all my life. Working on farms everything I've done. It's affected me a lot. (Male, DCM, diagnosed 2001)

Moving from full-time to part-time work in order to manage the condition was described by two respondents.

It hit me because I wasn't getting back to what I call normal. I was expecting to have all the pills and be fully functioning ... I tried to push and carry on and work full time. That's one of the things I've had to do, drop full time to part time. (Female, DCM, diagnosed 2012)

I work part time, I know when I'm getting overtired and I manage it. I've managed it for a long time now. It's getting that balance. It took a while obviously with a new baby but I got there in the end. (Female, PPCM, diagnosed 1991)

For women who experience a peripartum cardiomyopathy, advice around future pregnancies is often a 'grey area'. Being advised not to have any more children can impact on a woman's sense of self.

I was told way back, in no uncertain terms, 'don't have another baby' because it would be a death sentence. (Female, PPCM, diagnosed 1991)

Tiredness and the knock on effect that this had on everyday life was described in many interviews.

It's just very, very hard to accept, because I used to be active all the time and now I'm practically doing nothing .... I get so shattered it's unbelievable. That's another thing, if you haven't actually experienced it, even the doctors don't know what it really feels like, because I would never have appreciated how weak you can be. I don't know how many other people will tell you that. (Male, HCM, diagnosed 2008)

I get up and by the time I've done the breakfast for everybody, got washed showered and dressed I'm ready to go back to bed, even if it's just for 20 minutes, I'm exhausted. I don't because of the type of personality I have, but I have to rest. That's for 20 minutes, half an hour. (Female, HCM, diagnosed 1992)

....suddenly it's like walking into a glass door with the fatigue. It's OK and suddenly you just feel dreadful, there's no warning, it just comes on suddenly. It's frustrating having to pace yourself. I'm not always very good at that. Saying no to things. (Female, HCM, diagnosed 2012)

It can make you depressed. I do know people who have got into a real bad state. The drugs slow you up. (Male, DCM, diagnosed 2009)



The following respondent described her sense of frustration at having plans disrupted due to tiredness.

I'm always one that's had plans to do things. But I can get out of bed one morning and think it's going to be even hard to get up and get dressed and I've planned to go and visit somebody or go out somewhere. A couple of weeks ago it was my birthday and I wasn't feeling good that week but we tried to go out for my birthday lunch but we just drove halfway there and I said to my husband 'we'll have to go home'. And I find it really hard that I can't just plan things and I have to cancel a lot of things that have been arranged... And there might be days when I've done something like gardening that I haven't done for so long and next day or the day after I've been poorly. (Female, DCM, diagnosed 2012)

Respondents described how they dealt with friends. In the first quotation, a contrast is made between how friends reacted to cardiomyopathy as compared to cancer, with the respondent feeling better supported in her cardiomyopathy.

I think it's affected my friends as well. My friends are very aware when I'm out with them. That they're looking after me....I've noticed a great deal of difference between that and when I had cancer. When I had cancer people were more afraid. People would not give me eye contact even some friends didn't know how to cope with it and would walk on the other side of the road whereas with my cardiomyopathy they want to give support all the time, they don't seem to be afraid of that. (Female, HCM, diagnosed 1992)

And friends I think know now, because I always feel guilty if I'd booked to meet them for a meal and had to cancel at the last minute. (Female, DCM, diagnosed 2012)

In contrast, one respondent preferred not to disclose how he was feeling when out with friends.

And faking it. You fake it until you make it. When you are out with friends you smile because you have to and with family. But inside you are in absolute turmoil. (Male, HCM diagnosed 2013)

For those who had been very physically fit and enjoyed exercising, a diagnosis of cardiomyopathy and a curtailment in exercise was an extremely difficult life-change. In the following two quotations, both respondents described how the impact on them was so severe that they suffered depression and had suicidal thoughts. Over time they had re-interpreted the advice around exercise in order to cope with their condition.

I sat in this chair for the first 6 years after the operation. And then I went 'to hell with this'. I started going back and did a little bit swimming at first, then my shoulders were aching, so I

went back to the gym and did some very light weights, just to ease my shoulders up....but they'd told me not to do that, not to exercise. They said 'I don't even want you to lift a carrier bag for your wife'. And I said 'hang on a minute, I can't even lift a carrier bag for the wife?' and he just turned round and said 'has your wife got a bad heart?' and I said 'no' so he said 'well let her carry them'. He said 'that extra weight will put more strain on your heart. Don't do it'. And mind you he was right because as soon as I picked up any weight at all and tried to walk with it I was basically passing out. It just hits you that you're bad. It hit me anyhow (Male, HCM, diagnosed 2003)

I went through many months of that and feeling very negative and as I say, although I probably wouldn't have admitted to it, I was depressed and I felt awful. You know I always ran and going from running 3 or 4 times a week and now I've stopped and don't do anything, which makes me feel terrible because that's what I've been told to do. I can't run again. Everything was just black to me at that point. If it hadn't been for the fact that I decided to ignore the exercise advice and continue going to the gym, I honestly think I wouldn't be here. That's how bad I felt. It was the lowest that I had ever felt in my life. (Male, HCM, diagnosed 2013)

Both these respondents were aware that their low mood would have been difficult for their families.

.... I do feel 18 months were wasted in a dark, depressing place and I'm sure that I wasn't a very nice person to be around at that point because I was so down in the dumps (Male, HCM, diagnosed 2013)

I just got that fed up. I was sick of looking at this television and at these four walls. I was suicidal at times. I was playing hell with the grand bairns, playing hell with [the kids?], my wife was fed up with me, I just got so down and depressed. It was unbelievable. I just got so depressed with it. [Interviewer: And were you offered any kind of counselling or psychological support?] No.....it might have helped because I hit the drink and everything. I was drinking every night of the week and I was drinking far too much. (Male, HCM, diagnosed 2003)

As the quotations above demonstrate, patients were aware that their diagnosis of cardiomyopathy had ramifications for their families. This is explored further in the next section.

### **Section 3 The impact of cardiomyopathy on family members**

Respondents were aware of the impact that their cardiomyopathy had on family members. Some lamented the fact that they could no longer do some of the practical things that they once did, and as a consequence, family members had to take on extra duties.

He's taken on a lot of things I used to do – house work wise – and that's because I do just get so tired. We've three lovely dogs who I don't walk anymore because I just get so tired that he looks after them. (Female, DCM, diagnosed 2012)

Sometimes respondents felt that their partner's life had been curtailed by cardiomyopathy.

First of all I would say my husband worries a great deal about me that I push myself too much that I do too much. We used to do fell walking, climbing, all that has had to stop. I worry about the fact that he will not do it now because I can't do it with him and he doesn't want to just go and enjoy himself with something that I can't enjoy any more. I think it's a great worry to him. It doesn't sit on my shoulder all the time. I'm one of these people that doesn't think about it all the time and I get on with my life and try to do as much as possible. I think it sits on his shoulder a great deal especially when he sees me short of breath or very, very tired. Which I am getting progressively more tired now. I think it also worries my family. My son and my daughter they are both doctors and it worries them. (Female, HCM, diagnosed 1992)

Another respondent felt that caring responsibilities whilst working full time had taken a visible toll on his wife.

I found from a personal point of view it affected my wife and my family more than it affected me. As the person sitting in the middle of it I think you just kind of get on with it and it's the family that kind of suffer especially if you're close to your wife and children. I noticed that [wife] was really stressed. She was working full time at the time. Having to care for me and do full time work at the same time was incredibly stressful. (Male, DCM, diagnosed 2009)

Cardiomyopathy does not happen in isolation from other life events. Inevitably people with cardiomyopathy will experience other difficulties which may take their toll on both patients and carer.

Both my wife and I went through a pretty hard 2 years with it [cardiomyopathy] actually. We had other problems at the time with my daughter getting divorced and [wife] having to split herself between myself and our daughter. [She] lost four stone in weight during that period and she wasn't very heavy. (Male, HCM, diagnosed 2013)

As well as the practical impact, respondents also recognised the emotional impact of their condition on family members.

She'd just been offered place at a university medical school. But when I took ill she said she wouldn't go because she wanted to be next to me, because at that time I was really poorly. Nobody knew if I was going to come out of hospital at that point. They did say that. It affected her quite badly and myself. (Male, DCM, diagnosed 2001)

When you're bandying words about like 'heart transplant' it has a profound effect on you and your family. (Male, HCM, diagnosed 2012)

Parents with cardiomyopathy expressed concern about the emotional impact of their condition on their children, regardless of whether the children were grown up or not.

My son only being 19 was quite worried, especially when I was having bad days. I mean we didn't really know what was going on. He hid it. He tried not to show it and I think he was scared to ask. So I think we needed to share a bit more with him. (Female, DCM, diagnosed 2012)

I was sat on the settee one afternoon and my heart rate it just went up to about 220 very quickly within a few seconds, just at rest and I was sitting down. So it ended up my children calling the ambulance, a neighbour being called, and the ambulance coming and I was whisked off and by the time the ambulance came I was in sinus rhythm and I don't know what happened. I had a feeling of impending doom but I don't know if it was just that I panicked. I don't know. That was fairly frightening for them to see me going through that although nothing was proved about what was going on at the end. And then other times when I fainted and it was just a faint probably because of having had a meal and walking up a slope and I had a warm coat on. So they've seen that.... (Female, HCM, diagnosed 2012)

The same respondent was also dealing with the fact that her children may have inherited HCM so the impact of cardiomyopathy on the family was twofold.

Basically it's absolutely massive because my diagnosis has had a massive impact on my family. And it's direct and indirect because mine is having an effect on them and also the fact that it's hereditary will have an effect on them because they're going through screening and that's massive, totally massive because we've had some worrying results about my littlest who is 8 year old. Recently on April so we're not quite sure what's happening. It's just absolutely totally huge. (Female, HCM, diagnosed 2012)

Concern about passing on the condition to children was something that respondents highlighted during the interviews. It may be that this is a key time when extra support is needed.

I did struggle when we first found out he [son] had dilated cardiomyopathy. There was a sense of guilt really. Slight, but not massively. And as I say, seeing the counsellor, I've been able to address some of this stuff with the counsellor. I'm fearful for the other boys, especially one of them who has a very physically demanding job. At the moment he's not showing but potentially if he develops it then that would be the end of his career. So there's all that going on. (Male, DCM, diagnosed 2014)

It was getting my children and grandchildren tested. If someone would have explained that if you had passed it on to the next generation then someone else would have passed it to you, so it is not your fault. I think that even that little 'it's not your fault' would have been helpful. That was my worst period. ....I know now that there is nothing that I could have done about that, but that it was in my mind that I had given it to them and that frightened me. (Male, DCM, diagnosed 1997)

The main thing in the family is my two daughters. And this is where I would have loved to talk to someone because of the genetics. They've both got it. They're young and they're burying their heads in the sand (Male, HCM, diagnosed 2012)

## Section 4 Managing change

Over the time respondents had lived with their condition, some had experienced acute episodes and these occasions could result in new issues arising. The need for support at such times was evident.

Within our small sample, 13 respondents had devices (ICDs or pacemakers). The following respondent described being fitted with an ICD a year after diagnosis. ICDs have been fitted within a few days, weeks or months following diagnosis, to anytime up to 20 years after diagnosis. While having an ICD fitted may bring relief and reassurance to some, in the following quotation the respondent did not feel reassured by his device, and being provided with a home monitor only added to his concerns.

Worry, that's the main...it still is. Everybody says you seem to settle down and get used to having the ICD and don't worry about it, that's there to save you. But it's still there at the bottom that one of these days you are just going to drop down ... And of course then you start reading and 'Woah! Hang on a minute!' Frightened myself to death. I still am really. ... There's still a fear there at the end of the day ... I've now been given a home monitor which covers you 24 hours again as far as I know. But then again, is it there as a back-up or are they expecting something to happen? Why have I been given that? Is it more serious than I think or is it just there as a precaution? ...But at the bottom of it you still don't know what you are expecting and it's just a weird thing to have floating round in your chest so you've still got that...well I have anyway. (Male, HCM, diagnosed 2012)

Another respondent was 'terrified' of his ICD firing.

I think it paces on the odd occasion but I've never actually had a shock or anything. That terrifies me. (Male, HCM diagnosed 2012)

The firing of an ICD whilst potentially saving a life can also shake a person's confidence. The following respondent reported feeling 'OK' about getting her ICD inserted, but was more concerned after it fired. This happened twice, 6 months after it was inserted and again about 8 months after that.

It was a shock when it happened....just shaken up more than anything else just from the shock of it...I mean I wanted somebody with me all the time... I didn't like to go out by

myself. I had a fear of it happening outside... I just didn't go very far by myself at all ... I've got my licence back but I haven't got the confidence. I don't think I would drive very much by myself because I'd be frightened, not so much for me, but if it happens, you know, you could kill someone. I've only driven once since I got my licence back. (Female, HCM, diagnosed 1980).

Over time her confidence came back and she increased her independence.

I go out by myself now. I'm more confident. I mean I sleep on my own and stay in house by myself. (Female, HCM, diagnosed in 1980, device fitted in 2011, fired 2011 & 2012)

In four cases within our sample, deterioration in the condition resulted in the assessment for a heart transplant. At the time of interview, two had been deemed unsuitable for transplant, one was on the transplant list and one had already had a heart transplant.

I was quite happy plodding along with my heart failure and didn't think about what happened if it goes off the end of the cliff. It [transplant] exists in its own little world I think sometimes and nobody wants to think they're going to be in that position and everybody thinks it happens in the most extreme circumstances. It kind of exists in its own little bubble. It's a well-publicised bubble and it does get a lot of publicity, transplantation, but people don't like to think they will be in that situation. I certainly didn't. (Male, LVNC, diagnosed 2009, heart transplant 2013)

However, the Transplant Unit and the patient support services it offers were described by those who came into contact with it in glowing terms. In terms of patient support the Transplant Unit could be regarded as a model of good practice as all aspects of a patient's needs appear to be addressed. The following respondent felt that such a model would work well for all people with cardiomyopathy.

That unit is brilliant....for the transplant, they've got a specialist nurse and they come and talk to you about everything. They give you the books and all and then you see the psychologists and the surgeons and that's brilliant but that's for transplant and you're going to the extreme there. But if there was something like that, obviously not as in depth as what they do, but something like that, just somebody you could get in touch with. (Male, HCM, diagnosed 1998)

That [psychological support] should have been offered right from the beginning [at diagnosis of cardiomyopathy]. When you are in the system for the transplant it is there if you need it, even on the final day of the assessment, the social workers are there and they were there with the expectation that me or my family might be annoyed that I wasn't getting a transplant. So they were there to talk if I needed. But we knew that was the right decision. (Male, DCM, diagnosed 1997)

Throughout the research, respondents spoke of the need to have someone they could talk to and who could answer questions. Some respondents did not think they required psychological support, but did feel that they needed someone they could go to for reassurance or who could signpost them to other services if the need arose. Many felt that a specialist nurse would fulfil this role. Almost all respondents who had experience of a specialist nurse spoke highly of them and valued their support.

So I suppose she [BHF nurse] listened and she gave you space to talk about all sorts of things and to talk about how you were feeling and actually allowing you to feel it was normal to feel like this – the intense bereavement. (Male, DCM, diagnosed 2014)

## **Section 5 Experience of psychological support services**

Some respondents had experience of psychological support services. As stated, those who accessed the Transplant Unit were offered psychological support as part of the assessment process. Routes into psychological services varied for other respondents. Two had accessed counselling through their place of work. Two had been offered counselling through their GP but neither had followed this up.

One respondent who was offered counselling through his GP was put off by the long waiting time and so decided to go private.

...the NHS did offer counselling but I decided because of the waiting list, I could access it more easily myself, so I've been seeing a counsellor since actually. Much less often now, only occasionally now, but initially weekly from about the end of November. The GP did offer to set up counselling for me through the NHS. But my wife's a counsellor anyway and she knew the implication of the NHS and how long you have to wait and so I decided to see someone privately. (Male, DCM, diagnosed 2014)

The following respondent waited 3 months for an appointment and then decided he did not want to go ahead with it as he felt he would want a counsellor to have knowledge of cardiomyopathy.

I went to my GP and said 'I'm feeling quite down about things and I don't really understand what is happening' and he said 'we can get you an appointment with a counsellor'. I have to say I'm not really a great believer in counselling. I mean I'm probably wrong about this, but I've just always found ways to sort things out myself within the family. So I said 'well ok but I don't really know what a counsellor can say to me that I can't really say to myself. But I will

go with it'. But I have to say it took about 3 months to get an appointment and then when it came I thought 'no I'm not going, I don't think it is going to benefit me'. So that is all I was really offered. (Male, HCM, diagnosed 2013)

However, despite not following up the counselling, he did feel it was something that should be offered - although with the following stipulation – that the counsellor should have a knowledge of cardiomyopathy.

I definitely do. Specifically targeting this illness and somebody who knows about it. Not just some general counsellor at the doctor's surgery who spends 15 mins with you. I'd want someone specific to cardiomyopathy. (Male, HCM, diagnosed 2014)

Two respondents had seen specialist health psychologists based at the hospital. One respondent had been referred to the psychologist through the pain clinic that he attended for a co-existing health problem. The other had learnt about the availability of the health psychologist via his cardiac rehabilitation class.

...because you can go and talk to them because they know how to get your problems out of you. I mean sometimes I write a list and you forget half of them, but that was great. Very useful. I went to see her about 3 times. I've got her number at home on a card and she just says if at any time you feel as if you need to talk to someone just ring up and I'll arrange an appointment. (Male, HCM, diagnosed 1998)

Through the heart consultants I've been going to the heart rehab at the [secondary care hospital]. There's a lady there, called a psychologist, and I saw her [Interviewer: was she helpful?] A little bit but, still, you can't change the way your brain thinks.....the basic thing that she tried to get you to do was to think what you can do now and not what you could do in the past, which is hard really. (Male, DCM, diagnosed 2008)

I think my criticism was [the consultant] told me in front of the children...I think [consultant] should have asked me to go by myself. Of course it was such a difficult situation. My kids were crying.....I think [they] sort of realised [they'd] handled it the wrong way. I'm sure [they] did realise. They are under a lot of pressure and really busy. But then that was the point that [they] offered psychological services for my children. Basically, partly because of the way it was handled. I felt [they] kind of knew [they] had done something [they] knew [they] shouldn't have done but I'll give you some psychology to make up for it. It felt like that to me. I'm sure it was unintentional and everyone has different ideas about how to deal with these things. I don't want to be saying things behind people's back or have them think that you're saying things, but the way it happened wasn't right. (Female, HCM, diagnosed 2012)

However, the fact that the children were offered psychological support alerted the respondent to the availability adult psychology services, something which she felt she would have accessed at the time of diagnosis had she known.



We have been offered support for them [children] which has made me realise that there is adult support as well....[They're] a specialist in psychology in healthcare based at the tertiary care hospital. It's a very specialist area. But I think people should know more that it is there.... I wasn't offered it when I was diagnosed or I would have taken it. It's such a massive thing and I think I was probably quite depressed for quite a few months and it's just now that I was getting back to normal. (Female, HCM, diagnosed 2012)

Another respondent, who had cancer as well as cardiomyopathy, made the following observation about psychological services

I've never been told about them. That's the difference with cancer - you are told about these services. (Female, diagnosed with HCM in 1992)

From the experiences amongst this small sample, it does appear that there are long waiting times for counselling services accessed through a GP and that knowledge of specialist support services is limited and is not something that cardiomyopathy patients are routinely informed about.

## **Section 6 Carers' perspectives**

Five carers were interviewed as part of the research and, although only a small sample, their stories illustrated how intricately involved carers are with the everyday ramifications of cardiomyopathy. Carers use the terms 'us' and 'we' indicating how closely involved they are in all aspects of the patient journey. It was clear from the interviews that carers have their own concerns and issues and there are times when carers would benefit from support.

Diagnosis is a time that requires people to make a massive adjustment, and this was true for carers as well as patients.

We are living with it, we'll move on with it. I have to be honest and say it felt painful at the very start. (Male carer, partner diagnosed with DCM in 2012)

Carers took on a protective role and worried about what their partner should or should not be doing.

I think I'm a bit more protective than my husband is about things like what he should be lifting I'm still concerned about the limit to what he can do now. (Female carer, partner diagnosed with HCM in 2015)

You put this cocoon around them and try to protect them but you can only do that for so long. (Female carer, partner diagnosed with HCM in 2012)

Two carers described how they felt guilty about not recognising that their partner was poorly and not acting more quickly when their partner took ill.

I felt guilty after and I thought I shouldn't feel guilty but I did and I carried that guilt around for about a month. I thought I shouldn't have thought that as I know when he gets a cold it can go to his chest and he can be very poorly quite quickly but I think because it was so near Christmas, after Christmas and that, and everything was going on and all the hassle and that I was thinking it is only man flu, get over it, and then when you know he is really poorly you start thinking, this ain't right. (Female carer, partner diagnosed with DCM in 2001)

Oh yes, it was a relief [when husband taken to hospital] because by this point I was beginning to be full of regrets for not calling the ambulance sooner. I shouldn't have listened to what my husband was saying. I should have rung an ambulance sooner...so I was full of regret and guilt that I hadn't done it sooner. (Female carer, partner diagnosed with HCM in 2015)

Fear for the future was something that carers spoke about. This could include worries about their partner deteriorating or the increased caring responsibilities that they may have to undertake.

My big fears are just this whole thing with cardiomyopathy. How long do these machines last? And just things like is he going to make it past his 60<sup>th</sup> birthday. I know this machine is there to save him and if his heart went into an arrhythmia it would trigger it and start it up again. Yes he would have to go to the hospital and all that sort of thing but at least it is there, because if he didn't have it and anything happened and we weren't aware of these problems, then he wouldn't be with me. And I don't like the thought of being so young and on my own. I mean my father is now 83 and he needs another bypass operation but because of his age they won't give him it. I can see him deteriorating and that is terrifying but if it was my husband as well like that, I would be tearing my heart out. (Female carer, partner diagnosed with HCM in 2012)

In the following quotation the carer expresses her concerns for the future as her husband waits for a heart transplant

...we've got a friend who's had a heart transplant and his wife does all his medication because he keeps forgetting his medication. She has his little red book and she takes his temperature, she weighs him, she does all the medication and I'm thinking I'm going to have to do that later and that's the frightening part, the bit after. Leading up not so much, it's the bit after, how you're going to cope and that, so in a way sometimes you feel left on the shelf.

It's them because it's them who needs the care but you are sitting behind paddling like anything thinking if they would only take you to one side... sometimes you just want to be reassured what is going on, like talking about an LVAD - how long are they going to wait? Are they going to wait until he is so poorly or are they going to put it in before he's at that stage? I just want to know a little bit more, how long we are going to wait really or how long they are going to leave him. How poorly is he going to be or is he going to be too poorly to end up with one? So that's my main concerns. Every time the phone goes you're looking to see if it's the tertiary hospital. (Female carer, partner diagnosed with DCM in 2001, on heart transplant list at the time of interview)

Patients expressed concerns about children having inherited the condition and this was a concern for carers too. Even when told that their child does not have any signs of the condition, carers may still harbour fears about it developing in the future, especially when there is no on-going monitoring.

We've been told that she is fine at that stage....no monitoring or anything and that is frightening to me. (Female carer, partner diagnosed with HCM in 2012)

On a practical basis, caring brought other demands. Carers can sometimes find that their partners' cardiomyopathy also results in curtailment of their own activities. In the following examples, concerns about holidays are expressed.

One thing that really does worry me is not being able to go on holiday because we can't afford the insurance. To go abroad and we love to go abroad, but because of the insurance price now, not just with his heart but with his back too, the prices are just too much. And it is something that we both really want to do again.....why should you pay such extortionate costs? Then that prevents the carer from having a holiday as well. (Female carer, partner diagnosed with HCM in 2012)

It was my birthday last weekend and he's organised a trip to London and that's freaking me out because I'm wondering how we're going to manage but he wants to do it so we're going for a couple of nights in London. I'm worried about it because I'm thinking how we'll cope but he's going to take his scooter and things like that so that will be an adventure. He won't give up but when he's not well I think, are we going to manage or will we be able to cope? (Female carer, partner diagnosed with DCM in 2001)

... a couple of years ago we would go to the Lake District and walk. That's clearly off the cards now, we may have a quarter of an hour wander round the side of a lake rather than go up the side of a fell and things like that... it's just kind of making adjustments to what she is capable of. (Male carer, partner diagnosed with DCM in 2012)

Carers can also find it draining to combine their caring role with their employment and the continuous pressure can take its toll.

I've just gone back to work. I took about five years off and I had a very stressful job before that then with my husband becoming ill I just took some time off because I was very close to having a break down. So I've just gone back to work in the last year and I feel much more relaxed about it now because I know that he is at home and he is safe and has all these things around him and I'm getting something out of life for myself and it's not just all centred around my husband, because it was before. (Female carer, partner diagnosed with HCM in 2012)

It's hard. It takes its toll. I was having to keep down a full-time job at the time but I was lucky I worked just near the tertiary hospital. It's time consuming and I think you need a good support unit, you need your family round you, and if it's not your family you need somebody to talk to, and I don't think you should bottle anything up. You need to talk, you need to ask questions, you need to find out things. (Female carer, partner diagnosed with DCM in 2009)

Although the importance of having someone to talk to is emphasised in the above quotation, the following respondent described how she was unable to share her fears with one family member.

I was babbling away and getting myself upset, and she said no disrespect but I don't want to talk about it. That's how I handle it, she says I don't want to, and I'm thinking but why talk about it in the first place then all of a sudden cut off. She said I can see you're upset about it but I can't talk about it. (Female carer, partner diagnosed with DCM in 2001)

Two carers who were involved with the Transplant Unit were pleased that their husbands had accessed psychological support via this route and felt it had been valuable.

We did have to see a psychologist and it sort of brought him out of his shell a little bit... it was suggested by the hospital, because they always used to say, oh where's my husband, oh where is he? Always sitting there in the corner, the quiet little man.... I don't know what it was but he just was quite angry. If he dropped a spoon it would be ah, ah, things like this. Just the smallest thing would just set him on edge and I said I wasn't happy with it, just like sort of bad moods. [Interviewer: And did it help?] It did yes. He seems to bottle things and I'm the other way round....we went together....she is there if we need her. (Female carer, partner diagnosed with LVNC in 2009)

Whereas this carer went with her husband to counselling, the other carer did not. She felt that although her husband had probably benefitted from talking to someone, she was a little left out.

...with him being on the heart transplant team he was assigned a psychologist, because they all are, because before you go on if he has any problems he can ask to see her at any time but seemingly he had had a word with her and I didn't think he would because he is not the kind who likes to talk about things, he's a do'er rather than a talker and I think he thinks counsellors and psychologists and all the rest are just twaddle but I think he had opened up to her, which I hope he had. He had had a word with her and with a social worker as well because she had said that he had opened up to her a little bit his concerns about what lay

ahead of him so I'm pleased in a way somebody has, you know he has maybe unburdened himself to tell them..... but I think they forget you are part of that person as well. You've got their day-to-day health to think about and you are the one who sees them when they are not well, you know if they are deteriorating in front of your eyes. It's you who sees that not them, so just maybe now and again you be taken away from the patient and just asked 'Are you ok? Do you need somebody to talk to?' (Female carer, partner diagnosed with DCM in 2001)

In conclusion, it does appear that cardiomyopathy has an impact on the carer as well as the person with cardiomyopathy and there may be times when carers would benefit from someone to talk to in order to help them deal with ever changing demands that caring brings.

## **Conclusion**

This report has highlighted the impact that a diagnosis of cardiomyopathy can have on a patient and has also highlighted the on-going ramifications of living with a chronic condition on both the patient and carer. There are times during the journey with cardiomyopathy when emotional or psychological support may be helpful. Diagnosis has been identified as such a time. However there are other times that patients may face emotional challenges – 'loss of self' through having to make major life changes because of a decline in health; the need for a device; the need for a heart transplant; feelings about passing the condition on to children; and an awareness of the impact on family members.

The two patients who sought out support through a GP both faced long waiting times to see a counsellor. Specialist psychological support was available but patients were not routinely given information about these services. Some patients have therefore experienced a challenging emotional journey through cardiomyopathy without the professional psychological support which may have helped make their journey a little more manageable.

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## **Summary – Impact of Cardiomyopathy on the Lives of Patients and Carers**

- Cardiomyopathy impacts on the lives of both patients and their families

- Diagnosis is a time when both information and support are needed. Respondents have identified a need for psychological support around this time - but this is often lacking
- Support also appears important at other times on a patient's journey – when something changes e.g. condition deteriorates, having an ICD fitted or ICD firing, when family screening is raised etc.
- Adjusting to a chronic condition involves re-managing expectations. Over time, living with the condition impacts on working life and social life. Giving up roles and activities that were previously enjoyed and valued can cause low mood.
- Referral to a counsellor through the GP meant long waiting lists which patients found off-putting.
- Health psychologists were valued but the service was not widely known about and there was no obvious referral path meaning access was ad hoc.
- Family members and carers are affected through taking on more duties, curtailment of previous activities, stress of caring role, combining work and care & everyday concerns such as holidays
- Carers have their own psychological support needs too – fear for the future, guilt and concerns for children. Carers sometimes felt their needs were overlooked.
- Carers would appreciate someone to talk to and valued the support group
- The Transplant Unit was described as a model of good practice where both physical and emotional needs are addressed.

## **Patients' Experiences around Diagnosis**

Cathy Stark

### **Background to study**

Three members of the North East England Cardiomyopathy Support Group<sup>1</sup>, supported by Julie Goodfellow<sup>2</sup>, BHF Cardiac Genetics Nurse, have undertaken research to examine patients' experiences of cardiac care services in the North East region. Twenty-one members of the local Cardiomyopathy Support Group (16 patients and 5 carers) were interviewed in September 2015, using a semi structured interview schedule and the interviews were transcribed and analysed thematically.

### **Introduction**

For the purpose of exploring experience around diagnosis, it was decided to focus on those patients who had received a diagnosis in the last 10 years as this would avoid historical accounts which may, perhaps, be unrepresentative of current care practices. Of the 16 patients in our sample, nine were diagnosed in the last 10 years. Of these 9 patients, 7 were diagnosed relatively recently between 2012 and 2015 and the remaining two patients were diagnosed in 2008 and 2009.

Five of the subsample were diagnosed with HCM, 3 with DCM and 1 with LVNC. Five respondents were given their diagnosis at a secondary care hospital, 3 at a tertiary care hospital and one by their GP (following an outpatient's appointment at a secondary care hospital).

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<sup>1</sup> Ian Mackersie, Vera Mackersie & Cathy Stark

<sup>2</sup> Julie Goodfellow, BHF Cardiac Genetics Nurse, Freeman Hospital, Newcastle-upon-Tyne

The first two sections of this chapter are based around the experiences of this smaller number of respondents (nine respondents who were diagnosed in the last 10 years), so we have explored their experiences using case studies. The third section on 'feelings at diagnosis' is based on findings from all respondents.

This chapter covers three main topics:

- Section 1 - The pathways to diagnosis
- Section 2 - Patients' experience of care at the time of diagnosis
- Section 3 - Feelings about being diagnosed with cardiomyopathy

## **Section 1 Pathways to diagnosis**

We have been able to identify the different pathways interviewees followed to diagnosis and what went well, or did not go so well, at this time.

Respondents reached their diagnoses through the following pathways:

1. Emergency hospital admission following a 999 call
2. Via consulting a GP
3. As a result of investigation for a different condition

### **Pathway 1 - Emergency hospital admission following a 999 call**

Three of the nine respondents were taken into secondary hospital A&E departments following collapse, black outs or severe chest pains. Two had previously consulted their GP about their symptoms.

The following patient felt there had been little to suggest he would have an acute episode. He had been to his GP with occasional ectopic beats while out running, but felt reassured after an ECG had not captured anything unusual.

Well basically I was fit and healthy and then I arrested. (Male, DCM)

Another had experienced increasing 'tightness' across his chest but had not followed this up.



I was getting, I wouldn't say pain, but just being really uncomfortable across the chest and around my ribs, and this just went on and on for quite a while actually. Then one night I got quite a bad bout and it was getting my breath. [Wife] said she had had enough and rang an ambulance...she thought I was having a heart attack. The symptoms were all there, I was sweating and in pain. (Male, HCM)

On admission, both were initially assumed to have had heart attacks and treated as such.

The finding that patients with cardiomyopathy are sometimes initially assumed to have had a heart attack is one which we noticed several times in our data.

The third respondent was also admitted to hospital following a 999 call after he blacked out at home. He had been diagnosed with AF by his GP and referred to a cardiologist, but had not yet had this appointment at the time the black outs occurred.

I didn't understand. I thought I had AF and I had looked at AF on various reliable medical websites and the consensus view seemed to be while it was a serious enough illness, it wasn't life threatening and beta blockers usually did the trick. It was a matter of dosage and what was best so I wasn't unduly concerned. But I was getting these episodes and by this time I'd decided not to drive myself because it didn't seem very safe. But I'd no idea I had something else, I just thought it was AF. (Male, HCM)

This example highlights the importance of a prompt appointment with a cardiologist and the merit of being told what to expect whilst waiting to see a consultant.

## **Pathway 2 – Consulting a GP**

Most respondents' pathway to diagnosis began with a visit to their GP. In our subsample, 7 of the 9 respondents consulted a GP before being diagnosed, although, as demonstrated above, not all were investigated by a cardiologist before an acute episode occurred. Despite having begun their journey at the GP, their experiences were very different.

On consulting their GP, two interviewees were immediately sent to hospital.

One presented with what he thought was a persistent chest infection after having earlier been diagnosed with swine flu.

I went to see my GP and he took a sounding of my chest and straight away got me whipped off to the secondary care hospital. That was in 2009. (Male, LVNC)

Once at the secondary care hospital, he was admitted and described his diagnosis of cardiomyopathy as 'very quick'.

The following respondent was also sent to hospital as an emergency by her GP after becoming breathless walking home from work.

I didn't even get past the receptionist, the doctor just told the receptionist to get me straight to A&E either by an ambulance and they would ring one, or my husband could take me. So that's how I ended up in A&E. It all sort of started from there. (Female, DCM)

Most patients are not sent straight to hospital by their GP but instead reach hospital via a GP referral to a cardiologist. However, there is variation in both the length of time it takes to get an appointment with a cardiologist, and the role the patient plays in this process.

Experience of a quick referral process is described by a respondent who presented at his GP surgery with his 'heart racing' and was referred to a tertiary care hospital, by request, as his son had been treated at this hospital for cardiomyopathy. He described his referral as 'very swift', and felt this may have been due to the fact that there was cardiomyopathy in his family, plus he had other health conditions.

In contrast, the following respondent also had cardiomyopathy in her family but described her experiences of the GP referral process as slow and 'unsatisfactory'. She explained how she had lost her father to HCM and had been screened over 10 years previously and reassured that her echo was normal and the abnormalities on ECG were 'not unusual'. In 2012, she saw her GP and asked to be rescreened. Her GP sent her to the secondary care hospital for an ECG and echo and then rang her at home two days later.

He didn't tell me that I should come into the surgery and could he have a chat with me, he just said that my results were abnormal and obviously I knew the thickening was the diagnosis and he just told me that, just cold on the phone and I had a house full of children because I was having a friend's children round for tea. So I had a house full of children downstairs and there was pandemonium and I was told I had this thing my dad died of when I was 13. (Female, HCM)

The GP told her that they had sent a letter to the cardiologist at the secondary care hospital and the respondent assumed this was a referral. However, after several weeks of nothing happening, she discovered that the letter had merely sought advice from the cardiologist. She described this time after her initial diagnosis as:

A couple of months of being in absolute limbo. (Female, HCM)

She then asked for a referral to the tertiary hospital, and once this came through, she felt that everything quickly moved forward.

A male respondent eventually diagnosed with HCM described how his journey to diagnosis was not straightforward, and, despite having heart 'problems' from the age of 37, he was not given a 'proper diagnosis' until age 65 in 2013. After being suspected of having a heart attack and following ECGs at a local hospital, he was told many times:

'You have a very unusual heart beat but it's nothing to worry about'...I had many occasions where I had the same symptoms and I went to hospital and they said 'there is nothing wrong with you, go away'. Until 2009 they did actually diagnose something but never told me.  
(Male, HCM)

In 2013, the respondent went to his GP with a fast heart rate and was referred to a tertiary care hospital. 'Tests were unremarkable' but an MRI scan and follow up appointment were arranged

...and this is when all these things are starting to be told to me. (Male, HCM)

### **Pathway 3 - Diagnosis occurred as a result of investigation for different condition**

One respondent was admitted to hospital for an operation unrelated to his heart. However, whilst in hospital his abnormal ECG was picked up by a doctor who asked about heart attacks in his family. The doctor then ran further tests which led to a diagnosis of HCM. This particular patient experienced the challenges of having more than one health condition and the issues that this brings in terms of care. The challenge of care provision across departments and hospitals is explored in more depth in 'Experience of Hospital Care'.

### **Conclusion to section 1**

Pathways to diagnosis work well when a patient's concerns are taken seriously and result in a referral to a cardiologist and a prompt consultation. The pathway to diagnosis is less positive when a patient is left 'in limbo' or has to wait some time for a cardiologist appointment and difficulties can be compounded when a patient is not given adequate

information about what may happen in this interim period. Patients' experiences of care at the time of diagnosis are explored in the next section.

## **Section 2 - Experience of care at diagnosis**

Some interviewees were given their diagnosis as a hospital inpatient after being admitted due to an acute episode; others were diagnosed as outpatients. The findings in this section are divided into inpatient and outpatient care. Some interviewees positively described the care they received at diagnosis, while others portrayed their care experiences in less favourable terms. It is important to understand the patient experience to help identify how patient care at diagnosis could be improved in the future.

### **Experience of inpatient care at diagnosis**

After initially being diagnosed with AF by his GP, the following respondent was admitted to a secondary care hospital following an acute episode. His condition was stabilised although no diagnosis was given at this point.

They told me I didn't have AF, but they weren't too specific about what I did have....They said 'we think we know what it is' but they didn't tell me. It was clear to me that this was a lot more serious than just AF. (Male, HCM)

Aspects of the secondary care hospital were less than satisfactory.

Well I was starting to feel a bit better until the amiodarone kicked in and that made me very anxious and I couldn't sleep. Initially I was in a private room but then they put me in a ward with a guy who was dying, very noisily and messily, in the next bed, and some other blokes and it turned out that in that ward at [secondary care hospital] they had people with all sorts of conditions and not just cardiac conditions and I don't know but I must have ended up on a ward with everyone who was dying because it was a horrendous couple of nights. (Male, HCM, above)

A bank holiday weekend delayed his MRI scan for four days but a diagnosis followed immediately after the scan.

...It was half an hour after I'd come out of the scan that my cardiologist said 'we know what it is. This is what it is and this is what is going to happen'. (Male, HCM, above)

He was immediately transferred to a tertiary care centre and a device fitted.

I think I was relieved to know what it was and I was quite relieved to know I was going to a tertiary care hospital, which I've got, for other reasons, a lot of confidence in....and the following day after the diagnosis, I was fitted with the ICD and the following day I was out. ...It was very quick. Very, very professionally done. No complaints about the care I got at the tertiary care hospital...it was altogether a more genteel place. There was nobody dying in the next bed. It was more calm and there was clearly a lot more money about (Male, HCM, above)

...it was the difference between a city hospital and a suburban hospital (Carer of male with HCM, above)

The contrast between secondary and tertiary care hospitals is something that other interviewees have described. However, it is not a clear cut picture. There are aspects of care that are deemed positive and aspects that are deemed negative across both secondary and tertiary hospitals. This is returned to in 'Experience of Hospital Care'.

On discharge, the above respondent did not feel he had been adequately prepared for what to expect in the early days and weeks of living with an ICD. He had not appreciated that he may experience further episodes. He was keen to suggest that contact with a specialist nurse would have alleviated many of his - and his wife's - concerns. Managing expectations after diagnosis is a recurring theme in our data. The next case studies examine the difference in patients' experiences when a specialist nurse is available on discharge compared to when this service is lacking.

The value of the specialist nurse is emphasised by the following two respondents who were diagnosed at a secondary care hospital and, on discharge, care was provided by specialist nurses. They valued the support their nurse provided in the early days following their diagnosis of cardiomyopathy.

...the heart nurse I got from the secondary care hospital she was fantastic. They've got a great education programme across there. The support you get from the heart nurses, they're BHF supported. So they do a fantastic job. (Male, LVNC)

Another interviewee highlighted the practicalities of having a community nurse visit him at home when he was poorly in the early days following his diagnosis.

The community heart nurse...was champion, because it saved me going to the GP for blood tests and what not....that was good, they would come to your house. It's a lot easier than going down your GP's then giving blood and waiting for the results. (Male, DCM)

The following respondent felt the care he had received at both the secondary and tertiary hospitals as “absolutely spot on”. After several days in a secondary care hospital in an induced coma after a collapse, he was transferred to a tertiary hospital, had further tests and was given a diagnosis of DCM and fitted with an ICD. However, he did not feel he had been adequately prepared for life after discharge and struggled until a BHF nurse came to see him.

The care was fantastic, no problem at all. The only thing is, the discharge from the tertiary care hospital, not one told me what to expect. And I was told by one of the nurses, that I’d be back at work in 3 or 4 weeks and I think they were treating like I’d had a heart attack and clearly I’ve never been able to return to work and I’m still quite unwell, but my expectations were much higher than my recovery on my discharge from tertiary care hospital...you’ve got the ICD in now, you’ll be fine and they didn’t really explain what the cardiomyopathy meant and also they didn’t address the psychological effects which were devastating really. So that was very difficult. When we first came out and the first few days back home were – well they would have been difficult anyway – but I think we didn’t have the full picture at all and it was the heart failure nurse who came to see us just a few days later who was absolutely brilliant. She was a BHF heart failure nurse and she was incredibly helpful and really explained what was going on. (Male, DCM)

The respondent initially felt he was being treated like he had had a heart attack and that his recovery would follow a similar path. The confusion between cardiomyopathy and heart attack is apparent in the next case study.

The following respondent was in hospital for 3 days, during which time he was repeatedly asked if he had ever had a heart attack as his ECG appeared to suggest this.

There is a thing on my ECG that says I look like I’ve had a heart attack and it was this again when they got me into hospital and on the ECG it was picked up by the doctor and I got asked again have you ever had a heart attack in the past. Not that I know of. As far as I knew I hadn’t. This went on and on and on. (Male, HCM)

However, on his third day in hospital he was given an echo and then sent home with an appointment to come back and see the cardiologist at the secondary care hospital as an outpatient.

### **Experience of outpatient care at diagnosis**

The above patient received his diagnosis of HCM at an outpatient appointment. He felt both support and information were lacking at the time of diagnosis.

[I needed] some sort of help other than what I actually got. There was just nothing. I mean you could have knocked me out with a feather when I was walking along the corridor out of his office after he told me what it was ... (Male, HCM)

He was eventually transferred to the tertiary care hospital for an ICD and felt that his care and his understanding of his condition improved at this point as he valued his consultant.

I wish I'd been under him in the first place because he is an absolutely smashing guy. Totally different. He went into it all properly. He was easy to understand and he took the time, whereas others you just seem to be in and out (Male, HCM, above)

A comparison is drawn here between care at the secondary and tertiary hospitals. However, the most important issue for the patient was getting accurate information about what his condition was and what it meant. It does suggest that, regardless of which hospital he was attending, had this patient accessed appropriate information and support at the time of diagnosis, some of his concerns could have been alleviated and his questions answered at a much earlier stage, saving him, and his wife, stress and anxiety.

Other patients also felt their care at the time of diagnosis was less than satisfactory. Despite having been referred straight to A&E by her GP, the following respondent was sent home after a 'clear' chest X-ray and was given warfarin in case the pain she was experiencing in her legs was caused by an embolism. She was asked to come back the next day for an MRI scan but on arrival, she was told that the scan could not go ahead.

I did go back the next day but they hadn't got the paperwork signed by the right people so instead of ringing me to say we can't do it today I went back in. They couldn't do the scan because they couldn't interrupt the consultant. They said that even after the warfarin injection they were still going to treat me as if I had an embolism. But because I had the injection late at night, it was 11 o'clock, I was going to have to do it myself or they would have to get the district nurse out. I have a thing about needles so my husband did it and then I went back the next day for the scan. The scan showed that I had fluid on the lungs, even though they hadn't heard anything and there was nothing on the x-ray, they could see they said I had fluid on the lungs and that my heart was very enlarged and floppy and there was some problem. And I don't think they actually told me it was heart failure then, they just said that I would have to see the consultant and they gave me some beta blockers and some water tablets and sent me home (Female, DCM).

This respondent was also being treated in another department at the same hospital for a different condition. Whilst waiting to see a cardiologist, she received a clinic letter from the other department.

When I got his clinic letter he'd actually put in medical conditions – "heart failure". So I sort of found out by accident. I don't know whether I blocked it out but I didn't actually do

anything about it because I think by that time I'd got the appointment to go and see the consultant [cardiologist], so I just waited. (Female, DCM, above)

However, once she got to the cardiologist appointment, the process of diagnosis still did not run smoothly

Well it was a new registrar to start off and he didn't actually have anything in the notes, so he didn't know why I was there. So I told him that I had been to A&E so he sent someone away to the notes that were missing, then a scan, then he told me. Then he went and got his consultant to come in and confirm it. (Female, DCM, above)

In comparison to the positive stories about specialist nurses documented so far, this respondent's experience was, once again, less than satisfactory.

My one main bug about secondary care hospital was that you didn't get any information and they didn't answer your questions....No one to go into all the little bits and moans and things. The cardiac nurse once told me when I rang her I don't know why that's happening - go and see your GP. The GP couldn't believe it and that's when I transferred over to the tertiary care hospital. (Female, DCM, above)

She transferred from the secondary to a tertiary hospital and, like some other respondents, felt her care improved at this point.

However, in contrast, the following respondent received his diagnosis as an outpatient at a tertiary care hospital after many years of heart 'problems' and he felt that information and support from the tertiary care hospital were lacking at the point of diagnosis.

I didn't know what to do except wait for my next appointment and my next appointment was with the main man himself, a cardiologist. So he comes in with the full diagnosis of myosepto hypertrophy, mild impairment of the right ventricle as well and possible hypertrophic cardiomyopathy. So now I've got three things, four things including my aortic valve. So I'm petrified about them thinking am I going to die tomorrow. Nobody really tells you much. Again he said has anybody talked to you about your full diagnosis and again I said not really. They have told me bits and pieces but it doesn't mean a lot to me when people tell me these things. Again I left there feeling...well they don't give you any avenues through which you can find help. You've only got ten minutes in the meeting of course as well. So I've got these things and I'm thinking my god what is happening to me? So I left there starting to feel quite depressed to be honest and I think I went through a period of about 18 months being depressed, because at the same time I was getting diagnoses about other parts of my body which weren't very pleasant. So I was in a bit of a mess to be honest but like all things you fight your way through it. (Male, HCM)



In contrast to the findings on lack of information and support, another respondent spoke in glowing terms about her experience of diagnosis. Once she was transferred to the tertiary care hospital, she no longer felt she was 'in limbo'.

I was impressed at how quickly I was put through the tests and they got all the results  
(Female, HCM)

She described the care and support she received from the multidisciplinary team.

You know [cardiologist has been] absolutely amazing and [genetics nurse] has been amazing. When I first got diagnosed I had this consultation with most people in the room me and my husband and my friend who's a GP, she was there, as well because I'd been a patient at a secondary care hospital before coming here to see the cardiologist and he was there and [genetics nurse]. It was a very small room and he was going through loads and loads of stuff heavy stuff about needing the ICD and everything lots of really heavy stuff to do with the diagnosis, it was the second time I had seen him, he was actually sat on the floor next to me, just so nice just really caring. I'm just actually glad that I'm under the tertiary care hospital. (P12, 483-92)

She described her consultant by saying "he's just been great" and the genetics team were also held in high regard "the specialist services here are fantastic".

## **Conclusion to section 2**

Our findings suggest that the way in which a diagnosis is handled is important. The need for information and support at diagnosis is clear, both for inpatients and outpatients. The value of specialist nurses as information givers, support providers and practical helpers is highlighted, albeit with reservation in the case of one respondent. Detailing both positive and negative experiences is important when documenting patients' views. Suggestions for improvement at both secondary and tertiary hospitals include better communication between patients and medics in terms of information and managing expectations, and a faster referral process. However, examples of good practice have also been highlighted – clear explanations at diagnosis and follow up support on discharge.

The final section of this chapter examines how interviewees felt when given their diagnosis of cardiomyopathy. The findings reiterate that support and information are needed when a life changing diagnosis is received.

## **Section 3 Feelings at diagnosis**

Interviewees were asked how they felt after receiving a diagnosis of cardiomyopathy. A range of emotions were described ranging from 'relieved' to 'bereaved'. In this section responses from all interviewees have been included as analysis suggested that feelings were similar for those diagnosed in the last 10 years and those diagnosed more than 10 years ago. At the time of interview, two respondents had been diagnosed with cardiomyopathy less than a year; 5 had been diagnosed between 1 and 3 years; and nine respondents had lived with cardiomyopathy for 8 years or more, with 3 of these having the condition for over 20 years. The year of diagnosis is given in brackets after the quotation.

When reflecting on how they felt at diagnosis, respondents described a range of emotions from 'relieved' to 'bereaved'.

Feelings of relief were described by interviewees once an explanation had been given for what they had been experiencing.

When I came to the cardiomyopathy clinic a lot of people said you're newly diagnosed you'll still be in shock. And I kept thinking in a way I was relieved that they'd found what was the matter. I was relieved I had a diagnosis and they could do something about it. (Female, DCM diagnosed 2013)

Well better because I knew what it was....It settled me down. You know what I mean, because I couldn't find out what it was. (Male, HCM, diagnosed 2003)

I think I was relieved to know what it was (Male, HCM, diagnosed 2015)

In contrast, others described how a diagnosis could have a dramatic effect on their sense of self. One respondent described his diagnosis and the resultant loss of his working life as an "intense bereavement" (Male, DCM, diagnosed 2014). The commonly recognised 'stages of bereavement' (Kubler-Ross, 1969)<sup>3</sup> – denial, anger, bargaining, depression and acceptance – appear to be reflected in patients' journeys.

I was told I had this thing my dad died of when I was 13. Looking back I was probably in denial and it was a surprise to me (Female, HCM, diagnosed 2012)

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<sup>3</sup> Kubler-Ross, E. (1969) *On Death and Dying*, New York: Macmillan

Being diagnosed with a heart condition was a blow to the following respondent. His lack of understanding about cardiomyopathy at the time of diagnosis led him to wonder whether he was somehow to blame. He felt that his lifestyle was not the cause and therefore was left with unanswered questions.

Drained. I didn't understand it because I didn't know what cardiomyopathy was....I have always been a hardened worker, working on a farm. I played rugby until I was 37.... I never smoked. I hardly drink. Why me? That was the first question I asked myself. Why is this happening to me? That's as much as I can say. (Male, DCM, diagnosed 2001)

Being diagnosed with a heart condition was difficult for respondents who described themselves as physically very fit prior to diagnosis.

That was a big hit for me as a man who is a marathon runner. I was a very fit guy. I mean I had coped with this fast heart beat all my life and being short of breath, I've always coped well with it because you force yourself to. So I left there feeling in a mess to be honest and I didn't know where I was. Then you start to feel pretty alone with things, and think who do I turn to here? (Male, HCM, diagnosed 2013)

The feelings of isolation expressed in the above quotation related to 2013. Such feelings were also described by another respondent in relation to a diagnosis made over 20 years earlier in 1991.

I don't know I felt a bit freaky to be honest, like it was something very unusual that had just happened to me ... so it was quite isolating, I think is probably the word I would use, at the time. (Female, PPCM, diagnosed 1991)

Other interviewees described their feelings at being diagnosed with a condition that existed in their family.

Not surprised but not happy (Male, DCM, diagnosed 2008)

I was told that I could drop down dead at any time ... It floored me actually, when he told me what it was and what it could potentially do. Especially with what's happened in the past with my family (Male, HCM, diagnosed 2012)

Finally, the following respondent suggested that, in the 20 years since his diagnosis, he has accepted his diagnosis of cardiomyopathy.

Well I wasn't too happy, put it that way, but after a while you just say 'Well if you've got it, you've got it'. (Male, HCM, diagnosed 1998)

### **Conclusion to section 3**

Feelings around the time of diagnosis can vary from relief that the problem has been recognised and given a name, to feelings of bereavement as people try and cope with the losses and changes that such a diagnosis brings. It seems a diagnosis can be particularly devastating for those who have followed a healthy lifestyle and have kept themselves physically fit. Where patients are already aware that cardiomyopathy has caused death in their family, a diagnosis can be an extremely anxious time. Once again, the importance of support has been highlighted and diagnosis identified as a key time when this is needed.

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### **Summary – Patients' Experiences around Diagnosis**

- Experiences around the time of diagnosis focussed on a subsample of patients who had been diagnosed in the last 10 years in order to avoid historical accounts.
- Respondents reached their diagnoses via different pathways: emergency admission to hospital following a 999 call; referral to hospital after consulting their GP; as a result of an investigation for a different condition.
- Emergency admissions to hospital were sometimes initially suspected of having had a heart attack
- The pathway to diagnosis works well when a patient's concerns are taken seriously and result in a swift referral to a cardiologist and a prompt consultation.
- The pathway to diagnosis is less positive when a patient is left 'in limbo' or has to wait some time for a cardiologist appointment. Difficulties can be compounded when a patient is not given adequate information about what may happen in this interim period
- Feelings around the time of diagnosis can vary from relief that the problem has been recognised and given a name, to feelings of bereavement as people try and cope with the losses and changes that such a diagnosis brings.
- A diagnosis can be particularly devastating for those who described themselves as previously very physically fit and active.
- Where patients are already aware that cardiomyopathy has caused death in their family, a diagnosis can be an extremely anxious time.

- The way in which a diagnosis is handled is important. The need for information and support at diagnosis is clear, both for inpatients and outpatients.
- The value of specialist nurses as information givers, support providers and practical helpers is highlighted. Those who were visited by a community or BHF nurse at home on discharge from hospital felt that helped manage expectations and the condition.
- A comparison can be drawn between care received at secondary and tertiary hospitals. Tertiary care was, on the whole, reported positively. Suggestions for improvement at both secondary and tertiary hospitals include better communication between patients and medics in terms of information and managing expectations, and a faster referral process.
- Examples of good practice have also been highlighted – clear explanations at diagnosis, follow up support on discharge.
- The importance of support has been highlighted and diagnosis identified as a key time when support is needed.

## **Patients' Experiences of Consultant Cardiologists**

Cathy Stark

### **Background to study**

Three members of the North East England Cardiomyopathy Support Group, supported by Julie Goodfellow, BHF Cardiac Genetics Nurse, have undertaken research to examine patients' experiences of cardiac care services in the North East region. Twenty-one members of the local Cardiomyopathy Support Group (16 patients and 5 carers) were interviewed in September 2015, using a semi structured interview schedule and the interviews were transcribed and analysed thematically.

### **Introduction**

All the interviewees had comments to make about their experiences with consultant cardiologists. Some respondents had experience of consultants at both secondary and tertiary care hospitals. There were both positive and negative comments made about consultants and these were made in relation to both secondary and tertiary care hospitals. However, when asked to identify a person or persons who had been especially helpful in the patients' journey with cardiomyopathy, many identified their consultant as having been particularly helpful. It appears that when the consultant-patient relationship works well, it is highly valued as an expert source of information and support.

Patients value consultants who:

1. Inspire confidence due to their expertise
2. Take time with patients
3. Provide clear, jargon-free explanations
4. Are contactable between consultations

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Patients value consultants who:

1. Inspire confidence due to their expertise
2. Take time with patients
3. Provide clear, jargon-free explanations
4. Are contactable between consultations
5. Make the patient feel valued

### **1. Confidence in the consultant's expertise**

Respondents mentioned the importance of having confidence in their consultant's expertise.

...he's so knowledgeable about this subject I think he was probably the most helpful [person I saw]. (Male, HCM)

I feel confident with him. He knows his stuff and he's available. (Female, DCM)

My consultant is particularly good. He has an excellent reputation he is an excellent clinician from the patients' point of view. (Male, LVNC)

It's very reassuring to have the sort of confidence in your consultant, it's just priceless really. (Female, HCM)

Just confidence in him. We've known him through my son's treatment and mine. (Male, DCM)

## **2. Taking time with patients & providing clear, jargon free explanations**

Consultants who took time with their patients were valued. This went hand in hand with having the time to provide full, clear explanations. Avoiding or explaining medical jargon was also valued.

He spends time with you. He has a clinic it's supposed to finish at 12 o'clock and it's usually about 2 or 3 o'clock before it's finished....Yes, he takes time and he does drawings and says this happens and he does it in layman's terms, you know, instead of all these different names for things. (Male, HCM, secondary hospital)

I wish that I had been under him in the first place because he is an absolutely smashing guy. Totally different...He went into it all properly. He was easy to understand and he took the time, whereas others you just seem to be in and out. (Male, HCM, tertiary care hospital)

And he was there for a good hour and he was very good...after I'd spoken to the cardiologist stuff became an awful lot clearer. (Male, HCM, tertiary care hospital)

Conversely, most of the negative comments about consultants were centred on these same two issues – lack of time and lack of clarity.

I think that ten minutes is a little bit of a push to go through something in ten minutes when you are flooded with information like you could have a cardiac arrest and die, then see you later. (Male, HCM, secondary hospital)

I mean I've heard of bits and pieces like aortic valves but I didn't know what hypertrophic was or cardiomyopathy was, I still don't know really. So no, I didn't understand the jargon and nobody explains it because it's all done in ten minutes.....when it is your life, just ten minutes to discuss your situation... (Male, HCM, tertiary hospital)



I found like the cardiologist [at the tertiary care hospital] they haven't got the time to sit and go through things with you. They'll tell you exactly what's happening, take your blood pressure, examine you and then you're out. (Male, HCM, tertiary hospital)

It was suggested several times that the 10-15 minute time slot allocated to a consultation was too limited.

I mean Dr [X] is a lovely guy, a really nice chap, but his time is limited, 15 minutes or something like that. I mean I asked the questions I wanted to ask but it would have been nice to have a more general conversation about things. (Male, DCM, tertiary hospital)

Respondents also recognised the high demands on their consultants and that factors outside their control could cut a consultation short.

The only thing I find, everybody probably says this, is sometimes you come to see consultants and they've either been called away .... that seems to happen every time you come. They are either busy or they are late or ... I appreciate they have to go and treat patients who are more urgent. (Male, DCM, tertiary care hospital)

I've been in seeing the cardiologist at the tertiary care hospital and then he gets a phone call and he says sorry I've got an emergency and I've been in when sometimes he hasn't even examined me and he says I'll see you next time which I understand obviously when there's an emergency he's got to go. (Male, HCM, tertiary hospital)

### **3. Being able to contact the consultant between appointments**

As a result of recognising the limitations of the time-restricted consultation, being able to contact the consultant outside of this allocated time slot was highly valued.

[During a life threatening episode] I contacted my cardiologist. He had given me his direct phone number. If I had any problems to ring him. I rang his secretary. He rang me back.....He saw me the next day straight away in clinic and within two days I was admitted... So he acted very fast. I couldn't fault the way I was looked after. I can't fault the care I've had from the tertiary care hospital. (Male, DCM, tertiary care hospital)

Having an email address was particularly helpful.

He's even said, he's given me his email address, email me. Which you didn't get at a secondary care hospital. I've emailed him once and he came back straight away. That was just wonderful. (Female, DCM, tertiary care hospital)

The cardiologist is amazing. I've been worried about something. He's very modern I send him an email and he's really busy and I've had times when there's been something I want to ask him and I've sent him an email and he's replied to me a few minutes later. Not all the time but sometimes, I think that's just amazing. (Female, HCM, tertiary care hospital)

I got caught up in the reassessment for employment support allowance and disability living allowance and they tried to send me back to work when I was particularly ill and I emailed my consultant and said look could you do me a letter and within 15 minutes he got one back to me. That sort of thing. That's not just pretty good that's exceptional for a consultant. I don't think it's exceptional for him from the stories I've heard. He does that for all his patients. (Male, LVNC, tertiary care hospital)

#### **4. Feeling valued by the consultant**

Patients appreciated and valued consultants who seemed genuinely interested in their case.

Patients valued being listened to, having their concerns taken seriously and being able to ask questions.

...in fact a cardiologist was great he said there's not much point in me seeing you now because you're being seen by two centres but rest assured - which is really nice and I think is worth noting - he said 'if anything ever happened to you cardiac-wise and you were admitted to hospital tell them to ask for me and I will try to sort it as best I can'. (Male, HCM, co-morbidity, attends other hospitals)

He was there when I had the operation, he checked through the operation that I was fine. So I don't think I could ask for better than that. (Female, HCM, co-morbidity, secondary care hospital)

I mean he does, he gives you the opportunity to speak first. When he does his examinations tells you what he thinks then asks you if there's any other questions and I've got the opportunity to email him so really, what more do you want? There's been times when I've been in to see him for an appointment when he's said I think you should have a little echo or an ECG and he's waited until I've had them done and I've gone back to clinic and he's given me the results. Which is really good because a lot of doctors wouldn't have done that, you'd have waited to the next appointment. (Female, DCM, tertiary care hospital)

He was helpful because he took them [concerns] seriously which was quite reassuring that there was somebody there who was prepared to listen. (Female, PPCM, tertiary care hospital)

#### **5. Unsatisfactory experiences**

However, there were respondents who were not entirely satisfied with certain aspects of care they had received from their consultants.

...you walk into his place and go to shake his hand and he doesn't even want to shake your hand and you think 'well that's not a very good start to this 10 minute meeting I'm going to have'. Maybe that's just the guy's bedside manner and it's not a big deal and I can get over that. But I sort of think that you should be treated in the right way and treated as somebody important as a patient. You want to feel that they are interested in your problem. Not just a

'how are you?' 'I'm feeling pretty good' 'OK we will see you in 12 months goodbye'. I think there is more to my problem than that. (Male, HCM, tertiary care hospital)

The fact that there can be up to 12 months between consultations meant that patients could be left with unanswered questions during this time.

Then you think wow hang on...so I'm not going to get any better it's just going to get worse. That's what I'm left with for a year... (Male, HCM, secondary care hospital)

## **Conclusion**

Patients' perception of 'good quality care' appears variable. There are clear examples of some consultants providing a level of care that is highly valued by patients, for example, spending enough time with each patient to accommodate their needs and providing email addresses and responding quickly to questions by this route. However, not all patients experience this level of care. Some felt consultations were too short, explanations were unclear and they were left with unanswered questions between consultations.

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## **Summary – Experience of Consultant Cardiologists**

- Patients voiced both positive and negative experiences of their consultant cardiologists in both secondary and tertiary hospitals – but in general experiences were described as more positive than negative.
- When a patient-consultant relationship worked well it was valued by patients as an expert source of information and support.
- Consultants were often identified as someone who had been particularly helpful to the patient.
- Patients valued consultants who took their time with patients.
- Patients valued jargon free, clear explanations.

- Being able to contact a consultant between consultations was especially valued. Email contact was particularly appreciated.
- Patients liked to feel valued by their consultants which included being listened to, having their concerns taken seriously and being able to ask questions.
- The 15 minute consultation was felt to be too short.
- On occasion, the time between consultations was considered too long and patients could be left with unanswered questions.

## 4

# Experience of Hospital Care

Julie Goodfellow

### Background to Study

Three members of the North East England Cardiomyopathy Support Group<sup>1</sup>, supported by Julie Goodfellow<sup>2</sup>, BHF Cardiac Genetics Nurse, have undertaken research to examine patients' experiences of cardiac care services in the North East region. Twenty-one members of the local Cardiomyopathy Support Group (16 patients and 5 carers) were interviewed in September 2015, using a semi structured interview schedule and the interviews were transcribed and analysed thematically.

### Introduction

Interviewees have a vast experience of hospital care, both acutely, when they have been unwell, or at diagnosis and during ongoing care. Hospital care has been delivered at both secondary care hospitals (usually district general hospitals local to where the interviewees live) and tertiary care hospitals (hospitals providing specialist cardiology and other specialist services). There are examples where interviewees are cared for by more than one hospital and this is described as 'cross care'. The examples of hospital care described in this section are both positive and negative across both secondary and tertiary care settings. Examples of care described span many years, as interviewees have had diagnoses of cardiomyopathy for varying amounts of time, from very recent to 20 years plus. Interviewees were asked to particularly recall examples of acute hospital care within the last ten years.

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Much of the information within this section will overlap with information presented in other chapters, notably 'Experience around Diagnosis', 'Information Provision', 'Experience of Consultants' and 'Support suggestions'. Communication with and between professionals, quality of information given and support available have been touched on elsewhere, but are prevalent when describing hospital care. Examples are described as positive or negative by where care was delivered, direct comparisons between secondary and tertiary, differences in knowledge of hospital staff and examples of cross care. Carers also described hospital care given to their loved ones.

This chapter is divided into the following six sections:

1. Experience of care at more than one hospital
2. Cross care
3. Frustrations at pathways of care
4. Examples of good hospital care
5. Examples of poor hospital care
6. Suggestions for improvement

## **1. Experience of care at more than one hospital**

Most patients had experience of care at more than one hospital, usually a secondary care local hospital and a tertiary care specialist unit, often further from home. The following quotes reflect this experience.

I was taken into a secondary care hospital first then transferred to the tertiary care hospital...Then I was transferred direct back into the care of a tertiary care hospital so I missed out seeing any local cardiologists. I came straight into the care of a cardiologist there.  
(Male, DCM)

I attend a tertiary care hospital now but originally it was a secondary care hospital (Female, DCM)

### **Direct comparison between secondary and tertiary care**

Perceptions of expected care and perceptions of care actually received varied between secondary and tertiary care hospitals. Interviewees gave direct comparisons between secondary and tertiary care hospitals (both within and outside of the North East region).

Some participants reported a lot of confidence in the tertiary hospital.

I was quite relieved to know I was going to a tertiary care hospital which I've got, for other reasons, a lot of confidence in. (Male, HCM)

Then transferred to the secondary care hospital which I didn't like and then you come in to the tertiary care hospital and when they say something is going to happen it happens...It gives you confidence.....Things happen when they say it will, they listen to me and they include my family in things. (Male, DCM)

Some described why they have faith in the tertiary hospital.

...cardiologist at a secondary care hospital said that I would eventually need a heart transplant which is frightening with the thought of it. A cardiologist said he would have to argue with the transplant team about putting a heart into me having a [rare co-morbidity]. And I said to him 'I'm 53 years old it's taken 50 years to get to this stage' and yes he said that would be the argument he'd put forward to say it's worth trying transplant with me. A professor at a tertiary care hospital said 'nowhere near. It will probably never happen'...It's not about belief, it's about faith. Who do you put your faith in?...that's another example of who do you believe? (Male, HCM and co-morbidity)

The reputation [in response to being asked what attracted the patient to the tertiary care hospital. (Male, DCM)

Well, as I say, I was made very comfortable in the tertiary care hospital, you know I felt very comfortable and very safe in the tertiary care hospital because it's supposedly the best heart hospital in the country. (Male, HCM)

Well, since I've moved back the care at the tertiary care hospital has been brilliant. But I've had a couple of acute occasions when I've been admitted into a different hospital and I've got to admit the care was very poor. (Male, DCM)

There were direct comparisons made between secondary and tertiary care. In particular, perceptions of communication being better at the tertiary hospital were vocalised.

That is the difference between the tertiary care hospital and secondary care hospital. At the tertiary care hospital they tell you what's going on and at secondary care hospital they don't. (Male, DCM)

The tertiary care hospital came highly recommended by others in the [support] group....Absolutely fabulous. My one main bug about secondary care hospital was that you didn't get any information and they didn't answer your questions. (Female, DCM)

I think in terms of the difference between the hospitals, it is just that information part of it that would put our opinion of the tertiary care hospital in a better place than the secondary care one. You could talk to somebody, you didn't feel as though you were rushed through the appointment. They took the time with you. (Male carer of female, DCM, above)

One participant described how she had good care at both secondary and tertiary hospitals, particularly related to her faith in a consultant who is now retired.

Now it is the tertiary care hospital. It was for 20 odd years a secondary care hospital. And a cardiologist now retired ... Yes at both hospitals it's been very good (Female, HCM, talking about where care is delivered)

## **2. Cross care**

Some patients had experience of being cared for by more than one team of health professionals at the same time, usually between hospitals, but also commented on examples of care divided between primary and hospital care (referred to as 'cross care').

Cross care is often complicated and can cause some perceived and real problems with communication.

...because oddly enough, another cardiologist at the secondary care hospital doesn't have access to downloads from my device, cos I've got a monitor upstairs, whereas the RMT [Rhythm Management Team] have access to this all time, as does the cardiologist at the tertiary care hospital. I did raise this and they said 'oh it's a confidentiality matter'. No, they said it was 'a matter of interpretation'. (Male, HCM)

Well it's quite complicated. I was getting some care in secondary care hospital, the device was being looked after in tertiary care hospital but other heart related care was around the secondary care hospital. But everything is now centred under a cardiologist at the tertiary care hospital so it's been quite complicated..... But there was very little communication between the secondary care hospital and the tertiary care hospital. (Male, DCM)

So it got really complicated....Yes getting information across...basically I ended up being the conduit for information..... I've just found that the NHS is brilliant for the acute care but the longer term care, it's difficult, particularly between Trusts....I'd say above all else, communication across the network [needs improvement]. I'd say communication across the NHS network was very poor and in particular in between teams and trusts. (Male, DCM)

....every time you go you get these letters and I say can you send a copy to the doctor at the secondary care hospital so he knows exactly what's happening but he never gets them...It works that way but not from a tertiary care hospital. So all these letters I get from the tertiary care hospital I take to the doctor at the secondary care hospital and he just ends up photocopying them. But it shouldn't work that way. They should send him the information. (Male, HCM)



## Care across secondary and tertiary hospitals

Interviewees reported care across secondary and tertiary hospitals, where the tertiary hospital was used to provide clarification of a diagnosis.

..I've always been between the two. I originally got diagnosed by a secondary care hospital. They suspected that because they did a lot of tests over a couple of years and then they had to send me here for clarification of what they thought it was. (Male, HCM)

## Specialist care for different health problems at different hospitals

Some participants described how they receive specialist care for different health problems at different hospitals and this can sometimes cause problems.

Well what happens is they put it in and I think mine is set at 80 beats but you can have it lower or higher and then there's different things, I don't know what they're called, for when you're having these pulses in your heart. So they [tertiary hospital] did it and when I went to the Syncope Unit [at secondary care hospital] they wanted it changed. So I had to go in again [to tertiary hospital]. They got in touch and told them exactly what they wanted it set at. (Male, HCM)

...Now. There's a story. I actually attend 3 centres. I attend a secondary care hospital where I was diagnosed with a rare diagnosis....I am seen at the tertiary care hospital by their team and I am seen by the team at another tertiary care hospital....And there's a cardiologist at a secondary care hospital – how he came up with testing for the rare diagnosis only he knows. But he found it in my brother and suggested that I was tested. And I was tested at another secondary care hospital heart department and it was proven to be a rare diagnosis....it was a specialist at a tertiary care hospital that suggested I had a defibrillator put in. I had the defibrillator put in here at the tertiary hospital about a year later. (Male, HCM & co-morbidity)

The tertiary care hospital for all my heart problems and my vasculitis and my liver problems. But I go to another secondary care hospital for neuropathy. (Male, DCM, co-morbidity)

National Health Service and at the click of a button on a computer you should be able to send test results. And, if any consultants up here are listening to this one, I'm so angry about this I have actually tried to make an appointment at a local hospital to speak to one of the consultants who I'm see there for my kidneys. I said we have two centre of excellence in the North East, local hospital and a tertiary hospital and they do all the tests. I've never had a test anywhere but here, so why can't they send these results 'ah' they said 'they may not be as thorough as what we do'. But that is b\*\*\*\*\*t. (Male, HCM & co-morbidity)

... I said how come they are not getting in touch with my siblings to have a follow up and he just said 'I don't know, they're the ones who are doing it'. (Male, HCM)

### **Examples of good cross care**

Some participants reported that cross care between secondary and tertiary hospitals was good, with consultants suggesting solutions to cross care problems.

I mean when I got transferred over here I might have just been under the care of the tertiary care hospital but he [consultant] asked... because he said, 'I took you through it, I'd like to see how you get on'. Cos he was the one that phoned a cardiologist at the tertiary care hospital and said 'do you not think you should see if he is suitable for a transplant?' (Male, HCM)

I was more than happy to rationalise my care – in fact a cardiologist was great he said 'there's not much point in me seeing you now because you're being seen by two centres but rest assured', which is really nice and I think is worth noting he said 'if anything ever happened to you cardiac-wise and you were admitted to hospital tell them to ask for me and I will try to sort it as best I can'. (Male, HCM & co-morbidity)

Once they had decided they were out of their comfort zone in the secondary care hospital they were fairly swift in handing me across to the cardiology team at the tertiary care hospital (Male, LVNC)

### **3. Frustration at pathway of care**

Interviewees gave examples where they felt frustration at the pathway of care, or journey through the hospital system. Frustrations were largely around being admitted to a local hospital where they were not known, instead of the specialist hospital where they usually received their specialist care, or at the length of time it can take to progress through from referral to diagnosis and treatment, as well as not being able to attend their hospital of choice.

#### **Admitted to local secondary hospital in an emergency**

Several interviewees described how they found it frustrating to have to be admitted to their local secondary hospital in an emergency, but that their medical information was filed at the tertiary hospital, where specialist care is given.

'Ah' they said, 'well you're a tertiary hospital patient so why didn't you go there?' Well we know there's no emergency service at tertiary care hospital. The ambulance people always take you to the nearest A&E, that's just the way it goes. But because you're not a regular patient we have no notes on you. Well ring the tertiary care hospital. They've got everything you need to know there. You just feel because you're not a regular patient there as if you're

not...I wouldn't say welcomed because you are. You see I think if you were under one of their cardiologists it would be different. (Male, DCM)

We'll take him to the secondary care hospital and then get him transferred to the tertiary care hospital. There's no doubt if it was an emergency he would have to be taken to the secondary care hospital but he will then be transferred to the tertiary care hospital. They can't say he could be taken straight to the tertiary care hospital as they've got to go through protocol and take him to the secondary care hospital. (Female carer of Male, DCM)

### **Slow progression through system**

There was also a lot of frustration at how long it can take to progress through the hospital system.

I got sort of referred to a cardiologist at a secondary care hospital before I got properly referred to a proper expert...There was a delay and it felt like a long time at the time because I got the abnormal echo, I think it was in the November, the beginning of the November, and then I saw the cardiologist on Christmas Eve. So that's how long that process took from having the abnormal...to seeing the cardiologist. It would be couple of months. A couple of months being in absolute limbo. (Female, HCM)

I've also noticed that the appointments for me are being pushed back continuously. I've gone from August, to September and now it's in November. So I don't know if they are short of staff, or they are cutting back or whatever. But I've had three appointments cancelled so let's see if I get my one in November. (Male, HCM)

We went back for the scans, they weren't ready for us, the notes hadn't been passed across, that was it, the consultant from the night before had to sign off a certain form and he hadn't and so when we rocked up to do the scan they couldn't do it because it wasn't signed...In the end the department was closed, because it had to be delivered at 9 o'clock, exactly 24 hours since the last one was delivered which was 9 o'clock in the evening. The department was closed, they couldn't get the district nurse to come out so I ended up actually doing the injection myself at home, until we got back for the next scan which I think was the Friday of that week. (Male carer of female, DCM)

You will always have these questions around, well, why do we have to wait so long for a scan, why do we have to wait so long for an ECG or whatever it is? So if they are going to improve it they would have to reduce that time frame between asking for and getting certain things like an MRI scan. (Male carer of female, DCM, above)

### **Hospital of choice**

One participant described the difficulty they faced trying to get referred to their hospital of choice.

...Well I was first at a secondary care hospital and I had a terrible fight to get into the tertiary care hospital. Since then it has been absolutely brilliant...Well once I knew it was the heart I tried to get into the tertiary care hospital. They said 'no you need to go to your own hospital' so I was put under the care of a secondary care hospital. (Male, DCM)

A carer described frustration at hospital care being provided only during office hours, when patients are often unwell outside of these times.

I mean it was fine 9 to 5 because my husband could ring the arrhythmia section. But things don't always happen 9-5 Monday to Friday. He was having episodes in the evenings and then the biggest one was on the Saturday morning. (Female carer of Male, HCM)

#### **4. Examples where hospital care was good**

There were many examples given by interviewees of good hospital care. Interviewees valued being treated as an individual and having confidence in the staff. Participants were happy with care when they had confidence in the staff who provided it.

The cardiologist at the tertiary care hospital because he's so knowledgeable about this subject I think he was probably the most helpful. (Male, HCM)

The doctor at the secondary care hospital, you go to see him and you've got a 10 minute slot and you're lucky if you're out in under an hour and he's drawing pictures and everything....Yes, he takes time and he does drawings and says this happens and he does it in layman's terms, you know, instead of all these different names for things. (Male, HCM)

My consultant is particularly good. He has an excellent reputation he is an excellent clinician from the patients' point of view. He's very, very supportive not just of your care in hospital ...I was particularly ill and I emailed my consultant and said look could you do me a letter and within 15 minutes he got one back to me. That sort of thing. That's not just pretty good that exceptional for a consultant. (Male, LVNC)

It's very reassuring to have the sort of confidence in your consultant - is just priceless really. (Female, HCM)

Well as I say I was made very comfortable in the tertiary care hospital, you know I felt very comfortable and very safe in the tertiary care hospital because it's supposedly the best heart hospital in the country. (Male, HCM)

Interviewees gave examples of good professional care. Often these examples illustrated good communication and availability of staff, or time given to individuals.

I think that all the professionals I've come into contact with at the tertiary care hospital have been amazing. The cardiologist is amazing. I've been worried about something. He's very modern I send him an email and he's really busy and I've had times when there's been

something I want to ask him and I've sent him an email and he's replied to me a few minutes later. (Female, HCM)

I wish that I had been under him in the first place because he is an absolutely smashing guy. Totally different....He went into it all properly. He was easy to understand and he took the time, whereas others you just seen to be in and out....No but when I came here it was all explained properly in a nice environment. It was totally different and he explained it properly. (Male, HCM, speaking about care at the tertiary hospital)

But my cardiologist was great he would say, 'you know your own body better than anybody if you think you can reduce them do'...Yes. He was always there for me. And he turned out in the end to be more of a friend. (Female, HCM)

They [staff at tertiary hospital] all stand out because they have all listened. Even the nurses on the heart ward, they were absolutely brilliant ... Again I've got a little example of how good they are. When I come into the tertiary care hospital if I'm going to be staying a few days, I order a halal vegetarian curry for my religion and sure enough I will get a halal vegetarian curry and it is brilliant. I don't think they have ever failed. Not when I'm just going in for one day but when I'm in for three or four days. (Male, DCM)

## **5. Examples where hospital care was poor**

### **Lack of information or a lack of explanation**

Hospital care was perceived as poor when there was a lack of information, or a lack of explanation.

Well it was because the cardiologist at the tertiary care hospital kept saying 'it's just part of your symptoms' and I thought 'you shouldn't be blacking out', you know. I mean I had to accept what he was saying but when I spoke to that professor he said there's got to be a reason. It may not be to do with your heart. They should have sent you to get it sorted. (Male, HCM)

Not one to go into all the little bits and moans and things. The cardiac nurse once told me when I rang her 'I don't know why that's happening - go and see your GP'. That's the last place you would go, to your GP. The GP couldn't believe it and that's when I transferred over to the tertiary care hospital. (Female, DCM)

I was offered nothing at all from the hospital...So no I didn't understand the jargon and nobody explains it because it's all done in ten minutes...When it is your life, just ten minutes to discuss your situation...I'm sure it is nothing to them because they are seeing 40 people a day you know, so they just need to do what they can deal with in that time. (Male, HCM)

You're just lying in the bed in fear and my heart rate was galloping like a stallion horse, I mean it was incredible, I've never had such a fast heart rate in my life. So you are lying there in fear and of course you've got all of these other guys around you with pacemakers and ICDs and you just think is this the future for me? (Male, HCM, above)

...But it was just the lack of information but that is partly my fault as well for not asking. But again the NHS was doing its best. (Male, HCM, above)

## **Staff attitudes and poor communication skills**

Staff attitudes and poor communication skills had a big effect on whether care was perceived as bad.

When I saw him a few months ago he said 'well you aren't going to get any better, you're just going to get worse'. Then you think wow hang on...so I'm not going to get any better it's just going to get worse. That's what I'm left with for a year, that it's just going to get worse. (Male, HCM, speaking about the consultant at the secondary care hospital)

It was a little bit overloading. The information was there but I was just hit with it. It was a bit too much and very, not harsh but to the point. The same as the last time I saw him when it was just like see you in a year's time and it will only be getting worse in that time. Those were his words. When it was like that it just froze you. (Male, HCM, above)

Anyway they decided to keep him in overnight and the next morning the night locum cardiologist came and told him his heart's knackered what can he expect! They would give him some new medicine, pat him on the head and send him home...But just to have an awareness of people, what they are going through because not everybody can take that news, I mean a lot of older people might not know how far their heart has deteriorated so maybe not to be so blunt and so nasty with people. (Female carer of male, DCM)

I'd have to say no, to be honest. I mean little things like when you go to see the cardiologist, I'm sure that he is fantastic person and surgeon but you walk into his place and go to shake his hand and he doesn't even want to shake your hand and you think well that's not a very good start to this 10 minute meeting I'm going to have. Maybe that's just the guy's bedside manner and it's not a big deal and I can get over that. But I sort of think that you should be treated in the right way and treated as somebody important as a patient. You want to feel that they are interested in your problem. Not just a 'how are you?' 'I'm feeling pretty good' 'OK we will see you in 12 months goodbye'. I think there is more to my problem than that. (Male, HCM)

## **Pastoral care**

Some patients and carers cited a lack of pastoral care during and after hospital appointments and hospital stays. This caused distress.

But also pastoral care. You're in hospital and I know it's lack of time and that's the way it is but pastoral care - just to take time out to explain what is going on. (Male, DCM)

Some sort of other help other than what I actually got. There was just nothing. I mean you could have knocked me out with a feather when I was walking along the corridor out of his office after he told me what it was. (Male, HCM)

If we had understood better what to expect, how it would work, I think it would have been a far happier time for us. (Male carer of female, DCM)

...he thought my husband had hypertrophic cardiomyopathy and gave him some medication. But he didn't really go on to explain what hypertrophic cardiomyopathy was. So we came out feeling a bit like wow what just hit us here? So we went home and I went on the internet as you do these days and looked it up. (Female carer of male, HCM)

## **Lack of knowledge of staff**

Interviewees gave examples of occasions when staff seemed to lack the necessary knowledge about their medical conditions. This did not meet with expectations.

Especially the doctors who deal with you when you're taken into hospital. Like junior doctors. I think they need some basic teaching to recognise these things. Like in my case they said you've only got a chest infection and all the time my heart was getting worse and worse because nobody recognised it. (Male, DCM)

You see about information, going back to my first diagnosis when I met the geneticist at genetics clinic and he was saying there's a treatment...His words were that after 2 or 3 infusions you'll be like a new bloke. That's what he said. What a load of tosh. Cos I said I like my garden. He said you'll be able to get an even bigger garden, get an allotment as well. Misleading. That's what he said. Of course I get an infusion now once a fortnight and it lasts about 4 hours. I have it at home now. You're absolutely wiped out for the rest of the day. So again it's the misinformation. (Male, HCM & co-morbidity)

You're treated like I don't know...as if you're another species or something. Which seems odd because it's not that rare. I know it's not that common but to me it just doesn't seem to make sense to have more of an understanding because there are quite a lot of people who have this...There's a lack of understanding. You sort of think that people involved in your care know about all sorts of procedures that nursing staff they may not know much about them but they have a very sort of general idea. (Female, HCM, talking about secondary care)

Yes, yes in the hospital. To me the time I've had to go into the secondary care hospital for it, the A&E haven't got a clue. You mention cardiomyopathy and they look at you as if to say 'what's that?' (Male, HCM)

## **6. Suggestions on how to improve hospital care**

Suggestions made by interviewees about improving hospital care were largely around communication and information.

More communication between consultants and patients. But I think that's the case in all walks of life. More communication between medical staff and the patients...At the tertiary care hospital....One of the things that could be done with care at the hospital is communication back to GPs. To keep them more informed about people's problems and people's diseases like cardiomyopathy...Because GPs don't have a clue what it is, most of them. They know the basics. You find the patients know more about their condition than the GPs and the cardiac nurses in the practices. (Male, DCM)

Maybe there should be some sort of cross fertilisation between the heart failure and the transplant. To give smooth transition so you know whatever's going to happen to you if you're ever in that situation. (Male, LVNC then transplant)

Maybe the liaison between the various cardiac departments could have been better. The care I've got in each has been excellent but whether the transfer between the two has not been as good as it might. (Male, LVNC, above)

Well the care from the start to now could have been improved by me being given more information than I was. (Male, HCM)

## **Conclusion**

Patients had a wide experience of hospital care. This includes care at secondary and tertiary hospitals. Many had experience of being cared for at both types of hospitals, at times on different occasions and also simultaneously (cross care). There were examples where care was perceived to be good and other times when care was perceived as poor. Participants valued care experiences as mostly positive when they perceived it to be delivered by knowledgeable professionals, who treated them as individuals and communicated effectively. There was some frustration at systems, which dictated how and when patients progressed through hospitals. Hospital care was more likely to be perceived as poor when communication was poor, when staff did not give clear explanations, did not seem to have the expected knowledge and they did not communicate in an empathetic manner. Suggestions made to improve hospital care were largely around improving communication, especially between different health care providers.

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## **Summary - Experience of hospital care**

- Respondents have a wide experience of hospital care.
- Respondents have experience of care across secondary and tertiary hospitals.
  - On different occasions
  - Simultaneously as “cross care”



- Positive and negative examples of care across both secondary and tertiary hospitals were documented.
- Patient confidence in tertiary hospitals was evident.
- Communication between hospitals did not always work well.
- Frustrations about pathway of care were identified
  - Patients taken to local secondary care hospital in an emergency, when notes were at tertiary hospital
  - Length of time it took to progress through various stages of the system to get a diagnosis
- Care perceived as good when it was delivered by knowledgeable professionals, who communicated effectively, when treated as an individual and when time is given.
- Care perceived as poor when communication was lacking, when staff did not give clear explanations, or when staff seemed to lack knowledge, as well as when staff lacked pastoral care and empathy.
- Suggestions to improve hospital care were around improving communication (especially between hospitals) and providing better information and support.

## Patients' Experience of Devices

Ian Mackersie

### Background to study

Three members of the North East England Cardiomyopathy Support Group<sup>1</sup>, supported by Julie Goodfellow<sup>2</sup>, BHF Cardiac Genetics Nurse, have undertaken research to examine patients' experiences of cardiac care services in the North East region. Twenty-one members of the local Cardiomyopathy Support Group (16 patients and 5 carers) were interviewed in September 2015, using a semi structured interview schedule and the interviews were transcribed and analysed thematically.

### Introduction

Of the sixteen cardiomyopathy patients interviewed for this study, thirteen have devices (3 females and 10 males). Three have pacemakers (PCMs) and ten have implantable cardioverter defibrillators (ICDs). PCMs and ICDs have been fitted in patients with HCM, DCM and LVNC<sup>3</sup>.

The report covers the patients' understanding of why they needed a device and their experience of having it fitted. It summarises their accounts of the sources of information and support available to them at the time and some of the problems that resulted from lack of information. It covers patients' responses about living with a device, including their feelings about it, their understanding of how it worked, the sensations they experienced

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<sup>3</sup> Eight have HCM, four have DCM and one had LVNC but has since had a transplant. Pacemakers and ICDs are used in both patients with DCM and HCM. In our sample, 3 patients have PCMs (1 DCM and 2 HCM), and the 10 patients have ICDs (6 HCM, 3 DCM, 1 LVNC). Some patients were fitted with a device almost immediately following diagnosis whereas others were fitted several years later.

with it (short of triggering in defibrillator mode) and its effect on their day to day activities. The experiences of those patients with monitors which can be interrogated remotely by the cardiac Rhythm Management Department (RMD) are recounted. The experiences of the two patients whose ICDs have triggered in defibrillator mode are summarised. Finally, based on the above findings, the report makes recommendations for improving support for cardiomyopathy patients with devices.

The chapter is divided into the following 7 sections:

1. Patients' understanding of the need for a device
2. Patients' experience of the device implementation process
3. Device information and support
4. Patients' experience of the Rhythm Management Department
5. Patients' feelings about their device
6. Patients' experiences of their device
7. Activation of an ICD

## **1. Patients' understanding of the need for a device**

Patients' understanding of the need for a device varied. In many cases the need arose directly from a clinical episode.

Well basically I was fit and healthy and then I arrested. And that was on the 25 September. The ICD was fitted on 7 October. I think the cardiologist came to see me briefly before I had the procedure. (Male, DCM)

I've got AF. That's why they decided they had to put one in. I was getting chest pains... And then I get blackouts and they are getting worse, more regular I should say, and then I went to the secondary care hospital and ended up there for three weeks because the doctor insisted that I needed an ICD but he said if you go home you'll end up at the bottom of the list, so he said I'll keep you here and it will be classed as an emergency. (Male, HCM)

It transpired it was a reaction to the enzyme and not a heart attack but I'd blacked out and it was the specialist at the tertiary care hospital that suggested I had a defibrillator put in. (Male, HCM)

I think they put it in as a kind of failsafe. (Male, LVNC)

Well obviously because my heart had stopped because it was going too fast and then they said they would put an ICD in...Apparently I had ventricular flutters and then it just goes

haywire and then it stops...The only question I had was would it stop it from happening again and they said that's why they're putting it in in case it happens again. (Female, HCM)

They kept me in and gave me cardioversion...last year ( I had an ICD) fitted. The consultant I saw said it was 'just in case', but the more I've talked to people the more they're getting them so then I think they must need them more than 'just in case'. (Male, DCM)

None of the patients had heard of an ICD, far less what it did.

But I knew very little and had no idea about defibrillators or anything like that. (Female, HCM)

No, never heard of them (defibrillators). No idea. (Female, HCM)

I knew people who had pacemakers and I knew it could regulate your heart. But I didn't know about the other bit, that it could shock you. (Male, HCM)

Again it was just sort of... what's an ICD? I had never heard of one of them in my life. (Male, HCM)

Although there is a clear need for patients to be told more about why they need the device, in some cases they may be too ill to appreciate this at the time of implantation.

## **2. Patients' experience of the device implantation process**

The time lapse between formal diagnosis of cardiomyopathy and implantation of an ICD varied hugely - anything between 2 days (Male, HCM) and 37 years (Female, HCM).

They sent me (from the secondary care hospital) to the tertiary care hospital... the following day after diagnosis. And the following day I was fitted with an ICD and the following day I was out. (Male, HCM)

The experience of the actual process of implantation varied too ranging from positive to quite negative. On the positive side:

It was very quick...very professionally done. No complaints about the care I got at the tertiary care hospital. (Male, HCM)

Another is positive but contrasts the care at the secondary care hospital where he was treated initially and the tertiary care hospital where the device was implanted.

I wish I had been under him (the cardiologist at the tertiary care hospital who carried out the operation ) in the first place. He is an absolutely smashing guy...He went into it all properly. He was easy to understand and he took the time. (Male, HCM)

Many of the other comments from patients about events surrounding their implantation were negative. One said.

To me it was like a cattle market. There's that many people, so you're in, it's done, you know, I think it was about three-quarters of an hour, then you're out back on the ward. And usually they keep you in a couple of days but you go to the main ward then and then you just go home. You're just in and they do it and you can see 3 or 4 other people with different cardiologists or surgeons, whoever does it, you can see the others getting theirs done. Cos they just freeze it, they don't put you to sleep. (Male, HCM)

Another had an alarming experience during what should be a straightforward procedure.

Then in 2004 I first got the ICD fitted. Then from there, there must have been four or five ...my last ICD is the only one which lasted seven years. All the rest have been taken out. Another day about 7 years ago when I had the last ICD before this one because they had to go in through the back I was in intensive care... and was in a lot of pain and they tried to give me (medicine) and I argued with them that I couldn't have it because it drops the blood pressure that quickly. They said try it, and then the crash cart had to come. So if the doctors would listen...(Male, DCM)

Another described a rather harrowing experience.

There was a bit of a carry on at the [tertiary] hospital when I got the first one put in. It was the cardiologist, one of his lads, and he couldn't get the wires in, and I was there too long. And I had to lie still and I was getting cramp, cos they said it would take half an hour and it was an hour and a half and they had to start giving me morphine. I wasn't allowed to move my leg or lift my head. And then they got into a bit of an argument in front of me cos the cardiologist said 'I'm not doing it so you might as well get it done'. I was absolutely covered in blood, my hair, my face, and they sent me back to the ward like that and the wife was sitting there and she nearly passed out when she saw me with all the blood. The nurses got water and washed it off for me. It was on my shoulder, in my hair everywhere, because I'd moved my leg, with the pain I'd moved it, I got wrong for it and anyhow it spurted straight up to the top of my head. (Male, HCM)

### **3. Device information and support**

The full rationale for implantation was not always explained by the clinicians. It appears that the operation of the device and the remote monitoring were not fully understood by patients. They found out in various ways, booklets on the ward being one.

So they said one option we've got is that you're fitted with a device called an ICD and I think there were some booklets kicking around the ward so I may be read them. So I had a reasonable idea of what was going on. (Male, HCM)

When I was at the the secondary care hospital I picked up all them (BHF) leaflets and that's how I found out. I picked them up. (Male, HCM)

Another got information from doctors but was not able to absorb it, despite some medical knowledge, because of his mental state, but later he got the BHF booklets.

I think the cardiologist came to see me briefly just before I had the procedure. I can only remember seeing him very briefly on that occasion and then when he fitted the ICD. I don't think I had a real face to face conversation with him. When I met him two weeks ago it was like the first time I'd met him that I can remember... It might have been my psychological state at the time but I just wasn't taking it in, having a background in biomedicine I'm usually pretty well informed but I wasn't in the right place, I was pretty vulnerable, so I suspect he maybe told me more than I can remember but I didn't feel fully informed but that might have been to do with my state. When I went to the ICD clinic sometime afterwards, it wasn't me being difficult, I just genuinely couldn't remember. And of course no one was there at the time they explained it all so basically you just sign the form like they told you to do but I'm sure they did explain. Oh and they gave me the BHF booklet on ICDs and actually I did have time to read that and process that a bit more but it was probably after the event because the ICD went in fairly quickly. (Male, DCM)

Lack of information gave rise to real concerns about the device and what would happen if it triggered. A carer explains.

Well my husband was moved late afternoon so I came in to visit at 6.30 and it so happened that a young doctor came in to see my husband at that time so I was involved then. Then a cardiologist at the tertiary care hospital came to see him and tell him that he would be the first to be operated on in the morning so we had a few minutes with the cardiologist at the tertiary care hospital. But I think that at that point, you don't really know what to ask. Until it happens you don't know what to ask, because we thought getting the ICD fitted was going to be the answer to everything. I think because we just weren't prepared for (further episodes after he had been fitted with an ICD). He had the medication, he had the ICD, so we just thought that things would settle down. I think I would have liked to have been able to speak to somebody, or to just ask the questions. Or when we came home or before we came home, if somebody had just sat us down as said, 'look this is what has been done, the ICD is fitted, we have given you a level of medication, we think that should work, but for the next few weeks you could still have some more episodes but try not to worry about them. We will keep an eye on them. Maybe the medication needed adjusting'. If somebody had just explained all of this to us we would have been less concerned. (Female carer of male, HCM)

Others expressed similar concerns.

As I say you are on the ward. You never see the consultant again. You just see the ward doctors, junior doctors and they say I think you can go home and then you make an appointment to come back. (It would have been useful) just for someone to explain you've had this thing fitted and hopefully once we get it set up correctly - cos I didn't know about that either like. (Male, HCM)

Well initially I was very worried all the time about the ICD going off so I had lots of questions about what that would be like and what it would feel like if it defibrillated you, all those sorts of things. Because for the first few weeks you're just living with this cloud over you. And I'd heard people in hospital say 'oh if it goes off it's really not nice' so you're paranoid about it. How far you can walk? What's a reasonable amount of exercise to do in a day? Where do we go from here in terms of medical care? (Male, DCM)

Another was persistent and got more satisfactory answers from a specialist nurse.

There was one day when they sent an email about the pacemaker and half past 9 that morning I got a phone call telling me to phone this number and there was somebody at the end sitting and able to talk. They went over everything, what was happening and what was going to happen. It was brilliant... I phoned someone in the tertiary care hospital and it was a cardiac nurse and it was nice to have somebody to ring and who knew what I was worrying about. You know they say go and have a look on the internet but anybody can put anything on the internet and I have been down that road and it doesn't do any good... [the cardiac nurse] told me exactly what was happening and what would happen and how it was going to happen. The other pacemakers I've had have been taken out more or less in a hurry. Now this one was the first time it had ever lasted its life time. I had been told that when I get my new one, they were going to fit an external pacemaker. That worried me because I didn't know how they would actually do it. As time went on and it got nearer to the time it was going to happen I got more concerned and when I sent [an email] and spoke to the nurse it was brilliant. She listened to what I was saying and she was able to tell me exactly what was going to happen and that getting fitted with an external pacemaker wouldn't happen. So because somebody listened it helped. (Male, DCM)

According to one carer, specialist nurses often proved the best source of information in the weeks after implantation.

Because we saw the specialist nurse about a week and half after my husband's discharge and she explained some of that to us and that was very helpful. Although we were there about the genetics but we were obviously very concerned and just blurted all of this out. So she helped a bit there. But still whenever this is happening my heart sinks that this is still going on. (Female carer of male, HCM)

Patients also got help from the BHF nurse.

So I suppose [the BHF nurse] listened and gave you the space to talk about all sorts of things and to talk about how you are feeling. (Male, DCM)

She [the BHF nurse] had time...and spent two hours with us which was astounding. I mean I was in a bad way psychologically and she gave us time. And that's what was needed. And she listened. And we had a weep and all those things. She provided lots of information. She went through all the ICD stuff and explained it...she talked about diet and managing your time and managing your expectations and that sort of thing. (Male, DCM, above)

There is a need for expert advice sometime after discharge when patients will be more receptive and more questions will have occurred to them and their carers. The evidence suggests that specialist nurses might be best placed to deliver this.

#### **4. Patients' experience of the Rhythm Management Department**

Another source of information and advice were the physiologists at the Rhythm Management Department (RMD)<sup>4</sup>, but this was limited to their area of expertise and their availability.

Some found RMD very helpful.

...heart-wise it's just been the [tertiary care] hospital for the pacemaker. I had an operation and got pneumonia. We thought then that was because we had just had pacemaker changed that it was the pacemaker that got it wrong. I got an appointment that day or the next day [with RMD] and the technician came in and my wife told him I kept falling asleep. He got straight to the phone and got me an emergency admittance. I was in for seven days, I had caught pneumonia. (Male, DCM)

They [the physiologists] are helpful, yes. They answer what you ask them. Like everybody they're stressed and very busy. They're very nice when I go and they answer my questions. But it's funny before you go you think oh my goodness it's going to be some space age thing and following all these peoples' hearts it's going to be really high tech but it's all these cardboard boxes. It's like a sort of afterthought, like a sort of store-cupboard. They're pleasant enough. When I rang up about my cooker query. I thought they're really busy people with all these situations would they really like to spend time dealing with my choice of cooker. They were actually really nice and said 'you did the right thing, you did the right thing to ask us'. (Female, HCM, concerned about effect of magnets on ICD)

Others had to try to contact RMD out of hours, which was less satisfactory.

I phoned them up the other day because I'd been to the GP and what they think I've had is a fit. I thought it might have been my ICD going off when I was asleep at 2 o'clock in the morning and I phoned up and, of course, with it being the weekend they said I'd have to wait until a technician or somebody comes in. It was the bank holiday weekend gone and when they checked they just said nothing's come through but I don't fully understand as I think you have to actually manually send it through. Nobody's explained that to me, I'm a bit confused. I asked them on the phone and the gentleman just said 'just press the button'. I was sitting beside it and it went through a sequence, which I read about and whatnot and it went wrong, it didn't transmit, so I pressed it and did it again so it went through. Then later on I got a phone call back saying it's champion, everything is alright. That's the only thing as far as I know they didn't explain exactly what to do, even although there is literature. Unless it's my brain. Maybe it's a bit complex, you know. (Male, DCM)

Yes, I mean I had to send last week, traces 3 days a week and the first one I mustn't have done it properly so they were straight on the phone to me. Then I've got the number and they said if you are in the house and have a blackout send a trace and I did this morning when I had a blackout but no one will pick it up till Monday, well Tuesday, cos it's a Bank Holiday. (Male, HCM)

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<sup>4</sup> RMD can obtain information on some patients' heart rhythms remotely from Boston Scientific "Latitude" monitors installed in their homes. This information is collected by the monitor from the patient's ICD each time the patient comes within range and is retained there until uploaded to the BS server (in Belgium) over a phone link, the upload having been either prompted by the patient or achieved remotely by RMD. The monitor also records defibrillator activations automatically and flags these up specifically for the attention of RMD.



A few days after I came out of hospital I had an episode that was more serious. I'd had one or two episodes before I think, just you know very very brief and I thought well you know it must be that these will go after time. And then in the middle of the night, I think it was about 4 o'clock in the morning, I can't remember it might have been the Saturday, I had another episode and em that's when we rang for an ambulance and got taken into the secondary care hospital. I tried both of the numbers [given by RMD on discharge]. One was an answering machine and I wasn't happy leaving information on that in these circumstances. And the other was the CCU ... they said look if you feel unwell you have to ring an ambulance, so I rang an ambulance. (Male, HCM)

There is obvious concern among patients with remotely monitored devices that if they have to contact RMD for advice out of office hours there will be nobody available.

## **5. Patients' feelings about their device**

Although feelings about the device were mixed initially, with patients describing themselves variously as "terrified" (Male, HCM), "frightened to death" (Male, HCM) and "living with this cloud over you" (Male DCM), many later seemed to have learned to live with their device.

I think for me it was peace of mind knowing that I had something implanted that if it was necessary it was going to attempt to save my life. (Male, HCM)

He took the old one out and said I'm just going to put this one below the skin to get at it if we need to get at it, it sticks up more under the skin but that's all. The first one was under the muscle. It's easier, when I'm not touching it I don't know it's there. (Male, HCM)

But I know because of the ICD, that's my safety net and if I push then I've got it. (Female, HCM)

However, one respondent still seemed in fear of his device.

Everybody says you seem to settle down and get used to having an ICD and don't worry about it, that's there to save you. But it's still there at the bottom that one of these days you are just going to drop down. (Male, HCM)

## **6. Patients' experience of their device**

Sometimes patients experienced sensations from their devices short of full activation in defibrillator mode. One thought that his had been activated remotely by RMD, apparently as a test while he was at work.

Once I got the box in and there was the remote...now my wife said I did get a letter but it was three months ago this letter that I got, I'm a teacher and I'm standing in front of a class and I started getting chest pains and I thought oh my goodness I'm having a heart attack here. So I went to my desk, sat down, the kids were working. It passed and I just forgot about it. Then when I was driving home the pacing clinic rang me to say that at 11.30 we tested your device. They didn't tell me. I had a letter off them three months with a date in but when you're living a busy life...but I'm still working and that it would have been nice to

get a text on the morning because they've got your mobile number. You know it's happening. Because I didn't know they were testing it. I thought oh dear me this is nonsense, I could have been up a ladder. And you're going to say this bloke's not real but it's true. My brother they tested his minutes after and we were going for a walk of an evening and he said "hey I thought I was having a heart attack today" and I said "that's funny I thought I was having a heart attack as well". I said it was about 11.30 for me and he said it was about 11.15 for him. They had tested both of them on the same day. (Male, HCM)

This 'test' had practical consequences for this patient. He told the hospital and they told him he should not drive for three months.

I'm allowed to drive (now), yes. I think I couldn't drive for three months. So as long as I didn't have an episode for three months it carried on. So luckily for me I phoned them. The hospital were good about it and who would want to put anybody's life at risk. So it was three months. (Male, HCM)

Another reported an unusual event.

I haven't had any abnormal rhythms. There's been some sort of strange things, like there was once when it was very odd. I was at my in-laws house in Lancashire just for the weekend. I didn't take my Latitude machine with me. I was lying in bed and suddenly I felt a strange sort of vibration in my chest. It was really strange a really odd feeling and my husband felt my back and it seemed to be vibrating. I felt fine and I just went to sleep but I thought this was very odd. It was over a weekend and I think I ended up ringing the [tertiary care] hospital and I think they said I should go to the nearest hospital that had the equipment to download the data. So I ended up in this strange hospital in Manchester. They needed to admit me just to read the machine. Which was a bit ridiculous and a bit odd. It turned out there was nothing recorded and it was just bizarre. They didn't know why it was vibrating. Some of the devices have a vibratory alarm thing. Mine doesn't apparently. Never got to the bottom of it. (Female, HCM)

Others reported sensing some sort of ICD activity, short of full defibrillation, and taking action.

What it is I take two tablets to slow the heart down but the pacemaker is to kick in if my heart goes too slow, not if it goes too fast, if it goes below 50 bpm my heart, it kicks in to speed a little bit. It's happened a few times. Well it's when I feel bad you just get a tight chest and everything I mean I'm only supposed to wait twenty minutes then phone an ambulance but I don't, I wait for hours. (Male, HCM)

Yes I have [had episodes]. Last year for no apparent reason I would be sitting, I became very dizzy. And that happened two or three times. I was sent into the tertiary care hospital and I had an angiogram and they were very very clear it wasn't the angi, it wasn't my blood vessels. And then they had a look at my pacemaker and my pacemaker showed at certain times when I was having the dizzy spells it had gone out of sync. And that was causing what they thought was the dizzy spells. And then they wanted to change the timing on the pacemaker but it all of a sudden it just stopped and I thought it had taken so long to get the timings right originally that we should just leave it and it's been fine ever since. (Female, HCM)

**Practical implications of having a device.**

One of the implications of having a device raised by respondents was their restricted ability to drive.

I felt OK in the sense that I'd been fully investigated, I'd got the machine, the ICD, I felt it was just a case of rebuilding my strength and getting back to normal. I appreciated that there was stuff I couldn't do...heavy lifting, I couldn't drive and I appreciated that it would take a wee while. (Male, HCM)

I blacked out...then I couldn't drive for a couple of years after that. I've got my licence back but I haven't got the confidence. (Female, HCM)

I'm allowed to drive. I think I couldn't drive for three months. And as long as I didn't have an episode within three months it carried on. (Male, HCM)

## 7. Activations of an ICD

Activations of ICDs in defibrillator mode are infrequent, but two patients, out of ten interviewed, reported them. One said:

It has given me two shocks and I would say it saved my life in a sense because I had problems when my heart went out of rhythm. Went very fast. It shocked me twice in 10 minutes on the same day. (Male, DCM)

This respondent went on to describe what an ICD activation felt like and how he had used his experience to help others.

*Interviewer:* I remember you told me it's like getting kicked by a horse. You said 'I'm probably one of the few people here who know what it's like getting kicked by a horse' and that's how you know. That stuck with me. *Respondent:* Yes I did tell you that. I've been kicked by cows and God knows what. I've actually been asked by the cardiologists here to talk to a few people in the clinic who have been nervous. And have chats with them and put them at ease. Which you don't mind: it's helping people.

The other respondent's device activated 6 months after implantation and again 8 months later.

[The first time] I was just about to go in the shower and I went forward. I didn't hurt myself, but the second time I did...[the first time] I rang the tertiary hospital and they said 'yes you've had it but you are all right'. It had shaken me up more than anything just from the shock of it. (Female, HCM)

The second time [in 2012] I was just washing my hands and then I felt dizzy and it just went. I hit my head on the sink so I had a big bump. I blacked out. I did lose consciousness, but by the time I hit the floor because I hit the bathroom scales, I could hear the phone. (Female, HCM)

## Aftermath of activation of ICD

Activation is not without consequences. Of the two patients whose ICDs have activated in defibrillator mode, one had a mixed experience when taken to his local A&E.

It was treated as an emergency. I was taken into a secondary care hospital. I was kept in 24 hours just to monitor me until things settled down... the impression I got from the staff there... like I say the emergency care was good. I was taken into the resusc area of A&E and the care was good. The doctor there was brilliant. They got a cardiologist the first time quite quickly. The second time it took 48 hours before one turned up. 'Ah' they said 'well you're a [tertiary] hospital patient so why didn't you go there?'. Well we know there's no emergency service at tertiary care hospital. The ambulance people always take you to the nearest A&E that's just the way it goes. But because you're not a regular patient we have no notes on you. Well ring the [tertiary care] hospital. They've got everything you need to know there. You just feel because you're not a regular patient there as if you're not...I wouldn't say welcomed because you are. You see I think if you were under one of their cardiologists it would be different. That's the impression I got. (Male, DCM)

This patient's wife also reported effects of the activation as follows.

So we had that episode and from then he started to deteriorate a lot more. He was quite active before then and could do little bits and bobs in the garden. He would like to potter around in the garden and make little planters and things. He could do a little bit without being too poorly but since the defibrillator's gone off I've noticed a big change in him. There are lots of things he can't do and he gets frustrated because he can't do them. (Female carer to male with DCM, above)

The other patient had longer term consequences from a second event but is more relaxed about it now.

But I did black out because then I couldn't drive for a couple of years after that. The difference is whether you black out. I've got licence back but I haven't got the confidence. I don't think I would drive very much because I'm frightened, not so much for me but if it happens you know you can kill somebody else. I forget about it most of the time. I'm more confident. I mean I sleep on my own and stay in the house in my own. Well they [RMD] say that you don't need to contact them until it's gone off three times but for me I would rather contact them after each one because they can read what has happened and then they know. (Female, HCM)

## Conclusion and recommendations

This report makes the case for more and better information to be given to patients both about the need for a device and the issues surrounding its implantation. At the same time the medical and practical implications of living with a device should be explained clearly to

patients and carers to make them aware of what to expect in the critical weeks immediately following implantation.

Not all patients will be in a fit state to absorb detailed information at that time, so a follow up service is needed, a readily accessible reference point for patient and carer queries which arise in the weeks and months after implantation. Ideally, this service should be capable of dealing not just with the operation of the device but the wider issues associated with cardiomyopathy such as medication, lifestyle and genetics. Based on our findings, it appears that this service would be best provided by a specialist nursing team.

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### **Summary- Patients' Experiences of Devices**

- The time lapse between diagnosis and implantation of a device varied enormously.
- None of the patients in our study had heard of an ICD prior to having one fitted.
- Patients' understanding of the need for a device varied. It was not always fully explained by medics or understood by patients.
- Experience of the process of having a device fitted varied. Positive experiences included having the process explained beforehand and the procedure being quick and straightforward. Negative experiences included feeling that the clinic was 'like a cattle market', not being listened to by medics and the procedures not being straightforward.
- Information about the device and how it worked was not always given. Patients sometimes found this out from booklets that they picked up in hospital.
- Patients and carers with unanswered questions did not always know where to go to find answers.
- Patients acknowledged that they may sometimes be too poorly to take in information at the point of implantation and suggested there should be an opportunity to ask questions at a later date.
- Cardiac nurses emerged as an important source of information and support. However not everyone was allocated a support nurse.

- The Rhythm Management Department was a useful source of information but was only contactable during office hours. Outside of those times patients were left with concerns and unanswered questions.
- Having a device can be alarming initially but most patients appear to adjust over time.
- A number of patients reported experiencing sensations from their device. This can sometimes cause concern as the reasons for the sensations are not always obvious.
- The biggest practical implication of having a device was the potential restriction on driving.
- The activation of an ICD in defibrillator mode can affect a patient's confidence and cause an increase in anxiety.
- A&E Departments are not always equipped to manage patients who have come into hospital with a device -related issue.

## 6

# Carers' Experiences

Vera Mackersie

### Background to study

Three members of the North East England Cardiomyopathy Support Group<sup>1</sup>, supported by Julie Goodfellow<sup>2</sup>, BHF Cardiac Genetics Nurse, have undertaken research to examine patients' experiences of cardiac care services in the North East region. Twenty-one members of the local Cardiomyopathy Support Group (16 patients and 5 carers) were interviewed in September 2015, using a semi structured interview schedule and the interviews were transcribed and analysed thematically.

### Introduction

As part of the research into patients' experiences of cardiac care services in the North East region, five CARERS were interviewed. Although this is a very small sample it raises issues which may be of relevance to other carers of someone with cardiomyopathy. Without exception, all carers interviewed were heavily involved with what was happening to the patients, their husbands/wives, from early symptoms to cardiomyopathy diagnosis. Four of the partners were fitted with ICDs, one ultimately having a transplant and another being placed on the transplant list. All carers interviewed talked at length about their experience of living with and/or caring for someone with cardiomyopathy. Many of the issues raised were shared with the patient but some were particular to carers.

This chapter is divided into the following sections:

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1. Carers close involvement in the patient journey
2. Sources of information for carers
3. Suggested needs of carers
4. Carer support through the local cardiomyopathy support group
5. Experiences of carers of transplant patients
6. Impact of living with a cardiomyopathy patient

## 1. Carers close involvement in the patient journey

All carers use the words 'we' or 'us' throughout the interviews which is indicative of the closeness of the patient/carers relationships and how intricately involved carers are in all aspects of the patient journey.

**We** got a more precise diagnosis of cardiomyopathy...It was stage three heart failure so **we** were near the bottom...**we** were still in the dark as to what we could actually do with this because to get told you've got heart failure, what does that mean?...**We** have had a bout of depression to add to that as well. (Male carer of female with DCM)

The GP sent **us** to the hospital straight away...**we** just thought it was a chest infection (Female carer of male with LVNC)

Because of this close involvement, when carers were present during conversations with clinicians at all stages they were included in the explanations and were able to ask questions.

We still have to go to the secondary care hospital to see his cardiologist....The surgeon came to see us and told me what he had done and what it would prevent and what signs to look for in case it were to go off. (Female carer of male with HCM)

... a cardiologist and she came and spoke to us at great length about what she thought it was and the risks involved... I came in to visit at 6.30 and it so happened that a young doctor came to see my husband at that time so I was involved then ... (Female carer of male with HCM)

And his anaesthetist even spoke to me and told me what she had found and I saw her before the operation and she told me exactly what she was going to do ... (Female carer of male with HCM)

## 2. Sources of information for carers

Despite being with his wife throughout the long diagnosis process, one carer reported having to resort to the internet for information.



... we were both in a bit of a state of shock ... well we've got all these questions, where do we go ? We started looking online and things like that... we were floundering for information and we just couldn't get our hands on any information other than go online, the BHF, websites, that type of thing...(Male carer of female with DCM)

Also despite being included in the initial explanations some carers reported the lack of opportunity to ask questions soon after being given the diagnosis once they had time to think about what they had been told.

What I felt was needed was something like a follow-up call maybe a week later or the ability for us to ring somebody up a week later and say 'I've suddenly got a whole list of questions, can we talk about it on the telephone or perhaps come and see you'. (Male carer of female with DCM)

I just think that people need to be more aware when they are telling people that they have these conditions, they need to give them the full picture of what it is and what can be done for it, without sending them away and letting them worry about the next appointment... (Female carer of male with HCM)

Some carers reported that the genetics nurse at the tertiary hospital was excellent and a huge source of information.

I think the best source of information for us was the genetic lady at the tertiary hospital, who looked in to see if there was a family history of cardiomyopathy with my wife. I know it wasn't her job but she was a source of loads of information ... we could ask her questions and she was a source of a huge amount of information. (Male carer of female with DCM)

..... when he was going home a specialist nurse came in to see us about the genetics and she was very good. She told us all about the genetics side and made an appointment to see us properly after. (Female carer of male with HCM)

### **3. Suggested needs of carers**

Some carers identified a desire to be given the opportunity to ask questions or just talk to someone in private away from the patient. The following carer explains her feelings about this.

... it would have been nice to have a word with the transplant co-ordinator in private and say my worries are this, this and this but I didn't get to voice them because then it was a case of well we're not going to do it now, we're going to leave it for a while ... (Female carer of male with DCM)

Overall the experiences we've had have been good but little bits, just little bits I would like to maybe have on my own, sort of thing, rather than being in front of him sometimes because I think sometimes it worries him ... (Female carer of male with DCM, above)

I can't think of anything they could have done any more other than me being taken to one side

and said, you know, are you worried about anything or anything we've done or anything we've said ... (Female carer of male with DCM, above)

There was also a strong feeling that the carers would like the medical staff to occasionally consider the impact of the cardiomyopathy diagnosis or ICD operation or transplant operation on the carer i.e. someone to say 'are you OK?', and to appreciate they are the people to deal with any problems once the patient is home.

I think because you're the carer obviously they are more concerned about the patient because they have got to worry about them but I think they forget you are part of that person as well. You've got their day-to-day health to think about and you are the one who sees them deteriorating in front of your eyes. It's you who sees that not them, so just maybe now and again you be taken away from the patient and just asked are you ok, do you need somebody to talk to? (Female carer of male with DCM)

...it's the bit after, how you're going to cope and that so in a way sometimes you feel left on the shelf. It's them, because it's them who needs the care but you are sitting behind paddling like anything thinking if they would only take you to one side or just say in front something. I mean they are up front, they do tell you things but sometimes you just want to be reassured what is going on ...(Female carer of male with DCM, above)

We went to the theatre and we were told to ring up later on ... but no can't fault them. The only thing I could say is I was left a little bit just after. I didn't know where to go, I sort of went back to the ward, collected my things and then I went ... I felt a bit sort of left out there. (Female carer of male with LVNC then transplant)

The majority of suggested carer needs were around the theme of needing someone to talk to, someone to answer their questions and give reassurance.

But I feel that if we had been told these things to start with then when he had episodes, yes it would have been worrying but talking to somebody would have been reassurance and I feel that would have helped tremendously in the early stages. (Female carer of male with HCM)

..... you just want to be able to have a conversation with somebody about what's gone on. (Male carer of female with DCM)

#### **4. Carer support through the local cardiomyopathy support group**

On the whole carers were full of praise for the local cardiomyopathy support group because it is specifically geared towards patients diagnosed with cardiomyopathy. Carers did acknowledge that it was primarily for the patients, but they benefitted indirectly through them. When talking about the support group again they tended to use the word 'we'. They also found it a significant source of information on cardiomyopathy and mentioned the value of being able to talk with

other patients and carers in the same boat.

... it was nice when the local support group was set up as you are in a support group where everybody is in the same boat. But there again it is mainly for them and not for the CARERS. The CARERS go with you and you get the love from them but it's still them that gets the support because they're getting the support through the group but it's a big help to you because you know everybody in that room and we've made some lovely friendships, we've got some lovely friends from it. (Female carer of male with DCM)

As I say the couple who've had the heart transplant his wife's been brilliant for me because she's been where I am now ... (Female carer of male with DCM, above)

We find the support group really, really useful. Just being able to chat to other people about the kinds of problems you've got and how you are feeling. Just for the lads to sort of say how are you feeling? Or even the girls because there are quite a few women that come along to the group as well. (Female carer of male with HCM)

We tend to speak to the rest of the people who go to the Cardiomyopathy Association meetings. We think my wife gains a lot of comfort from that because when she talks to the ladies and they say 'I know exactly how you feel that's happened to me this past week/month' and you think, 'ah, that's a normal day'. (Male carer of female, DCM)

Although one carer expressed her own feelings of the risk of a cardiomyopathy group having an adverse effect on patients because they see and hear what could possibly happen to them, she did agree that on balance it was good to see others looking fit and getting on with their lives.

Sometimes I think in these situations it can make it worse if you speak to somebody that has had a terrible time of it and it makes you think, oh, could that happen? So there are pros and cons ... It is nice to see people who are fit and healthy and getting on with their lives. It is nice to see that. (Female caring for male with HCM)

Two carers had tried general carer support groups, either online or local branches, but found their needs were not met because the carers at these groups were predominantly 'a lot of people looking after their elderly relatives with dementia'. These groups were not geared towards issues related to cardiomyopathy and were felt to be of little or no benefit.

....they have support groups as well for carers but it tends to be older people who've got relatives with dementia or you might have a younger one that's got arthritis. So to me that support group wasn't helpful. Then I'm in the Carers UK that's online .....and there again it's a lot of people looking after their elderly relatives with dementia. There's nobody in the same boat as you are... (Female carer of male with DCM)

However, one carer did mention a positive aspect of a local group which provided 'time off' from 'caring' in the form of free cinema tickets and massages.

I'm part of our local Carers Association where you can get free cinema tickets or you can go for a massage or all of these things, so you do get time away. (Female carer of male with HCM)

## **5. Experience of carers of transplant patients**

One carer had supported her husband through a heart transplant and, at the time of interview, a second carer was supporting her husband as he waited on the transplant list. The carer of the post-transplant patient was full of praise for the tertiary hospital in dealing with both patient and carer leading up to, during and after the operation. This was reinforced by the interviewee whose husband is currently on the waiting list for a transplant. Once again the word 'we' was widely used. The only negative point mentioned by both is they would like to have had time with the transplant team on their own to ask questions.

... the senior transplant consultant, one of the main ones here, nothing was too much trouble. Ask a question and it was explained to you ... (Female carer of transplant recipient)

They let you stay night and day until late ... I could come in any time. (Female carer of transplant recipient, above)

Ask (questions) at any time. You have to learn about the drugs, why he has to take them, the side effects and what he can and cannot eat and can't do. (Female carer of transplant recipient, above)

The transplant co-ordinator will always say if he is not well ring him, not to bother about anything or worry about anything, just to ring him ... It's just been a heck of a learning curve. (Female carer of husband on transplant list)

This carer described the agony of waiting for the phone call to say a heart was available.

.... where you're having to wait, and wait, and wait, when every time the phone goes you're looking to see if it is the tertiary hospital. (Female carer of husband on transplant list, above)

## **6. Impact of living with a cardiomyopathy patient**

Carers reported how it affected them on a daily basis living with someone diagnosed with cardiomyopathy or having had or are waiting for a transplant. In some there were feelings of regret and guilt because of interpreting a situation wrongly and not taking the appropriate action at the right time. Adjustments had to be made to their daily lives together and some worried about what the future would be like. One carer also expressed the difficulty in trying to

relate a diagnosis of a possible heart transplant to a step daughter and another expressed the worry of living with the possibility of having passed on the condition to their children.

### **Adjusting**

We are living with it, we'll move on with it. I have to be honest it felt painful at the very start. (Male carer of female with DCM)

It's been a heck of a learning curve. To learn about it is bad enough but to live with it is another thing. (Female carer of male with HCM)

### **Guilt**

He said 'you thought I just had man flu didn't you?' and I felt guilty after and I thought I shouldn't feel guilty but I did and carried that guilt around for about a month. (Female carer of male with DCM)

(Q: Were you pleased that he was taken in?) Oh yes, it was a relief because by this point I was beginning to be full of regrets for not calling the ambulance sooner. So it was a relief that he was being cared for by a professional. (Female carer of male with HCM)

### **Fear for the future**

My big fears are just this whole thing with Cardiomyopathy. How long do these machines last? And just things like is he going to make it past his 60th birthday? (Female carer of male with HCM)

My main concern at the moment is that my husband's defib is in a batch of faulty ones and we don't know. Whether it's the battery or ... Yes we've been told it's a batch of faulty ones and they are just monitoring it to see whether my husband's is a faulty one or not. So yes it can be a bit stressful. (Female carer of male with HCM, above)

Well, you can get rejection at any time so that's always at the back of your mind. (Female carer of transplant recipient)

(Q: Right so your husband got fitted with an ICD and at that point you thought that would stop the episodes but it didn't. How did that make you feel when you realised that wasn't the case?) Concerned. I think because we just weren't prepared for it. He had the medication, he had the ICD, so we just thought that things would settle down. (Female carer of male with HCM)

I think it is the limit of what he'll be able to do, that is my main concern. Also the long term outcome of him having an ICD fitted and the long-term condition of his heart. That is a concern. (Female carer of male with HCM, above)

### **Holidays**

One thing that really does worry me is not being able to go on holiday because we can't afford the insurance to go abroad and we love to go abroad... (Female carer of male with HCM)

... a couple of years ago we would go to the Lake District and walk. That's clearly off the cards now, we may have a quarter of an hour wander round the side of a lake rather than go up the side of a fell and things like that ... it's just kind of making adjustments to what she is capable of. (Male carer of female with DCM)

It was my birthday last weekend and he organised a trip to London and that's freaking me out because I'm wondering how we're going to manage but he wants to do it so we're going for a

couple of nights in London. I'm worried about it because I'm thinking how we'll cope. (Female carer of male with DCM)

## **Work**

Combining work and caring can be difficult.

It's hard. It takes its toll. I was having to keep down a full-time job at the time ... (Female carer of male with LVNC then transplant)

One carer had to give up work because she found the strain of dealing with a stressful job and acting as a carer too much. She was on the verge of a breakdown and gave up work for 5 years.

I've just gone back to work. I took about five years off and I had a very stressful job before that, then with my husband becoming ill I just took some time off because I was very close to having a breakdown ... You put this cocoon around them and try to protect them but you can only do that for so long. (Female carer of male with HCM)

## **Impact on other family members**

His daughter... she actually had a place to go to medical school ... but as soon as her dad had been diagnosed she didn't want to do it. (Female carer of male with DCM)

When she was told by her step mother, who was very upset, that her father was probably going to be placed on the transplant list she 'didn't want to know'.

... she said no disrespect but I don't want to talk about it. That's how I handle it, she says, I don't want to. (Female carer of male with DCM, above)

Another carer expressed concern about passing on cardiomyopathy to their children.

We've been told she is fine at this stage. No monitoring or anything and that is frightening to me. I just find it frightening because of our family history. (Female carer of male with HCM)

One carer suggested that it would be helpful if more was done to make people aware of cardiomyopathy so that even families become more aware and would thus be more supportive to carers. If something should go wrong at a family gathering, for example, members would know what to do.

People need to be made aware. There needs to be more information out there for people so that the carer gets support from their own family even. (Female carer of male with HCM)

... if you are getting together ... and something goes wrong, just so that they know what to do and what signs and symptoms are to look out for. (Female carer of male with HCM, above)

## **Conclusion**

Although this is a small sample of carers a number of important issues were raised, the most common among which was the need for carers to have access to information and support. They wanted to be able to contact someone when worries and questions arose and occasionally have the opportunity to speak to someone on their own away from the patient.

This need to access information and support arose both during diagnosis and at home after treatment, particularly in the early days. It is evident that they looked elsewhere for this either online, from general carer support groups or the local cardiomyopathy support group.

It was also evident that a diagnosis of cardiomyopathy on one partner in a close relationship has a huge effect on the life of the other.

## **Summary – Carers' Experiences**

- All carers were heavily involved with their partners throughout the diagnosis and treatment of cardiomyopathy. The use of 'we' and 'us' by all carers was a strong indication of this closeness.
- Carers echoed many of the same issues expressed by patients around the need for information and support.
- Carers needed information about the condition, sometimes searching online, and wanted to be able to contact 'someone' when worries and questions arose.
- Carers who had met the genetics nurse were full of praise for her and found she was a much valued source of information.
- Carers suggested they would value the opportunity to speak to someone on their own, away from the patient, and they would appreciate medical staff occasionally considering their feelings and the impact on them.
- Carers sought out support, in some cases either locally to them or online, but these groups did not appear to meet the needs of carers of cardiomyopathy patients.
- Although they acknowledged the local cardiomyopathy support group was primarily for patients, it was valued by carers as a place to share experiences with other carers. Only one carer commented that meeting people in a worse situation could cause anxiety.
- The Transplant Unit and Transplant Team were held as a model of good practice. However,

even there, carers would have welcomed the opportunity to ask questions away from the patient.

- Carers expressed feelings of guilt, regret, fears about the future and about the impact of the condition on other family members.
- Other issues raised by carers were around combining caring with work and difficulties around holidays.
- One carer suggested there was a need to raise awareness of cardiomyopathy amongst the general public.



## 7

# Exercise and Cardiomyopathy

Cathy Stark

### Background to study

Three members of the North East England Cardiomyopathy Support Group<sup>1</sup>, supported by Julie Goodfellow<sup>2</sup>, BHF Cardiac Genetics Nurse, have undertaken research to examine patients' experiences of cardiac care services in the North East region. Twenty-one members of the local Cardiomyopathy Support Group (16 patients and 5 carers) were interviewed in September 2015, using a semi structured interview schedule and the interviews were transcribed and analysed thematically.

During the interviews, respondents were asked about their experiences on their journey through cardiomyopathy. Exercise arose as an issue that many respondents struggled with and we elicited a great deal of information about their experiences, concerns and support needs. We also learnt about the benefits that patients gained from cardiac rehabilitation. It is these findings which are presented here.

### Introduction

During the interviews, respondents expressed a number of anxieties and concerns about exercise. Information about exercise is sometimes lacking or ambiguous and when this is the case, there is evidence that patients and their carers struggle to make decisions about what they should and should not be doing. Lack of guidelines increases anxiety for patients and

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carers. In addition, when a patient who has previously enjoyed exercising is told to stop doing so, the negative impact on self-esteem and self-confidence can be dramatic.

Amongst our sample, access to rehab for patients with cardiomyopathy appeared variable. Some patients were referred to rehab by a medical professional after being diagnosed or experiencing an acute episode; some requested or sought out rehab themselves, while others appeared to want some kind of support around exercise but had not managed to find a way of achieving this. The time at which patients accessed rehab varied enormously from immediately following diagnosis to 15 or more years after initial diagnosis. Where rehab had been accessed, positive experiences have been documented and patients reported additional benefits to rehab than just support with exercise. However, there is a suggestion from one of our interviewees that the transition from rehab classes to exercise without supervision is daunting.

Throughout this report, the quotations are given context by indicating whether or not the patient has accessed cardiac rehab.

## **Living with Cardiomyopathy**

Respondents described what it was like to live with cardiomyopathy and how the chronic condition impacted on many aspects of their lives, including their capacity to exercise. The following quotations highlight the fact people sometimes lack confidence around exercise and worry that exercising may make them feel worse. This can be based on personal experience, but also arises from anecdotal evidence which serves to exacerbate concerns.

... I get so shattered it's unbelievable. That's another thing, if you haven't actually experienced it, even the doctors don't know what it really feels like, because I would never have appreciated how weak you can be. I don't know how many other people will tell you that. (Male, DCM, accessed rehab)

I've sort of lost my confidence now in a sense. I sort of feel that I know what my limitations are and that's fine...but I seem to be doing less and less and I can be doing something and I'm OK then I'm wiped out for the rest of the day. And even if I've been doing something like a yoga class and I'm thinking I'm all right but for the rest of the day I'm just feeling dreadful. And it's just a bit of yoga it's not a huge amount that I'm doing so it almost puts me off and oh well, I just don't try to do stuff.... It's the hills though isn't it, to me walking on the flat's OK but the moment you put on the slightest bit of gradient that's when you sort of realise you can feel it on your chest. It's just incredible. It's like uphill is just impossible...I think that I

need to do a bit but I've lost my confidence I was thinking about you know you get these cardio rehab people... I might feel a bit more confident maybe. (Female, HCM, no rehab)

I cannot remember if I was told not to lift things. I am sure I remember a case where there was a young lad, footballer only 18 or 19, collapsed and then had a defibrillator inserted and was told his footballing days were over. But he went to a gym, lifting weights dislodged one of the wires and it killed him. (Male, HCM, no rehab)

[I know someone with cardiomyopathy] her doctor referred her to a gym to do an exercise programme but she said because she looks OK she didn't think that the person who was instructed to help her do the exercise didn't know about her condition ... he was really pushing her and it made her ill. (Female, DCM, no rehab)

It is also evident from our interviews that people with cardiomyopathy sometimes lack the confidence to exercise on their own.

If I don't go to the gym 3 times a week, if my friend is away looking after her grandchildren, I walk with my husband with the dog, so I have always got somebody with me. If I was on my own I feel a little bit insecure. Just in case something happens. (Female, HCM, no rehab)

Just the fact that you can exercise and you know that somebody is there if something went wrong. Do you know what I mean? (Female, HCM, rehab several years after diagnosis)

Exercise also raises concerns for carers too.

So we would try and do the right things like go for little walks. I remember one walk though, it was a windy day and we were walking towards the wind and when we turned around to walk home he had an episode. We were a mile away from home and I didn't want to leave him. So we had to stop and wait until it had passed and then start walking back. Then half way back he had another one and again I didn't want to leave him to get the car in case anything happened, so again we had to just sit and wait. So things like that are just very worrying. (Female carer of male with HCM, no rehab)

## Information about Exercise

There is clear evidence from the interviews that advice and information around exercise is lacking and respondents have found it very difficult to get unambiguous advice. Even when a patient broaches the topic with a medical professional, be it a GP or a consultant, information is not always forthcoming.

I think exercise is a very difficult one because you're never sure what you should or shouldn't be doing and it is a bit of a grey area. (Female, DCM, rehab many years after diagnosis)

... I've said to consultants can I join a gym? They'll never give you a definitive answer and I've even been to my GP who totally just ignored the question. They said just do what you think and be sensible. (Male, HCM, no rehab)

... I don't know what to do, I don't know what exercises I can do and how far to go with exercise before I should stop. (Female, DCM, no rehab)

I wanted to know what exercise I could do, because they kept saying that I need to exercise but I didn't know what I could do in my condition. (Female, HCM, rehab many years after diagnosis)

I think my biggest worry was I was not told what I could do physically. (Female, HCM, no rehab)

Let them know what's coming. Don't just say 'go home and sit in the chair'. (Male, HCM, no rehab)

Sometimes the information that is given is difficult to put into practice as it is not clear cut or is not individualised. This can lead to further questions for patients.

How tired or breathless should you feel? Because when you're exercising you do need to push yourself and diet as well. I mean I know how to eat sensibly but an exercise plan for me personally. Somebody who would tell me what exercise was best. What you should be like. What to do and what not to do. How you should feel? If you can't breathe and talk at the same time you've gone too far. Things like that. The triggers of when to stop. And how to build it up. I think you should be offered that – you don't have to take it up. I would like somebody to do a little exercise plan to tell you what you can do and what you can't do. (Female, DCM, no rehab)

And I do remember a doctor at the secondary care hospital saying that the first week after it has been fitted stay in the house and for the second week, she used the words 'go out in the community' which meant go for little walks. And she said by the third week you should start doing normal things again, but he just wasn't able, it just wasn't happening. So we were thinking what's going on? ... [The consultant] said 'don't push heavy furniture' etc. and that's fine, but it's just what is the limit? We are still working that out. (Female carer of male with HCM, no rehab)

Guidance, for my wife where she is what can she do physically to improve her health, you know whether it is walking, running, cycling, swimming. I think we got mixed stories even on swimming because one consultant was saying 'well don't swim because of pressure on your chest when you move through the water' and another said, 'well, you should be alright'. The information from the hospitals I feel has been poor. We've got more information from the Cardiomyopathy Association and probably more with the consultant at the tertiary hospital. (Male carer of female with DCM, no rehab)

*[Interviewer: Has the advice about exercise changed at all over the two years that you have been diagnosed?]* No, nobody has really asked me anymore about the exercise that I do in the follow up appointments that I have had. (Male, HCM, no rehab).

But I'd been told off by the cardiologist at the tertiary hospital, because to be honest when I'd been seeing the doctor at the secondary hospital [they] said just carry on with the gym, with the weights and treadmill. [They] said you'll be alright cos the valve that's leaking into your chest is leaking back into the heart it's not leaking out so you'll be alright. Then when [they] found out what I had from the [tertiary hospital] [they] said 'oh you've got to stop this and stop that, don't exercise, you cannot exercise, don't lift weights.' And I said 'you were

the one who told me to do it' *[Interviewer: So you had conflicting advice between the two?]*  
Oh did I, yes, big style. And I've talked to another doctor and he said '[they] should have stopped it when [they] found out you had a bad heart'. (Male, HCM, no rehab)

In the following example, a mother with a family history of HCM was given information about exercise for her school-aged children which she found difficult to interpret.

...it's difficult because they [children] haven't been diagnosed and yet they're [consultant] saying they shouldn't be doing competitive sports and you say to them, 'what do you mean by competitive sports? Can my daughter do swimming lessons? Can my son do cross country in a PE lesson at school?' 'No', they're saying 'we can't tell you'. I'm thinking 'well what does that mean?' I just don't know what it means. ... I'm trying to tell teachers my children can't do competitive sports, 'Well what can they do?' I don't really know. Well I just don't think they should exercise when they're pushing themselves when they're racing and doing personal best that sort of thing. It's just so nebulous...I just would like a bit more sort of concreteness because obviously it's anxious on the mum. My husbands the same and obviously you want to be more cautious but not hold them back, you want them to have a normal childhood. Oh dunno, it's just very, very difficult. It's harder for us because if the hospital was saying 'you can do this and that but you can't do that' you can say 'the consultant says you can do this' and it doesn't come down to us. Whereas if I'm saying 'I don't think you should be doing cross country' oh it's like 'I want to be doing this'. It's just a tricky situation to be in. (Female, HCM, no rehab)

However, where advice was more individualised or carefully explained, patients and carers found it easier to understand and follow.

I'm still concerned about the limit to what he can do now so I did ask that question and he [consultant] did explain in a way that I thought was good. He said my husband should be driving along but not in top gear. That's a good analogy. (Female Carer of Male with HCM, no rehab)

...they [doctors] said I don't even want you to lift a carrier bag for your wife. And I said 'hang on a minute; I can't even lift a carrier bag for the wife?' And he just turned round and said 'has your wife got a bad heart?' and I said 'no' so he said 'well let her carry them'... He said that extra weight will put more strain on your heart. Don't do it. And mind you he was right because as soon as I picked up any weight at all and tried to walk with it I was basically passing out. It just hits you that you're bad. It hit me anyhow. (Male, HCM and myectomy, no rehab)

But I don't do anything competitive which they did tell me not to do and that was good advice, I do agree with that. (Male, HCM, no rehab)

Both the male patients quoted above were told to stop their current exercise regime.

Exercise had been an important part of both their lives and self-identity, so this advice came as a blow. It impacted on self-esteem and even resulted in depression.

He [consultant] said 'you've got to stop what you are doing. You've got to stop running, everything. All you can do is walk twenty minutes a day'. That was a big hit for me as a man who is a marathon runner. I was a very fit guy. I mean I had coped with this fast heart beat all my life and being short of breath, I've always coped well with it because you force yourself to. So I left there feeling in a mess to be honest and I didn't know where I was. Then you start to feel pretty alone with things, and think who do I turn to here?... Ruined my self-confidence, it took everything away from me to be honest. I had always been quite a confident guy and a very fit guy and to be told to stop today and you can only walk twenty mins was just like 'oh my god'. And I still think that it was the wrong advice to be honest because yes, I have got what I've got, but I still don't think I'm anywhere near as bad as other people with these problems. I still go to the gym four times a week. (Male, HCM, no rehab).

Well I think what would have helped me was, what 6, 7 years, some information. Somebody to turn round and say look this is what you are going to have to do. And I sat in this chair for the first 6 years after the operation [myectomy]. And then I went 'to hell with this'. I started going back and did a little bit swimming at first, then my shoulders were aching, so I went back to the gym and did some very light weights, just to ease my shoulders. But they'd told me not to do that, not to exercise ... I just got that fed up. I was sick of looking at this television and at these four walls. I was suicidal at times. I was playing hell with the grand bairns, playing hell with [the kids], my wife was fed up with me, I just got so down and depressed. It was unbelievable. I just got so depressed with it. *[Interviewer: Did you talk to anybody about how you were feeling?]* Well my own doctor I did. I was in tears. I just said 'look I'm sick to death of this'. And he said 'there's nothing I can do about it, I daren't, you're under the consultant and I daren't'. He said 'you'll have to sort it out with him'. *[Interviewer: And did you go back to see the consultant?]* Yes, and he said 'look, go swimming, but very very very light'. (Male with HCM and myomectomy, no rehab)

There is a suggestion in the above quotations that in the absence of clear guidelines and without access to rehab, people 'do their own thing' with regards to exercise. Other respondents explained that they too had devised their own 'exercise programme'.

I've had to do all that myself. Work out how much my body can take. ...I had to do it myself with the support of my husband and my friends. And I worked out how much I could do. And then I had the advantage of having a son who is a doctor and talked that over with him. So I have been supported outside of the hospital as well. But there was nobody in the hospital who could give me that kind of support what I could do what I could not do. I didn't know whether I could lift weights or not. ... I can walk on the flat for a long time but you put me on an incline and I immediately slow down and become short of breath. I try to build it up so that when I'm on the treadmill I put the incline up to 1.5 - 2 to try to get my body used to that but of course again I'm the personality and I want to do everything fast and that doesn't go with the heart. (Female, HCM, no rehab)

...last summer I bought a second hand electric bike which has given me the opportunity to have these small cycle rides with my children...I can do like a little cycle ride with my kids

which I couldn't do before. If I'm on it too long - I can do things on it that I could never dream of doing without it - but if I'm sat on it too long just the act of sitting on it holding the handle bars is too tiring. But if you like cycling you can do it on pedal assist and you have to nudge pedals and it's the motor. So you're just getting really gentle exercise. Or you can do it on full throttle but it goes slowly...but they're really good. (Female, HCM, no rehab)

The female patient above believed that her ICD would act as a 'safety net' which would fire if she overdid it.

But I do know because of the ICD that's my safety net and if I push then I've got that. (Female, HCM, no rehab)

There were comments from respondents who felt they would benefit from some guidelines about what exercise would be appropriate for them. The following comments came from two patients who have not been offered rehab. If a patient is not referred by a medical professional, they may be uncertain what support is available and how to access it.

I was thinking about you know you get these cardio rehab people... I might feel a bit more confident maybe. (Female, HCM, no rehab)

I would like somebody to do a little exercise plan to tell you what you can do and what you can't do. (Female, DCM, no rehab)

## **Experiences of Cardiac Rehabilitation**

Respondents told us how they had accessed cardiac rehab and shared their experiences about it. It appeared that those who accessed rehab found it a very useful resource. They also described the transition from rehab to exercising without supervision.

Routes into rehab were varied. Some patients were referred to rehab by a medical professional after being diagnosed or experiencing an acute episode whilst others accessed rehab after making enquiries themselves.

Through the heart consultants I've been going to the heart rehab at a secondary care hospital weekly. There's a lady there, called a psychologist, and I saw her. It's only supposed to be for 10 weeks and then it's supposed to stop, but I have been lucky up to now because they have been short of patients. (Male, DCM, accessed rehab)

Well basically as a result of that conversation with her [BHF nurse] I started going to the cardiac rehab group. That was a bit later, about two months, at least two months and that

was really helpful. That staff were every bit as good as the BHF nurse. (Male, DCM, accessed rehab)

I had joined a gym but when I went anywhere near a machine my pulse rate was right through the roof. It happened that when I was in the gym there was a cardiac nurse in there with some patients and she said 'you're going too high, you need to go back to your GP and get something sorted out'. (Female, DCM, accessed rehab)

Some respondents had been to cardiac rehab on more than one occasion. The following patient first accessed rehab by asking her GP and then was pleased to be able to re-attend sometime later when she was told that there were spaces available by a friend who was already attending the group.

I just asked the GP who consulted a cardiologist who wrote back and said there was a cardiac rehab group. (Female, HCM, rehab many years after diagnosis)

It was at your last meeting [of the local Cardiomyopathy Support Group] when [current member of rehab group] asked for volunteers, and I rang up on the Monday and the receptionist said 'ask your consultant', and I've been back since then. (Female, HCM, above)

Another patient accessed rehab twice as he moved areas. When reflecting on his journey through cardiomyopathy, he described the cardiac rehab team as 'outstanding'.

One of them [rehab nurses] had been on the ward when I'd been admitted [to secondary care hospital] and she'd been on coronary care and the she was on rehab so she'd followed the whole story and it was really, really helpful talking to them and being in that group of people... I mean there's some really tough guys in rehab, and yet they burst in to tears and then you recognise your reaction in other people's reaction and in doing that you calm yourself... the rehab and the British Heart Foundation nurse, I could say they were outstanding. (Male, DCM, rehab after diagnosis)

This respondent found the care provided by the rehab nurses went beyond just exercise support during the sessions, and he had found them invaluable on a number of occasions.

Once I got to cardio rehab, I had a telephone number for them, if I had any concerns I would ring them. That lasted a long time ... (Male, DCM, above)

He experienced an episode of palpitations during the early weeks of living with his diagnosis of DCM and an ICD. He felt that the hospital staff in the local hospital had wrongly



investigated him as having a heart attack and it was to the cardiac rehab nurses he had turned for reassurance.

.. I was still having cardiac rehab at that time and they had an ECG, a 12 lead ECG, so they could check, so the next time I went, which I think was the next day, they put that on and then reassured me. And actually when you're 2 or 3 or 3 to 4 months in, I can't remember when I went there, that anxiety, you're hypersensitive to what's going on inside anyway, and that anxiety, you think it's something going on with your heart, but the cardiac rehab people reassured me. (Male, DCM, above)

Once he moved on from cardiac rehab, he still felt able to contact the rehab team if any queries arose.

... I've joined a gym now, an ordinary gym, and I had to check things out with the rehab people, in fact the gym wanted a letter from them to make sure I was OK to go. And I rang them about 4 or 5 weeks ago and they got back to me in a few hours. So I know I could [contact them] if I needed to ... You know the association of people I have is adequate at the moment. If things started happening that would change quickly and I think I would start with the cardiac rehab people. (Male, DCM, above)

There was further praise for the rehab teams from other respondents.

The cardiac nurses were lovely, they were really good. They just said to use the machine this way and use it that way and don't let your pulse rate go too high so that was OK. (Female, DCM, rehab many years after diagnosis)

You are supposed to go for ten weeks but it was a bit more than that. Then of course they've all got cardiomyopathy. You do some exercise but it's not that strenuous. Then they do the talk, you know they have a psychologist come or a dietician and that sort of thing... Just the fact that you can exercise and you know that somebody is there if something went wrong. Do you know what I mean? ... It's just being able to talk to people who have the same sort of conditions as you. You pick up things that they say and how they feel and obviously there is always someone worse than you, because a few of them had artificial valves ... the sister who ran it, she's retired now, but she ran the social side of it so I still keep in touch with them... (Female, HCM, rehab many years after diagnosis)

I did some heart rehab at the secondary care hospital so there's the heart rehab nurses there as well... I used to go and see the consultant at the secondary care hospital every two or three months and the nurse in between it was kind of an outreach exercise in that you would go to your rehab classes and they would just have a chat to you which I thought was really good ... They've got a gym at the secondary care hospital you go in and do exercises. You have a class and everybody in the class is monitored individually. You go through the programme. You start off with the basic level of exercise and you gradually recover to the level they think you're comfortable with. It's like circuit training you do a minute and then it goes up and up. It's about getting you up to a level where you can go away and do your own exercise. When you graduate you get reduced rates at the gyms and things in town. You get a little card and off you go. Yes. I thought it was very well thought out. And it gives you the incentive to go and do it as well. (Male, LVNC, accessed rehab on different occasions)

However, not everyone felt the transition from rehab class to 'ordinary' gym sessions ran smoothly.

The only thing is when I finished last time, not this time I'm there now, I was going to a place in the centre of the city. Because of my health and medication the lady there couldn't cope so she stopped me going so I don't know what happened after that. They were investigating it, you know. The sister who's at the heart rehab now she's quite friendly and she said it's a pity there wasn't something to follow on from this and she was going to have a word with some of the consultants. Something rather than nothing. (Male, DCM, accessed rehab)

After the ten weeks you are supposed to go to ten free lessons at your local leisure centre which is run by cardiac nurses, and that was alright. But after that you're put to the big wide world sort of thing. I mean they will help you if you want but it's not the same because you are in with people who are really fit ... I did go to the other sessions after that and then I stopped going to them and went back to the cardiac rehab class. (Female, HCM, rehab many years after diagnosis)

... they didn't offer any sort of rehab after transplant which I thought was a bit strange. I asked the heart nurse if I could go back and do some rehab work with the heart patients at the other hospital. I thought that was a bit strange. Obviously the physios come and see you but it's not the same. And I think it's often a confidence thing when you've had a transplant you don't always have the confidence to go out and exercise. (Male, post-transplant)

As can be seen from the examples above, within our small samples there are people who have made the transition from rehab into their own exercise regime, and examples of those who have found this more difficult. However, what is clear from our research is the benefit that people have found in rehab, and that this benefit extends beyond support with exercise. Respondents have highlighted the social benefits, meeting others with the similar problems and learning from them, having questions answered by nurses, and being able to contact the nurses in times of need. Rehab classes also include talks by other professionals, such as dieticians and psychologists, which enables patients to expand their knowledge base and access other types of support to further promote wellbeing.

## Conclusion

This research with members of the North East England Cardiomyopathy Support Group has highlighted the fact that respondents have many unanswered questions around exercise.

Patients have concerns about what they can and cannot do, and this concern is shared by carers too. In the light of the obvious benefits that involvement in cardiac rehab can bring, it is unfortunate that so many patients have not been offered this as an option and so continue to struggle to find their own way through the maze that a diagnosis of cardiomyopathy brings.

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### **Summary – Exercise and Cardiomyopathy**

- Information about exercise is often lacking or ambiguous.
- When this is the case, patients and their carers struggle to make decisions about what they should and should not be doing. Lack of guidelines increases anxiety for patients and carers.
- Respondents lack confidence around exercise and some worry that exercising may make them feel worse.
- Some people with cardiomyopathy lack the confidence to exercise on their own and prefer having someone with them in case something 'goes wrong'.
- When a patient who has previously enjoyed exercising is told to stop doing so, the negative impact on self-esteem and self-confidence can be dramatic.
- Information that is not clear cut or individualised can be difficult to put into practice. This can lead to further questions for patients. Where advice around exercise is more individualised or carefully explained, patients and carers found it easier to understand and follow.
- Access to rehab appeared variable. If a patient is not referred by a medical professional, they may be uncertain what support is available and how to access it.
- Where rehab had been accessed, reports are overwhelmingly positive.
- The benefits of rehab extend beyond support with exercise and include social benefits, having questions answered by nurses, and being able to contact the nurses in times of need.
- There is a suggestion that the transition from rehab classes to exercise without supervision can be daunting.

## Information Provision in Cardiomyopathy

Cathy Stark

### Background to study

Three members of the North East England Cardiomyopathy Support Group<sup>1</sup>, supported by Julie Goodfellow<sup>2</sup>, BHF Cardiac Genetics Nurse, have undertaken research to examine patients' experiences of cardiac care services in the North East region. Twenty-one members of the local Cardiomyopathy Support Group (16 patients and 5 carers) were interviewed in September 2015, using a semi structured interview schedule and the interviews were transcribed and analysed thematically.

### Introduction

The interviews highlighted a real need for accurate, timely and targeted information. Respondents talked about why information is important, when it is needed, what they wanted to know and the sources of their information. They also described some of the complexities around taking information in when in a distressed state and the importance of how information is conveyed by medics. This chapter provides an insight into patients' experiences of being given information. It includes examples of good practice, and explores the difficulties experienced when information is lacking, poorly delivered or inaccurate. We learnt a great deal about patients' experience of getting information on the topic of exercise and have addressed this in a separate chapter entitled 'Exercise and Cardiomyopathy'

This chapter is divided into the following sections:

1. Why information is important and when it is needed
2. Patients' experiences of receiving information from medics
3. Sources of information
4. Summary of findings

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<sup>2</sup> Julie Goodfellow, BHF Cardiac Genetics Nurse, Freeman Hospital, Newcastle-upon-Tyne

5. Recommendations on how to improve information-giving to patients with cardiomyopathy

## **1. Why and when is information important to patients?**

It is clear from the interviews that accurate information helps patients to manage their expectations. Harbours unrealistic expectations can result in bewildering or even frightening circumstances for patients. There are key times in the patient journey when information is needed: at diagnosis, on discharge from hospital, after an 'acute episode' and when a patient's circumstances change due to everyday life events.

When first diagnosed, it appears that some patients are told that they have cardiomyopathy but are not given information about what this actually means for them. They are anxious about what the future might hold and lack of information and support at this time exacerbates these feelings of anxiety.

I just thought I was going to die and that my heart is wrecked and I've got a nasty heart. But what does that mean? .... We need better information. We need to be told the road we are going down. (Male, HCM)

I mean I knew what I had but I didn't know what I had – I knew what it was called but I didn't know what it was ... Let them know what's coming. Don't just say 'go home and sit in the chair'. (Male, HCM)

In contrast, a further male with HCM describes the difference that accurate information and a considered delivery can make. This patient was transferred from a secondary care hospital where "there was just nothing" in terms of information to a tertiary hospital where his condition was explained to him.

I wish I had been under him in the first place...he went into it all properly...I understood what was going to happen and what could happen. (Male, HCM)

Discharge from hospital is another time when accurate information is needed to help patients realistically manage expectations.

The only thing is, the discharge from the tertiary care hospital, no one told me what to expect. And I was told by one of the nurses, that I'd be back at work in 3 or 4 weeks and I

think they were treating like I'd had a heart attack and clearly I've never been able to return to work and I'm still quite unwell, but my expectations were much higher than my recovery on my discharge from the tertiary care hospital. (Male, DCM)

I kept thinking I will get better...it hit me because I wasn't getting back to what I call 'normal'. I was expecting to have all the pills and be fully functioning. (Female, DCM)

Interviews also highlighted the need for information after there has been an acute episode of some kind. In the following quotations, the 'acute episode' is the insertion of a device. There is an expectation that, once the device is fitted, previous symptoms would be a thing of the past. The following patients had not been told that the medication may take time to become effective, or that the device may need adjusting.

I didn't appreciate it would take a wee while for the drugs to work, that's one thing I didn't appreciate ... I hadn't expected further incidences. I was kind of prepared for little incidences but I wasn't prepared for the episode that actually occurred at that time. (Male, HCM)

Just for someone to come and explain, even if it was just the sister on the ward, just to explain you've had this thing fitted and hopefully once we get it set up correctly – cos I didn't know about that either. (Male, HCM)

If someone had just sat us down and said, 'look, this is what has been done...but for the next few weeks you could still have some more episodes but try not to worry about them' ... If somebody had just explained all this to us we would have been less concerned. (Female carer of male with HCM)

The need for clear information after having a device fitted in order to help patients and carers manage expectations is clear. Lack of information on what to expect after a device has been fitted may result in people accessing medical support when in fact this could have been avoided. Further findings around devices are presented in a separate chapter.

The fact that quality, timely information benefits both patients and medics is summed up by the following patient.

It all goes back to the diagnosis and if somebody could just point you in the right direction, it is not only easier for the patient, but also for the hospital. (Male, DCM)

Respondents also described a host of other life events which necessitated the need for information. Sometimes the information wanted was of a very practical kind, for example:

what is meant by 'healthy eating'; driving after diagnosis or after having a device fitted; and managing medications and their side effects.

They say eat a balanced diet – well give us an idea. (Male, HCM)

I've got my license back but I haven't got the confidence. (Female, HCM)

...somebody who could offer practical advice about driving and all the other stuff and I guess that some of these drugs have side effects and it might be useful to talk to somebody about that. (Male, HCM)

[re: symptoms] It's hard to know what's the condition and what's the medication, and which medication. (Female, HCM)

What I would say to anyone who has a heart problem is to ask their doctor what the tablets are and why they have been prescribed them. (Male, DCM)

With hindsight, it might have been good to have known what the side effects of amiodarone were and I mightn't have felt quite as jumpy. (Male, HCM)

Other life events which necessitated the need for information covered more complex issues: concern about relatives and the need for information around screening; coping with depression and the need for information around psychological support; and exercise and the need for information around what is safe.

She is at the stage in her life now where her and her husband are thinking about having a family and I worry myself sick about it. I'd rather know that she was fully safe and was being monitored before she got pregnant, if that was possible. (Female carer of male with HCM)

He [son] was running the Great North Run and although I would never have said it to him, I just had that little kind of worry 'is he OK to be doing this?' (Female, PPCM)

I didn't know there was counselling. I was ill for over a year and had depression because I think I always had it in my mind I would get better. Then I didn't and it really sort of hit me and I actually had counselling through work. (Female, DCM)

...there is adult support as well. I don't think I need it now I think I've got there myself. I'm getting there by other means, but it should have been offered at the time because I think it's such a humungous thing. (Female, HCM)

It is clear that the need for information is continuous throughout the patient journey.

Information is needed which is responsive to the current and constantly changing needs of patients. Once again, this raises the question of where do patients go to get the information

they need? The chapter on ‘Support Suggestions’ explicitly made by patients, highlighted the need for patients to have ‘someone’ they can go to for accurate information and support. The findings in this section on information reinforce the need for that provision.

## **2. Patients’ experiences of receiving information from medics**

The flow of information between medics and patients is not a one-way process and factors arise which can disrupt the flow. Respondents have identified times when they have been ill or in a state of mind where they could not absorb information. They may not have been able to ask the ‘right’ questions at the time they had the opportunity to do so. A patient may not understand or may misremember or misinterpret what they have been told. This may reflect the quality of the information given and the fact it may be confusing or inaccessible, or it may reflect the patients’ state of mind at that time.

Our interviews suggest that there can be issues in the way in which information is imparted by medics. Delivery may be rushed or insensitive, patients may be ‘told’ information without being given the chance to discuss it. Information given may be partial or limited, and patients may be given conflicting advice by different medics. Respondents described scenarios where the medic appeared to lack knowledge of cardiomyopathy, and on occasion, patients felt they had been given inaccurate information.

On balance, we also have examples of good practice where respondents described feeling fully informed and supported. We have examples amongst our interviews where appropriate information was given and where information addressed a patient’s questions and allayed their fears and concerns. Examples of good practice are highlighted at the end of this section.

The issues which can disrupt communication between patients and medics have been emboldened and are discussed in turn below.

Patients recognised that they may have been **too poorly or overwhelmed to take information in.**

It might have been my psychological state at the time but I just wasn’t taking it in, having a background in biomedicine, I’m usually pretty well informed but I wasn’t in the right place, I



was pretty vulnerable, so I suspect they maybe told me more than I can remember but I didn't feel fully informed but that might have been to do with my state. When I went to the ICD clinic sometime afterwards, it wasn't me being difficult, I just genuinely couldn't remember. (Male, DCM)

I would probably say that they probably asked if I had any questions. I can't totally remember. But I would think that they would have said things like that. But I can't honestly remember that because when you are lying in that bed and you are quite confused and your heart is banging away and they probably ask if you have any questions and you don't really respond. So I'm not 100% sure to be honest. (Male, HCM)

These honest accounts underline the fact that there is a need to be able to access information again at a later time when patients are more able to take in information.

As explored in the chapter on 'Experience of Consultants', having the opportunity to ask medics questions during a consultation does not necessarily mean that patients will collect all the information they need at that point in time. **Questions do not always occur to patients at the time the medic is available.** Questions often arise when a patient has had time to reflect on what they have been told. Indeed, **it can sometimes be difficult to know what questions to ask.**

...I probably didn't know the right questions at that point ... I think being half asleep and the drugs I think I was pretty low. (Male, HCM)

In fact it was the next time I saw him [consultant] that I started to ask questions. (Male, HCM)

You kind of don't know what you don't know. (Male carer of female with DCM)

There may be many months between consultations. Having the opportunity between consultations to have questions answered in a timely manner deemed important.

**Some patients valued having someone with them when receiving information.** This gives a 'second bite' at the information as the companion may remember information or ask questions that the patient has forgotten.

I mean my wife was there all the time because I know I wasn't in a good place for taking in information anyway. (Male, DCM)

He came out in a rash and it wasn't until I mentioned it he said 'oh that could be a side effect of one of the pills'....my husband doesn't speak up sometimes, whereas I'm the opposite. (Female carer male with LVNC)

I said, to me, a layperson, it [tightness in chest] seems linked to the fact that you are increasing this particular medication...and the light seemed to come on with the nurse, making the link between increasing that med is making that symptom worse, 'oh yes, we'll stop doing that, we'll knock it back a notch'. They did and it worked... (Male carer of female with DCM)

Having the support of a relative or friend when receiving information can be valuable and may help recall, and provide an opportunity for discussion with someone who has also heard it 'first hand'. Respondents told us that it is important for family members to have access to information as this can help reduce concerns and enable them to better understand the situation.

I think information for carers and friends, we need to get [that]... it's up to me obviously, I think they [family] were very worried and as soon as you mention heart I think and heart failure. That's scary. It sounds like you're going to die within a few weeks. (Female, DCM)

Interestingly, when asked about information, it was suggested that some patients may not wish to know certain information or be frightened by it.

But this is again – a lot of people don't want to know. So it's strictly one for them to work out whether for them to tell you or not certain things, but I think you should be given the option. (Male, DCM)

I don't know. Some people can take it but some people could be frightened by it all, couldn't they? (Male, HCM)

I think it depends again on the personality of the people...I found a difference in how people approached the illness, some like me just got on with life, others just wanted to talk about it all the time, it was on their mind, so if those people were given all the information maybe it would affect them badly. (Female, HCM)

However, none of our interviewees expressed this concern around information and all stated that they wanted information. Nevertheless, it does highlight the importance of considering what a patient can deal with.

Whereas none of our respondents said they 'did not want to know' information, there is evidence in our interviews that being given information can heighten anxiety. It appears that **the manner in which information is communicated** is key here.

I was told that I could drop down dead at any time ...It was a little bit overloading. The information was there but I was just hit with it. It was a bit too much and very, not harsh, but to the point. The same as the last time I saw him when it was just like see you in a years' time and it will only be getting worse in that time. Those were his words. When it was like that it just froze you. (Male, HCM)

Cardiologists really need to think about how they present information to patients.... I met a cardiologist down there about a month ago who said according to a technician my heart had got thicker by a centimetre. I said 'I'm telling you my heart hasn't grown in thickness by a centimetre because I would have felt something'. And the doctor actually said, 'I agree with you but it's open to interpretation by the technicians' and that was with the echo. It leaves me pretty nervous. (Male, HCM)

Well after I'd been in and out of hospital a few times, he just turned round and said 'look we need you in as soon as possible because you need to have this procedure done because you could end up [unclear] dead, basically you could snuff it, if you go down you'll not get back up. (Male, HCM)

I think my criticism was that [doctor] told me like that in front of my children and [they] didn't even know what to say. [They] didn't know [they] had to go back to the team. I think [they] should have asked me to go in by myself and said we're not really quite sure yet. (Female, HCM)

Patients acknowledged that sometimes the information they needed to hear would be difficult, "it's that kind of info, it's hard" (Male, HCM), but the manner in which information is given is important.

Another issue which patients found difficult was being given **information perceived as 'conflicting'**. Patients were told something by one medical professional which was then contradicted by another. This could leave patients feeling anxious and confused.

Then when [doctor at secondary care hospital] found out what I had from the [tertiary hospital] they said 'oh you've got to stop this and stop that, don't exercise, you cannot exercise, don't lift weights.' And I said 'you were the one who told me to do it' (Male, HCM)

A cardiologist at a secondary care hospital said that I would eventually need a heart transplant which is frightening with the thought of it... a professor at a tertiary care hospital said nowhere near. It will probably never happen. We will probably keep the heart you've got going and you'll probably never need a transplant. So I've got like all shades of the same spectrum....One of the options that was mentioned other than a heart transplant was they

could slice a shaving from the heart. Then another cardiologist said 'no way'. The bit that's left has lost its elasticity and, then again. That's another example of who do you believe? (Male, HCM & co-morbidity)

In the following quotation, the patient suggests that being given an explanation for the apparent conflict would help allay concerns

They kept chopping and changing saying I would be going home in three days and then they come back six hours later and say well you could be going home in the next hour. Then I did go home in the next hour. It just wasn't very consistent what they were telling me. .. My heart was still beating fast and I suppose they've got the monitor on and they base the decision to send me home on that because maybe I'm not as bad as the guy in the next bed. But maybe they should tell you that and say, 'You're not as acute as other people and we think you are going to be ok so we are going to send you home and you can rest at home', but nobody says this to you. (Male, HCM)

It has been seen that lack of information can result in unrealistic expectations. It appears from our interviews that respondents were sometimes given **partial information** rather than 'the full story'. This again can lead to increased anxiety.

Well when I was waiting for the last pacemaker it was starting to become an issue. At first they said I had 18 months on my battery. Then it went down to 3 months. Then you start thinking hang on a minute. So I phoned up and they said it's not a problem, we have you booked in for such and such day....They say you've got 18 months and then if they had said 18 months and there is a date pencilled in... [Interviewer] That would take some of the anxiety away? [Respondent] Yes. (Male, DCM)

Two respondents found out their diagnosis 'by accident':

And I don't think they actually told me it was told me it was heart failure then. They just said that I would have to see the consultants and they gave me some beta blockers and some water tablets and sent me home....It was in the December but unfortunately before then I'd seen an endocrinologist because I was having really hot sweats. When I got his clinic letter he'd actually put in medical conditions – heart failure. So I sort of found out by accident. (Female, DCM)

No and I am not sure I was actually given the phrase cardiomyopathy at that point. I was told I was in heart failure. They used the term heart failure/enlarged heart but I don't think cardiomyopathy was used. That came quite a bit later actually....I think the GP was filling in a form for something and I said 'oh what's that?' and he said 'that's what you've been diagnosed with, peripartum cardiomyopathy'. But I hadn't been told that by the hospital, I was just told it was heart failure. It was probably a few months [later]. (Female, PPCM)

One respondent who have been diagnosed over three years prior to the interview commented

I haven't been sat down and explained that this is what's happened to your heart and this is what hypertrophic cardiomyopathy is. Its' all been second hand (Male, HCM)

There is evidence in our interviews that at times, **information is not given to patients or is not discussed** with patients.

To be honest, I remember asking for information when I had my operation [myectomy] and they basically couldn't give me any. She said 'there's very little information we can give you'. (Male, HCM)

No medical personnel advised us to have her [daughter] tested or anything. (Female carer of male with HCM)

No nobody had suggested it, it was off her own back. It was us. We said you better go and get checked out....They said she was ok at the minute but I don't know...what happens now, does she keep going? Does she have it done every other year, or is once enough? Nobody has said anything. (Male, HCM)

I was in there and all the doctors were at the bottom of the bed talking about me. And I said 'excuse me, I'm the patient, I should be included in the conversation' and they didn't like that idea. (Male, DCM)

I don't think they actually talked to me, they just told me that they were going to do it [insert ICD]. (Female, HCM)

There are comments which suggest patients felt **knowledge of cardiomyopathy to be lacking amongst some medical personnel**. If medical professionals lack knowledge then it is unlikely that any useful information can be imparted to patients. Respondents described scenarios involving A&E staff, GPs and ward staff where they did not have confidence in a medic's expertise. Once again, this was not a finding across the interviews and on balance some respondents hold their GP and hospital staff that they have dealt with in high regard. However, there are examples where respondents felt that they had been given misleading or inaccurate information by medics, and it is important to examine these examples so improvements can be made.

During an acute episode resulting in a 999 call, respondents can find themselves in A&E. It appeared that some staff in A&E have not had a great deal of experience of cardiomyopathy or of devices, and this was reflected in the unsatisfactory experiences of some respondents.

It is also very clear from our interviews that people with cardiomyopathy are often treated as if they have had a heart attack, both while in A&E and once admitted onto a ward. In these circumstances, the patient and carer may become the information giver.

They were waiting for the blood test to see if you've had a heart attack, the blood has a raised level, and I said 'look I haven't had a heart attack' and I even got [wife] to come down and bring all my results from the tertiary care hospital including the angiogram to show that my coronary arteries are fine. So it was very poor care. So in the end by negotiation, I said 'I'm not at risk of a heart attack' and they said 'OK we'll let you go'. So that hospital was a poor experience. (Male, DCM)

The twice I went in after I was diagnosed with hypertrophic cardiomyopathy, they treat me as if I had had a heart attack and I've never had a heart attack...To me the time I've had to go into the secondary care hospital for it, the A&E haven't got a clue. You mention cardiomyopathy and they look at you as if to say 'what's that?' (Male, HCM)

Especially the doctors who deal with you when you're taken into hospital. Like junior doctors. I think they need some basic teaching to recognise these things. Like in my case they said 'you've only got a chest infection' and all the time my heart was getting worse and worse because nobody recognised it. (Male, DCM)

They took him in and I would say 'no he hasn't had a heart attack' and they would take no notice and go through the whole thing.....All he really needed was his device checking because that would tell us more than taking his blood and things. When you are telling people that he has got his device and this is what happens and this is what you need to do, and because I don't think that it is something that turns up very often in a hospital in an emergency, they just don't know what to do. Especially when it's after 5pm or at the weekend when people aren't there to do the device checking. (Female carer for male with HCM)

The fact that you have an ICD and you're being treated here and treated there, all of this has got to be explained to them and I'm never too confident that in an A&E department they know what to do with things like an ICD. (Male, HCM)

But it is sometimes frustrating when you go to see doctors who haven't a clue but because you've had something wrong with your heart they naturally think you've had a heart attack or got angina or something like that. (Female carer of Male, DCM)

At the secondary care hospital they put me in a box. They say that's what's wrong with you. They put me in the angina box and I said 'no I don't have angina'. (Male, DCM)

Basically I got no care at all. I was on a general surgical ward and I never got onto an ECG at all and when the cardiologist did eventually come he got really confused by looking at someone else's ECG, I'm not making this up, and told me there was nothing wrong with my heart, and he'd got the patient's [results] in the next bed. If I hadn't been so freaked out, I mean I've discussed this with friends who are medics since, and they've said you should have made a complaint, because that's incompetence. (Male, DCM reporting on an experience in hospital out of the region)

There was some evidence of lack of knowledge amongst medical staff about heart transplants.

The nurse in the A&E said, 'oh, you are on the transplant list when are you getting your heart?' He [husband] says well ' how long is a piece of string, I cannot go to Tesco's and buy one off the shelf you know'. 'Oh, I thought you might know how long you're going to wait'. He [husband] says, ' well, how long's a piece of string?' And you think we'll that's a professional asking you. You haven't got much hope really have you, but if they don't deal with cardiomyopathy or they don't deal with heart problems, they are in A&E, they don't realise. (Female carer of Male, DCM)

There was nothing from the hospital. It took a week to ten days to diagnose. I went on the internet and read different things. Then one day I was in the secondary care hospital and I was reading the newspaper and this nurse came out and I said 'excuse me, is this what I've got to look forward to?' and somebody had cardiomyopathy and he was waiting for a heart transplant and she said 'yes you've got about 6 months'. That's the kind of thing I was getting off the internet as well. You know things like so many die within the first year and then after that such a percent will die within five years. But stuff like that isn't true. (Male, DCM)

Respondents also suggested that GPs could lack knowledge of the condition.

I don't believe that our GPs are clued up on it enough. Not unless it is a specialist areas of theirs. And because of their workloads and they are doing very difficult jobs in very tight circumstances, I don't think many of them are aware of the support that is out there for people with cardiomyopathy, or even what cardiomyopathy is all about. (Female carer of male with HCM)

One of the things that could be done with care at the hospital is communication back to GPs. To keep them more informed about people's problems and peoples diseases like cardiomyopathy. Because GPs don't have a clue what it is, most of them. They know the basics. You find the patients know more about their condition than the GPs and the cardiac nurses in the practices. (Male, DCM)

The level of understanding within our own GP practice was low and disappointing. (Female, HCM)

Absolutely hopeless. (Male, HCM)

I don't have an enormous amount of faith in my GP to be honest, for various reasons. (Male, DCM)

In my own GPs surgery we have two nurses that deal with cardiac patients and do like regular monitoring, one believes that you can't have cardiomyopathy unless you've had a heart attack. But she says you only really get heart failure if you've had a heart attack. I gave her all the literature to prove different. No it doesn't work as simply as that. I said you're just putting everybody in the same boxed squares. I said you need to read up a bit more and I gave her all the information. Next time I went to get a blood test done she apologised and she has read up on it now. (Male, DCM)

When in hospital for an unrelated condition, the following patient experienced a lack of knowledge about cardiomyopathy and devices from the nurses on the ward

You're treated like I don't know... as if you're another species or something. Which seems odd because it's not that rare. I know it's not that common but to me it just doesn't seem to make sense to have more of an understanding because there are quite a lot of people who have this...Of course all the nursing staff on the [non-cardiac] ward where I was they didn't have a clue. They asked me where the off button was [for device]. They had no idea, it was really funny. Like I was from the planet Zog or something. (Female, HCM)

The following patient described his experience of being given information about treatment for a co-existing condition

His words were that after 2 or 3 infusions you'll be like a new bloke. That's what he said. What a load of tosh. Cos I said I like my garden. He said you'll be able to get an even bigger garden, get an allotment as well. Misleading. That's what he said. Of course I get an infusion now once a fortnight and it lasts about 4 hours. I have it at home now. You're absolutely wiped out for the rest of the day. So again it's the misinformation. (Male, HCM, speaking about co-morbidity)

However, this same patient wanted to emphasise that information which, although inaccurate, was not given to deliberately mislead.

No 100% I can say I've not come across a person who is trying to deliberately to mislead. They're not. But it's about trying to gather all the information you've been given and then really it's about assessing it. You're left to your own devices to assess it when really that person's saying this and that one's saying that. Is it somewhere in the middle. And that's the grey area. I might be seeking something that's not there. I don't know. (Male HCM with co-morbidity, above)

### **Good practice in information provision**

Although this section has highlighted the shortcomings in information provision in order to highlight areas for improvement, there were examples of good practice in the interviews. Some respondents stated that they had been given the information they needed in an appropriate manner. The holistic approach taken by the Transplant Unit is highly praised by those who have come into contact with it and these respondents appreciated the inclusion of their family members during discussions.

I'm in a position where [wife] is with me and they aren't just explaining it to me they are explaining it to [wife] as well. So it is not just the patient that is getting it, the people they are with too. They don't come in and say that you have to leave because the doctor is on his rounds. The doctor comes in to talk to you and you can introduce who is with you and then



they are then included in the conversation. They are even allowed to ask questions themselves (Male, DCM, transplant assessment)

As previously mentioned, specialist nurses have been identified as valuable sources of information and support.

She [BHF nurse] became like the hub of information....she was like a lifeline....she gave us her mobile number and said ring at any time and leave a message and I'll get back to you....she became the conduit to lots of other things and we could always go to her....at that time she was the focus of everything really. Help, encouragement and reassurance. (Male, DCM)

This point about specialist nurses as sources of information and support is explored in the next section, section 3.

### **3. Sources of Information**

Respondents were asked about their sources of information and the following were identified:

- Medical personnel
- Internet
- Literature from hospitals
- Cardiomyopathy UK
- Patients

#### **Medical personnel**

Specialist nurses were identified by respondents as being a very helpful source of information and also an important source of support. Specialist nurses were referred to as: community cardiac nurses; hospital based cardiac nurses; genetics nurses and rehab nurses. Specialist nurses were reported as providing the following type of information and support:

Time. Reassurance. ... re-managing expectations (Male, DCM)

They've got a great education programme...The amount of trivial questions I used to ask the nurses at the secondary care hospital. Nothing seemed to faze them. (Male, LVNC)

[The genetics nurse] was really good and went through the whole procedure and explained everything perfectly and she even answered questions that we had been asking the doctor I suppose. Well my sister went in. My sister's one who likes to write everything down, with

her notebook and her questions and I think she really had a lot to ask [the genetics nurse] and it wasn't really her place to answer them - she was there for genetic testing sort of thing - but my sister came away and said I feel like I know everything now. (Female, DCM)

It happened that when I was in the gym there was a cardiac nurse in there with some patients and she said you're going too high [pulse rate], you need to go back to your GP and get something sorted out. (Female, PPCM)

As time went on and it got nearer to the time it was going to happen [insertion of device] I got more concerned and when I ... spoke to the nurse [ward based cardiac nurse] it was brilliant. She listened to what I was saying and she was able to tell me exactly what was going to happen and that getting fitted with an external pacemaker wouldn't happen. So because somebody listened it helped. (Male, DCM)

Many respondents stated that their cardiologist was a valued source of information.

Findings on consultants are reported in a separate chapter. Personnel in the Rhythm Management Team were identified as providing information. Personnel included those at the end of the phone when respondents rang up with a query, staff dealing with readings from devices, and the surgeons who fitted the devices.

When I rang up about my cooker query. I thought they're really busy people with all these situations would they really like to spend time dealing with my choice of cooker. They were actually really nice and said you did the right thing, you did the right thing to ask us. (Female, HCM, concerned about effect of magnets on device)

...they just sat down on the edge of the bed and we had a good chat. (Male, HCM)

Two respondents commented that they asked questions during the fitting of the device

I'll ask you questions as we go along. And he said well you'll be slightly sedated with the local anaesthetic and that was it. So I did. And even in the middle of the thing I was asking questions and he was answering. (Male, HCM)

He explained what he was doing as he went along. (Male, HCM)

Other medics who were identified as sources of information were:

- Family members or friends who were doctors (3 respondents)
- GPs. A few respondents spoke highly of their GP and felt they had been helpful in their journey with cardiomyopathy. However, patients' views on GPs were very mixed and some respondents spoke negatively and described their GP as lacking in knowledge about cardiomyopathy.

One respondent thought that medics had become more guarded when giving information to patients because of the 'blame culture'.

Not many like to answer the question. They beat around the bush. If you ask them a direct question they say they say 'we'll have to see, we'll have to speak to your consultant before we answer you'. Nobody wishes to answer the question...I think it's about the culture we've all got in the UK now. About finding who's at fault for everything....Yes the blame culture. That's what I think it is. (Male, DCM)

### **Internet based information**

Unsurprisingly perhaps, most of the respondents had done their own research into cardiomyopathy following diagnosis and this invariably involved the internet. Many respondents recognised that information on the internet was not necessarily reliable. As a response to this, respondents told us that they tended to visit 'reliable' or 'official' websites, including NHS site, British Heart Foundation (BHF) or Cardiomyopathy UK. GPs and specialist nurses had sometimes signposted patients to reliable websites and warned them away from general 'googling' of the condition. Nevertheless, it was almost inevitable that in this internet-age, some respondents had done just that and given themselves a fright.

I frightened myself half to death. I still am. (Male, HCM)

You've got to be careful or you think you are for the knacker's yard when you read some of this stuff. (Male, HCM)

You know they say go and have a look on the internet but anybody can put anything on the internet and I have been down that road and it doesn't do any good. (Male, DCM)

You've got to be very careful with the internet. (Male, HCM)

Yes I went on the internet but all I was reading was other people's experiences of what I've got and they've got pacemakers and ICDs and people are dying left right and centre with this cardiomyopathy. (Male, HCM)

Well I have occasionally but I wouldn't go too much into it on the internet because it always ends in death on there you know. (Female, HCM)

As a result of being 'terrified' by visiting 'random' websites, respondents tended to use more 'reputable' or 'official' sites. GPs and specialist nurses warned patients against 'looking it up' on the internet but recognised that they would do so and so signposted them to 'reliable' websites

The GP told me about one, it's the one they use, and so it was the GP who told me about it. Yes I can't remember the name. I've got it at home. The GP said if you're going to use the internet, and I advise you not to use it, but if you are going to use it, use this one cos it's a British one and 95% of them are American. (Male, HCM)

And you look at the internet and that's the worst thing to do. I think one of the first things they said to me when I was diagnosed is 'don't look at the internet'. (Male, LVNC)

And the specialist nurse I saw on the day I got the diagnosis officially said, 'You'll probably go away and Google it but try to stick to sites that are proper sites like BHF'. He said 'because otherwise you'll probably get wrong information or you'll get totally scared'. (Female, DCM)

I have realised it's quite dangerous to be looking at random sites on the internet, it's quite terrifying. So I've tried to find that out from reputable sources I suppose like Cardiomyopathy UK now and BHF and try not to look at other stuff but understand that it's not current and scary. When I was first diagnosed I went on the American one, the HCMA and that's very scary to say the least. (Female, HCM)

I've never bothered looking at them. I tend to stick to the ones I trust and I think if you go to the government or NHS one it should be fairly reliable. A lot of these other ones, some of them are terrifying. (Male, DCM)

I think you have got to be very careful on the internet. I tended to go with the CMA [Cardiomyopathy Association]. I'd done all the internet but I mean there wasn't even the internet in 1991. I'd been at the medical library at the University and looked at everything I could and read it but it wasn't very reassuring so I shouldn't really have done that. I would never recommend that people look it up on the internet. I would always suggest that they go to Cardiomyopathy UK now. It's great that that's there now, obviously it wasn't there then. (Female, PPCM)

The following two quotations highlight a difference in opinion on the value of NHS websites.

I did find the NHS websites very, very good. (Male, HCM)

I've looked on NHS websites which are very poor for cardiomyopathy sufferers. Lots for people that have had heart attacks. There's lots of information for GPs for people who have had heart attacks and go into heart failure for that reason, but not for people who have got an illness like cardiomyopathy. There isn't the information there. (Male, DCM)

In addition to visiting websites, one patient had contacted a hospital in Southampton who answered questions through postings on their website. He had found the information from this means extremely informative.

You know when you are just mucking about on the computer and it came up with Southampton. I sent them a couple of questions which I'd asked my own cardiologist in the secondary care hospital and I wasn't getting anything back. But these people talked to me. But it was sad to be getting my information from Southampton when I was in a hospital in

[this region] . Why couldn't the secondary care hospital give me the same information?  
(Male, DCM)

## **Literature in hospitals**

A number of respondents mentioned 'picking up' or being given literature whilst in hospital. Often it was not specified exactly what this literature was, although the series of small BHF booklets were mentioned by name. Interestingly, some respondents spoke of 'picking up' literature, rather than being given them by medics, which might suggest a somewhat ad hoc approach to providing patients with printed literature.

I had enough information. As I say there were booklets kicking around the hospital...I picked them up myself. (Male, HCM)

I picked up all them leaflets and that's how I found out. I picked them up. (Male, HCM)

.... when I got the ICD fitted I got the ICD booklet from the hospital. (Male, HCM)

They gave me the BHF booklet on ICDs and actually I did have time to read that and process that a bit more but it was probably after the event because the ICD went in fairly quickly.  
(Male, DCM)

The most helpful ones I find are, you know the little heart booklets, the British Heart Foundation. (Male, DCM)

## **Cardiomyopathy UK**

Respondents identified Cardiomyopathy UK (or the Cardiomyopathy Association as it was previously known) as a source of information and support. However, as all respondents attended a support group run through Cardiomyopathy UK, it is perhaps unsurprising that people found the charity a useful source of information.

In addition to the website, other aspects of the charity which provided information were: the Helpline, Patient Information Days, booklets and the local support group.

The telephone Helpline is staffed by cardiomyopathy support nurses. The following respondents found the Helpline useful:

They've been very useful actually, over stages. We've been having some concerns about my youngest daughter at the moment and they've been very helpful with phone calls so.  
(Female, HCM)

...you can also ring Cardiomyopathy UK and they've got nurses and they've even helped me with work issues as well. (Female, DCM)

I mean they say you could phone them up and I did a few times and when you phone them up they are ok like. (Male, HCM)

...having been in contact with them I think that just gave me the confidence to think 'yes well actually it is worth me following this up' and just checking that everything was OK. (Female, PPCM)

The charity also offers information and support by email.

On occasion the lady I emailed said 'I don't know I'll find out' and she came back and said 'I will find out for you just give me a while'. So I knew somebody was going to come back and help. (Female, DCM)

Each year Cardiomyopathy UK hold 'Patient Information Days' for people with cardiomyopathy and their families to hear medical experts discuss the different types of cardiomyopathy, developments in care and latest research. The meetings are held across the country and Newcastle has been a venue on several occasions. Findings suggest that respondents found these 'Information Days' a valuable source of information.

Perry [Elliott] – a mine of information. (Female, HCM)

...when I found out there was a cardiomyopathy meeting at the Holiday Inn when they had got Dr Perry [Elliott] he was there and the head of Cardiomyopathy UK, so I went to that first and listed to that and thought they seemed to know their stuff, so I then came to the support meeting and it's nice that you can talk to the people here. (Female, DCM)

I've been to lots of meetings where there's been professors from London and whatnot, which were good. (Female, DCM)

I learnt that at that Information Day. It's a diagnosis of excluding everything else, no blocked arteries and therefore it's cardiomyopathy. I didn't know any of that at the time. (Male, DCM)

Yes a professor, the one from London ... he said 'there's got to be a reason for it [blackouts], don't [let them off?]' so I did, I went to see the cardiologist at the tertiary care hospital and told him what he'd said. And I don't think he was very happy but he said 'well OK I'll send you to the Syncope Unit and see what they can find out'. (Male, HCM)

The charity sends out email updates and offers information through a digest of latest research

I mean at least once or twice a week. I get the update emails and I like to read about all the latest developments. I like to keep up on the literature and Cardiomyopathy are quite good at picking it up anyway, letting you know. And with my background in the sciences I'm completely fascinated by all that stuff... I've got both booklets [Living with Cardiomyopathy

and Dilated Cardiomyopathy]. I gave them to my son and he found them very helpful. (Male, DCM)

### **Patients as sources of information**

Patients can offer information and support to other patients. As stated, the local Cardiomyopathy Support Group is a patient run group. Respondents' views on the support group are presented in a separate chapter.

The only support that I have had has been off yourselves [cardiomyopathy support group] and off literature that I have picked up ... The books I've gotten have been from yourselves [support group], from the Cardiomyopathy Association. (Male, HCM)

Two respondents described the way in which they had supported other patients

I've actually been asked by the cardiologists here to talk to a few people in the clinic who have been nervous [about devices]. And have chats with them and put them at ease. Which you don't mind, it's helping people. (Male, DCM)

He [retired cardiologist] asked that I went down to a hospital in London and for a few weekends and was trained as to how to counsel people ... but he would chose the patients that he thought would be helped through me and he would phone them up and get them to talk to me, to have me as a friend. And that worked out quite well for quite few years. (Female, HCM)

Although these examples appear to be more about providing support, they do raise the question about the role patients could play as information providers.

### **Conclusion**

The interviews have highlighted a real need for accurate, timely and targeted information. It has been seen that the flow of information between medics and patients is not a one-way process and factors arise which can disrupt the flow, be this the psychological state of the patient or the manner in which information is imparted by the medical professional. Good quality information which is presented in an accessible manner can help make the patient journey more manageable. Patients have highlighted examples of good practice which involve not only being given good quality information but also having the opportunity to discuss that information and have family involved in discussions. As the patient journey continues, new questions and issues arise and so information is needed which responds to these changing circumstances.

## 4. Summary – Information Provision

- Patients want information about their condition.
- The key times during the patient journey when information is needed are:
  - at diagnosis
  - on discharge from hospital
  - after an 'acute episode' (such as the insertion of a device)
  - when a patient's circumstances change (e.g. issues arise around screening arise)
- Timely and accurate information helps patients manage expectations.
- Respondents indicated a need for information on practical aspects of living with cardiomyopathy which included:
  - Diet
  - Exercise
  - Medication and their effects
  - Driving restrictions
- Patients also expressed a need for information around family /genetic implications and access to psychological support.
- Patients may be too poorly or overwhelmed to take in information at the time it is given.
- Patients may not initially know what questions to ask or questions may arise over time.
- Patients value having family members present when being given information and value having them involved in discussions. Carers appreciate being involved in discussions about their loved ones.
- The manner in which information is imparted by medics impacts on how well it is received and understood by patients.
- A lack of information or conflicting or partial information causes increased anxiety for patients.
- There is evidence that some medics (for example some A&E staff, ward staff & GPs) lack an understanding of cardiomyopathy.
- Within the examples of good practice, patients value medics who take the time to fully explain the condition and answer questions.



- Examples of good sources of information include specialist nurses, some cardiologist and some members of the Rhythm Management Team.
- Patients who did not have access to a specialist nurse would value having 'someone' they could go to with their questions and concerns.
- Patients inevitably sought information on the internet, which was not always accurate or reassuring. However, some were directed to reputable sites such as BHF, Cardiomyopathy UK and NHS websites by medics such as GPs and specialist nurses.
- Patients found paper based literature available in hospitals helpful. However, as patients sometimes just 'pick this up' rather than being given it, distribution is somewhat ad hoc.
- Cardiomyopathy UK and the local support group were identified as valuable resources for patients with cardiomyopathy.
- The potential role patients could play as information-givers was raised.

## **5. Recommendations on improving information-giving to patients with cardiomyopathy**

- Fundamentally, patients need information about their condition: what has happened to their hearts, and how the condition will affect them now and in the future.
- Patients need timely and accurate information to help manage expectations.
- Patients would value 'someone', possibly a specialist nurse, who they could go to at any time with their questions and concerns.
- In addition to the above, information is required on:
  - exercise
  - family screening
  - sources of support to manage the condition (including psychological support)
  - managing medications
- Patients may be too poorly or overwhelmed to take in information first time round and so require a further opportunities to receive information.
- Initially, patients may not know what questions to ask or questions may arise at a later time. Again, patients require further opportunities to receive information.

- Once information has been given, there should be an opportunity to discuss this information.
- Family members should be included in information exchanges and discussions.
- When giving information to patients, medics should:
  - Avoid giving conflicting information
  - Share information fully and avoid giving only partial information
  - Deliver information in a sensitive manner
- All medics should have a basic understanding of cardiomyopathy.
- All medics should have a basic understanding of devices.
- As it is inevitable patients will seek information on the internet, medics should signpost patients to reliable, high quality sites such as Cardiomyopathy UK.
- Patients have found paper based literature available in hospitals helpful. Literature should be provided to patients in a consistent rather than ad hoc manner.
- Cardiomyopathy UK & the local support group are valued resources for patients with cardiomyopathy. The profile of the charity needs raising amongst medics. Patients should be signposted to the charity by medics.
- The role patients could play as information-givers warrants further consideration.

## Genetics and Family Issues

Julie Goodfellow

### Background to study

Three members of the North East England Cardiomyopathy Support Group, supported by Julie Goodfellow, BHF Cardiac Genetics Nurse, have undertaken research to examine patients' experiences of cardiac care services in the North East region. Twenty-one members of the local Cardiomyopathy Support Group (16 patients and 5 carers) were interviewed in September 2015, using a semi structured interview schedule and the interviews were transcribed and analysed thematically.

### Introduction

All of the interviewees commented on genetic or family issues associated with diagnosis and lifestyle. Comments were around 4 themes: awareness of genetic implications, feelings associated with the knowledge of inheritance, family reactions to genetic implications of disease and comments around the process of genetic screening, both clinical and genetic testing. This chapter is divided into these four sections:

1. Awareness of genetic/family issues
2. Feelings associated with knowledge of inheritance
3. Family reactions
4. Experience of family screening

### 1. Awareness of genetic / family issues

#### Awareness through different routes

Respondents became aware of the possibility of their condition being inherited through a variety of different routes, including medical staff, specialist nurses, support group and literature.

When we found out that my husband had cardiomyopathy, one of the things we found out at the group [support group] was to have her [daughter] tested as well. (Female carer of male with HCM)

It was at that time she [consultant, secondary care hospital] told me it was genetic too, which I hadn't realised ... she just said it was genetic and could be familial and therefore could be passed on and it was a 50/50 chance because it was autosomal dominant and she left it at that. (Male, HCM)

I think he [doctor] said your family is going to have to be tested as well...your family have to be tested for this as well because it doesn't miss a generation, or something. (Male, HCM)

Well the specialist nurse [genetics nurse] went through everybody because my dad died of a heart attack and my mums got heart failure. (Female, DCM)

...and then they [midwives] said could you find out more, could you find his [father's] death certificate which I did. And then they referred me to the geneticist at the hospital in London and that was back in 1999. (Female, HCM)

No the hereditary side wasn't really went into at all. That again was leaflets that I have read and correspondence that I had about genes and stuff. It was never mentioned to me at all about genes by medical staff. It was all just what I read in the correspondence. (Male, HCM)

## **Prior awareness**

Prior awareness and knowledge varied enormously.

Apparently it's there from birth but it lay dormant and it didn't sort of present itself until late on, in his 40s. We didn't know he had it. (Female carer of male, LVNC)

...there's a slight chance it's familial...so for a number of years I was told it was pregnancy related and I couldn't have passed it on, so it was just something that happens to pregnant women. But that's not necessarily the case now so I was quite keen on having my son checked out. (Female, PPCM)

All I know is that I was asked if there was any history in the family and I'd said that I had no clue and I had my mother and father checked and my brothers and sisters. (Female, HCM)

## **Knowledge of where condition comes from**

Some respondents didn't know where the condition had come from and described lack of knowledge and confusion even in professionals.

We got a more precise diagnosis of cardiomyopathy but, then, where does it come from? (Male carer of female, DCM)

They still think it's inherited. Even though mine was a virus they still think it was underlying and would have come out at some point. The trigger was the virus. That's what a lot of consultants seem to think now. It's never actually been said directly to me that. When you read articles about it...that seems to be it...something triggers it. It's in your genes anyway. (Male, DCM)

..but certainly the bicuspid valve was because of a defect from when I was in the womb, a womb gene. So that happened when I was being born. But neither my father or mother had heart problems. But I have read it can be hereditary but I don't know where mine has come from. (Male, HCM)

Dilated cardiomyopathy. I think they class it as inherited as well ...I think if you don't fit the norm when something goes wrong with you they are completely lost. At least they are honest, they say well it is all coming back negative, the results. And the NHS will only allow them to do certain tests you know. (Male, DCM)

...so it's on both sides of the family, whether it's inherited or not I don't know...well I think it must be. When I say to consultants they don't say 'no you are wrong'. They did say it was unusual to have it both sides of the family. (Male, DCM, above)

It's not always a physiological thing, it can be a genetic thing and you don't know that until something happens. Nobody in our family knew that these things had happened, they just all died quickly and young and nobody even suggested that it might be anything. (Female carer of male, HCM)

## **2. Feelings associated with knowledge of inheritance**

There were a myriad of emotions associated with the knowledge of inheritance of a condition.

### **Worry and Fear**

The overriding emotions seemed to be worry and fear for the safety of offspring.

He [son] was running the Great North Run and although I would never have said it to him I just had that little kind of worry is he okay to be doing this? (Female, PPCM)

And I am going to see a genetic counsellor quite soon and actually some of this stuff might get addressed then, about the whole psychological impact of passing it on to your kids ... I'm fearful for the other boys. (Male, DCM)

But I was still very concerned about passing it on to the boys. (Male, HCM)

Also fear for themselves and the impact this had on families.

I was scared to death and so my fear was passed on to my wife and family. (Male, HCM)

I suppose part of me wants to just brush it under the carpet and think that's not going to happen. (Female carer of male, HCM)

It's still a big impact but it's the worry about them [children] now is more and more. (Female, HCM)

## **Guilt**

Guilt at the prospect of passing on the condition to children featured.

I did struggle when we first found out he [son] had DCM. There was a sense of guilt really. Slight, but not massively. (Male, DCM)

It floored me actually, when he told me what it was and what it could potentially do. Especially with what's happened in the past with my family...yes, that [knowledge of inheritance] was a shock because I've got a daughter. (Male, HCM)

I was frightened I had given it to my daughters and grandchildren ....if I had given it to them I didn't want to know. That frightened me. I mean I have had lots of episodes where I have been frightened but that really frightened me ... If someone would have explained that if you had passed it on to the next generation then someone else would have passed it on to you, so it's not your fault. I think that even that little "it's not your fault" would have been helpful. That was my worst period. (Male, DCM)

## **3. Family reactions to genetic implications of disease**

Family reactions varied, with several interviewees describing reluctance in relatives to being screened.

He does seem alright with it. But what's going on under the surface nobody knows. They seem to be alright going through the tests for cardiomyopathy but as of yet they haven't done anything about it and we haven't pushed it. (Female carer of male, HCM)

...she [daughter] can be genetically tested but she doesn't want to.....'I don't want to talk about it. That's how I handle it', she said 'if it's going to happen it's going to happen' (Female carer of male, DCM)

We have advised them to go [for screening] but you can't push people to do it. We can give them all the information that we need to but until they are feeling ready to do anything or feel a need to then they aren't going to do anything. (Female carer of male, HCM)

They [daughters] are both young and are burying their heads in the sand. They're saying they don't have any symptoms...well I wouldn't have had symptoms at their age. (Male, HCM)

Other families accepted advice more readily.

He was quite happy to go along [with screening]. I don't think that at that age you have any concerns about it. (Female, PPCM)

She [sister] thought because she'd had an echo and ECG she was clear and she hadn't understood that they only meant she was clear at the moment and unless they do the gene test thing she won't really know if she's clear or not, so although she had seen the nurse, she hadn't heard that, she thought she was perfectly fine. So there's the potential for confusion. (Male, DCM)

Some interviewees described strong reactions in the family.

Well she wasn't too happy when she first heard it. But she's right as rain. Cos they told her that sometime people go through their life and there's nothing and then look what happened to me. (Male, HCM)

Well my son.....was quite worried, especially when I was having bad days....I mean we didn't really know what was going on. He hid it. He tried not to show it and I think he was scared to ask. (Female, DCM)

When I told them [sisters] that I had fluid on the lung and a heart problem well they admitted that they went into panic mode because they didn't have the information either. (Female, DCM, above)

Basically it's absolutely massive because my diagnosis has had a massive impact on the family. And it's direct and indirect because mine is having an effect on them and also the fact that it's hereditary will have an effect on them because they're going through screening and that's massive. (Female, HCM)

I think he's [son] feeling quite isolated in terms of what do I want to know, have I got 10 years, 20 years, 60? (Male, DCM)

#### **4. Experiences of family screening**

The process of family screening and advice given to patients and families varies hugely.

##### **Some families had to be proactive to seek screening for family members**

But we've had to go round and I suppose inform the family as much as we can what the issues were but from what I can tell they've all gone to the doctors and the doctor has been fully understanding and supportive and they've got on with it [screening]. (Male carer of female, DCM)

But they were just given some letters [by the genetics doctor at the research centre] and they went to their GPs and the GPs did the tests. (Female carer of male, LVNC)

##### **Some patients were apparently not given any advice about the screening process**

No medical personnel advised us to have her tested or anything. (Female carer of male, HCM, talking about daughter)

..no, nobody had suggested it [screening of relatives], it was off her own back. It was us. We said you better go and get checked out. (Male, HCM)

**Some patients were offered screening originally, but further professional intervention was not forthcoming, or could have been better.**

This included an identified need for counselling or the availability of support and more information.

Well again I think some guidance on how you should approach it with your family. I mean I am a pretty intelligent guy to be able to talk to people about things but sometimes you still need the guidance of people who are doing this day in and day out and know how to phrase things without scaring people to death. (Male, HCM)

...her GP sent her for a heart scan and it came back and said she wasn't at risk...I don't know whether I am convinced if that is sufficient....No monitoring or anything and that is frightening to me. (Female carer of male, HCM)

Yes [brothers and sisters] they are all obviously aware but I don't think anyone has been followed up. There's this thing about first degree relatives but it's not something I was ever asked to do. (Female, PPCM)

But the annoying thing was they said 'we'll follow-up every five years' but nothing...no, no follow-ups, nothing. I mean she had no symptoms but they said 'after 5 years we'll send back for you. You don't have to get in touch with us'. (Male, HCM)

Genetics centre and I was talking to somebody there, a professor there and he was looking through and he said 'there's nothing here of yours but they've probably been to Middlesbrough'. So I thought 'oh what's the chance?' I just gave up. (Male, HCM)

There was never any kind of counselling, never anybody around you could just offload a bit ....And this is where I would have loved to have talked to somebody because of the genetics. (Male, HCM)

**Where professionals got it right, interviewees were very positive about their experiences.**

I think the best source of information for us was the genetic lady at the tertiary hospital, who looked in to see if there was a family history of cardiomyopathy with my wife. I know it wasn't her job but she was a source of loads of information. She was more interested in finding out the problem with the genes but we could ask her questions and she was a source of a huge amount of information..... It was just the ability to ask questions and get almost a layperson's reply from her in terms of bringing it down to our level and use terminology we could understand and think about. (Male carer of female, DCM)

Then we met the [genetics] specialist nurse and then I got to know the full implications and what had to be done by way of assessment. And she gave me various letters and forms to give to the boys and to my sister. (Male, HCM)

She [practice nurse] got all my sons and that in to get checked straightaway and it only took a couple of weeks for them to get in and she made sure they got proper checks and this and that and the other. (Male, HCM)

...so I think that once I tapped into the specialist service....the specialist services here are fantastic. The level of understanding within our own GP practice was low and disappointing. (Female, HCM)



## **Conclusion**

Interviewees' experiences of how the genetic implications of their conditions have been handled varied enormously. There was a wide level of prior knowledge about genetics and past experience with genetic services (two families had experience of other genetic conditions and one interviewee had a professional knowledge of genetic science, while the majority of families had no prior experience).

Impact of the knowledge that cardiomyopathy could be passed onto other family members was huge. Some interviewees reported having no or little support from professionals and this probably added to negative memories of the process. When professionals were available to support interviewees, through provision of correct information, counselling and navigation of the process of family screening, the process seemed to be a little easier.

### **Summary – Genetic and Family Issues**

- Respondents became aware of genetics and inheritance of cardiomyopathy through a variety of routes, including medical staff, specialist nurses, support group and literature.
- Prior awareness and knowledge varied enormously.
- The way respondents acquired knowledge was also varied and there was some confusion about possible origins of cardiomyopathy, even from some professionals.
- There were a myriad of emotions associated with knowledge of inheritance, including: worry and fear for relatives, guilt and fear for themselves and impact on families.
- Families reacted to knowledge of inheritance in different ways, including: a reluctance to be screened, acceptance of advice and many reported how this had a massive impact on lives.

- Family screening advice given to patients and families varied hugely. Some had to seek it, others received no advice and some were originally offered screening, but this was not forthcoming.
- When knowledge was given by the genetics nurse respondents said it resulted in a greater understanding, leading to a much more positive experience.

## **The Need for Support**

### **What people with cardiomyopathy would like in terms of support**

Cathy Stark

“...sometimes you just need somebody to guide you through the maze”

#### **Background to study**

Three members of the North East England Cardiomyopathy Support Group<sup>1</sup>, supported by Julie Goodfellow<sup>2</sup>, BHF Cardiac Genetics Nurse, have undertaken research to examine patients' experiences of cardiac care services in the North East region. Twenty-one members of the local Cardiomyopathy Support Group (16 patients and 5 carers) were interviewed in September 2015, using a semi structured interview schedule and the interviews were transcribed and analysed thematically.

#### **Introduction**

During the interviews, respondents made explicit suggestions about how they felt their care could have been improved and it is these suggestions that are explored here. Suggestions often related to specific points in time: at diagnosis, at and around discharge, after an acute episode, after a consultation, when something 'changed'. Overwhelmingly, respondents suggested that they would have liked 'someone' they could talk to, who could act as a 'central point' for information. Patients wanted someone who could answer their questions at the time questions arose. Waiting several months between consultations with unanswered questions could be difficult. Patients also wanted to speak with someone who knew them and their situation.

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<sup>1</sup> Ian Mackersie, Vera Mackersie & Cathy Stark

<sup>2</sup> Julie Goodfellow, BHF Cardiac Genetics Nurse, Freeman Hospital, Newcastle-upon-Tyne

The suggestions made by respondents provided insights into *what* people wanted to know (content), *when* they wanted it (timing) and *how* they would like the information provided. Responses were fairly consistent around what form this 'someone' might take and what role they might play, with the idea of a 'specialist nurse' looming large. Respondents who had experienced the positive support provided by a specialist nurse suggested that all patients would benefit from this service. Those with experience of the Transplant Unit suggested that this service was a model of good practice in terms of patient information and support.

The suggestions made by respondents about how their experience of cardiac care services could be improved are presented under the following subheadings:

1. Someone to answer questions
2. Someone to help manage expectations
3. Psychological support
4. Support related to devices
5. Support related to family screening
6. Experiences of specialist nurses

## **1. Respondents' Suggestions for Support - someone to answer questions**

Respondents suggested that having 'someone' to go to with questions and concerns could relieve a lot of worries. Although many consultants were praised for giving patients the opportunity to ask questions, in reality, questions often occurred to people once they had time to reflect on the consultation.

Well one of my suggestions was – I know that you will go in and be told it and you'll either take it all in and then you go away and things start going round in your head with loads of questions. I think it would be handy if you had the opportunity so say a week later to see somebody again or you can just speak to them over the phone just to go over these things that have built up. Relatives ask you questions, work ask you questions if you could just go back in and speak to somebody a week or two later.....if I'd had that meeting a week or so after I'd have got a lot of questions answered. I would have known a lot of things were normal and not worry about them and I think I would have been in a better place mentally and physically to cope with it. (Female, DCM: support needed shortly after diagnosis)

It could be sometime before the next consultation and so having someone to direct questions to was suggested as important.

....if they had a specialist nurse like they do for other things, like you know if you have cancer, who you could get in touch with. Cos what happens is you come out and they hoy all this information at you and you come out and say 'I should have asked this'. And then you can't get in touch til the next time you see them and that could be 3 or 4 months down the road. (Male, HCM, support needed after a consultation)

To be perfectly honest, you know people go on about cardiac nurses, I'd never had a cardiac nurse, never....[It would have been useful] just if you had any questions you could ask them, you know, if you are worried about something (Female, HCM, support needed early days)

Likewise, any 'change' or 'event' could raise questions for patients. Having timely access to information was important.

Well when things start happening....Information, reassurance, both of those. If there was somebody to just put your mind at rest and say 'that's normal' you know 'don't worry about it'. (Male, HCM, support needed when things change)

Maybe when I came out of hospital because nobody came to see me once I got out of hospital after the cardiac arrest....when you think about it there possibly should have been some support and that didn't happen. (Female, HCM, support needed after an event)

## **2. Respondents' Suggestions for Support – someone to help manage expectations**

When asked what would have improved their experience of care, respondents suggested someone they could talk to in order to discuss what a diagnosis of cardiomyopathy *meant* - what they could expect and what might happen in the future. Suggestions linked to 'managing expectations' were often made in relation to the time around diagnosis and the early days and weeks of living with cardiomyopathy, emphasising the importance of this type of information at this particular time.

Possibly someone there to take me through what I could expect (Male, HCM, suggestion related to diagnosis)

If somebody had just sat down with me and said 'listen there are people living to 80 and 90 years of age with this, and if you do this and do that, then this will be the likely path you will go down'.... I don't know what my future is and I know nobody can really answer that fully but just some general guidance on what is the path I'm going to take, you know. Am I looking at an ICD or pacemaker? What is going to happen?...What's going to happen next? Am I going to need an operation in two years' time? You want better information. We need better information. We need to be told the path we are going down. (Male, HCM, suggestion related to diagnosis)

Well I think what would have helped me was, what 6, 7 years ago, some information. Somebody to turn round and say look this is what you are going to have to do. And I sat in this chair for the first 6 years after the operation. And then I went 'to hell with this'. (Male, HCM, suggestion related to diagnosis)

In the following quotation, the respondent describes how a nurse had suggested a much quicker recovery time than he actually experienced. This left him trying to manage expectations despite lacking accurate information.

The only thing is, the discharge from the tertiary care hospital, no one told me what to expect. And I was told by one of the nurses, that I'd be back at work in 3 or 4 weeks and I think they were treating like I'd had a heart attack and clearly I've never been able to return to work and I'm still quite unwell, but my expectations were much higher than my recovery on my discharge from [Tertiary care hospital] and you know, from being really quite ill they discharged me into [my wife's] care and then we had to drive back across here [to North West] and so we didn't really know what to expect and we hadn't really appreciated what that meant. 'You've got the ICD in now, you'll be fine' and they didn't really explain what the cardiomyopathy meant and also they didn't address the psychological effects which were devastating really. So that was very difficult. (Male, DCM)

This respondent also highlighted the psychological impact that being diagnosed with cardiomyopathy can have. The need for psychological support is something that has been raised by other respondents.

### **3. Respondents' Suggestions for Support – psychological support**

In the following quotation the respondent is grateful for the support she received from the 'genetics nurse', but she emphasises that further support would have been helpful.

I think there should be more special psychological support which there was in general, the genetics nurse was great, but I think it's such a massive shock, such a trauma in itself being diagnosed with something like this so there should be an opportunity for referral for psychological services at that time. That wasn't something that was ever offered to me. (Female, HCM)

In the time since her diagnosis, this patient has managed to access psychological support and found it helpful. However, she believes that it should have a higher profile.

I wasn't offered it when I was diagnosed or I would have taken it. It's such a massive thing and I think I was probably quite depressed for quite a few months and it's just now that I was getting back to normal. She's specialist in psychology in healthcare based at the tertiary care hospital. It's a very specialist area. But I think people should know more that it is there. (Female, HCM, as above)

The point about the specialist nature of the counselling required is echoed in the following quotation where the respondent emphasised the importance of talking to someone who understands the condition.

Specifically targeting this illness and somebody who knows about it. Not just some general counsellor at the doctor's surgery who spends 15 minutes with you. I'd want someone specific to cardiomyopathy. (Male, HCM)

Another respondent felt that some kind of counselling would have been helpful, particularly around the time of diagnosis when patients are trying to adjust to the potentially life changing implications of their condition

People have been on the level but I tell you what I think was lacking and is still lacking is when you get a diagnosis of whatever disease....there was never any kind of counselling, never anybody around you could just offload a bit. So at the time of diagnosis, I've always been a very positive person very happy go lucky but I've got to be honest, then you start questioning your future, have you got one? How much of a future have you got? (Male, HCM)

A further account of patients' experiences of psychological services can be found elsewhere in this report under 'The Impact of Cardiomyopathy on the Lives of Patients and Carers'.

The suggestions made by respondents have emphasised the fact that support is needed at different times during a patient's journey through cardiomyopathy. The need for support around the time of diagnosis and the early days, weeks and months of living with the condition is apparent. Respondents also identified subjects and events that raised concerns, particularly issues around devices and around family screening. The suggestion that there should be 'someone' to help with these concerns was a theme in our data.

#### **4. Respondents' Suggestions for Support - support around devices**

The research has identified that patients experience a number of issues around devices. Being told that a device is needed, having a device fitted and living with the aftermath raises a number of concerns for patients. There is evidence of some gaps in support as patients try to make sense of why they need a device, what it does and how to adapt to living with a device. Patients' experiences of these issues are fully explored elsewhere in this report in

‘Patients’ Experiences of Devices’. However, the following section focuses on the support suggestions which respondents felt could have improved the quality of their care around devices.

A little bit more understanding because you haven’t got a clue what it’s all about or what it is, I hadn’t even seen one, I’d just seen a picture. Possibly a follow up appointment with somebody else to go into it more easily .... (Male, HCM, device related)

I think if somebody, before you actually went in, if somebody came and sat down and had a chat with you, you know. And said we’re going to do this and hopefully it will stop you getting this that and the other, you know. But there was none of that...Just for someone to come and explain, even if it was just the sister on the ward, just to explain you’ve had this thing fitted and hopefully once we get it set up correctly – cos I didn’t know about that either like. (Male, HCM)

.... I can see why in the period after the ICD is fitted and before you return to normal life, it might be helpful for others to have somebody who could offer counselling, somebody who could offer practical advice about driving and all the other stuff and I guess that some of these drugs have side effects and it might be useful to talk to somebody about that. Because if you do get side effects, I’m never too sure which drugs causing them cos I’m taking 3 different drugs and a medical person would be able to help you with that. So I can see how counselling, practical help and emergency help like my visit to [secondary care hospital] might have been particularly useful, particularly at that couple of month period after I’d been fitted with the device. (Male, HCM)

So yes, to have had someone to talk to about the little things, especially on a weekend. That would have been quite nice. As I say, we weren’t prepared for him to have further episodes after he got his device, we were totally naïve about that. (Female carer of Male with HCM)

Patients suggest that there should be ‘someone’ available to answer questions as they arise, particularly in the early weeks after having a device fitted. Respondents with devices were aware that the Rhythm Management Team (RMT) was available at the tertiary hospital during office hours and they had been provided with contact telephone numbers.

However, as the carer in the above quotation noted, the need for support may well arise outside of office hours which highlights again the need to have access to ‘someone’ to offer timely support.

...there should be somebody at the end of it to answer your questions or some means, I can’t think what that might be, other than having a human being there who could answer your questions. (Male, HCM)

## **5. Respondents’ Suggestions for Support - support around family screening**



Family screening was another area where respondents had definite suggestions to make in order to improve care services. Cardiomyopathy is a condition that can be passed on in families and therefore it is suggested that first degree family relatives should be screened. Patients' experiences of living with a condition that is familial are explored elsewhere in this report under 'Patients' Experiences of Genetics'. Some respondents suggested that this was an area where better information and support was needed, particularly around understanding what was involved in the process of family screening and how to broach the subject with relatives.

Well to me that's where these specialist nurses come in. That's where I would have went to first off, and asked her if she could find out who was running it at the hospital or if it's been stopped. (Male, HCM)

Something down in black and white properly from the hospital saying you need to be doing this or this needs to be done. (Male, HCM)

Well again I think some guidance on how you should approach it with your family. I mean I am a pretty intelligent guy to be able to talk to people about things, but sometimes you still need the guidance of people who are doing this day in and day out and know how to phrase things without scaring people to death. I mean I was scared to death and so my fear was passed on to my wife and family. So maybe if you could get your family together and go and see someone...not a counsellor but someone who knows about this stuff and can explain to you exactly what was happening. (Male, HCM)

One respondent had previously experienced family screening due to having a different inherited condition in her family.

I think first time around we felt it was important that somebody other than us told them about the condition - which was my condition - and that actually happened. So I think if it had been the first time it had happened in the family it would have been invaluable to speak to somebody independent. The specialist nurse would have been the person or a geneticist. (Female carer of Male, HCM)

When her husband was diagnosed with cardiomyopathy, she felt able to broach the topic of screening with the family herself. Her husband felt that the care he had experienced relating to family screening was helpful and would be valuable for others.

They [other patients] need to know exactly what she [specialist genetics nurse] gave us and that was a full explanation of what it was, and how it could affect, and what the chances were that somebody else would have it. And also she gave us letters to give to the boys to give to their GPs to give to their consultants who would do the ECGs and echocardiograms. (Male, HCM)

This respondent was keen to suggest that the excellent care he had received should be 'rolled out' for everyone.

Likewise, respondents who had experience of the Transplant Unit were especially keen to point out that the way care was provided there could be used as a model of good practice.

### **Respondents' Suggestions for Support – care by the Transplant Unit as a model of good practice**

The North East boasts a world renowned Institute of Transplantation and six of our respondents (4 patients and 2 carers) had experience of this institute, either through assessment for suitability for transplant or in one case, actually having a heart transplant. The institute offers 'holistic' care and this was something valued by patients and carers alike.

It's an incredible place. An incredible institute, the Transplant Institute. I think everybody with cardiomyopathy should go there and talk to the transplant people. ...one of the things this Trust is really good at is preparing you. They go through absolutely everything, you know, no stone left unturned. (Male, post-transplant)

This is when I was in getting the tests for the transplant. That's what I'm saying. That unit is brilliant... I prefer that, being able to get in touch with somebody. That's why I keep saying a specialist nurse would be it. For the transplant, they've got a specialist nurse and they come and talk to you about everything. They give you the books and all and then you see the psychologists and the surgeons and that's brilliant but that's for transplant and you're going to the extreme there. But if there was something like that, obviously not as in depth as what they do, but something like that, just somebody you could get in touch with... because there's only a limited number that get sent for transplants but there must be hundreds or thousands who are just like me. (Male, HCM)

### **Respondents' Suggestions for Support – local cardiomyopathy support group**

Respondents who had found the local cardiomyopathy support group particularly helpful suggested that patients should be signposted to the local support group by their clinicians. The value that some respondents put on the support group has been explored elsewhere in this report in a chapter entitled 'What do members value about their support group?'

## **6. Respondents' Experiences of Specialist Nurses**

Our respondents have suggested that having ‘someone’ to contact for information and support would be extremely beneficial with the idea of a specialist nurse for cardiomyopathy looming large. The next section presents our findings around specialist nurses<sup>3</sup> and it outlines respondents’ ideas about how the services of a specialist nurse might work.

The positive value of having a ‘someone’ to go to with questions and concerns, for carers as well as patients has been highlighted. For those who had come into contact with specialist nurses during their journey, the experience had been overwhelmingly positive with one clear exception.

Respondents who had experience of specialist nurses were keen to describe the positive difference the specialist nurse had made to their care.

When we first came out and the first few days back in [North West] were – well they would have been difficult anyway – but I think we didn’t have the full picture at all and it was the heart failure nurse who came to see us just a few days later who was absolutely brilliant. She was a BHF heart failure nurse and she was incredibly helpful and really explained what was going on... The conversation we had with the BHF nurse when we got back to [North West], if that had happened in the hospital I think we would have had a much better understanding about what was going on...She gave us her mobile number and said ring at any time and leave a message and I’ll get back to you and she became like the hub of information. I didn’t ring her that many times but we always knew that there was someone there who we could ring. At that time we didn’t have any support network around us at all and I hadn’t come under the care of the cardiac rehab then, so she was like a lifeline. So I could ring her and she explained what would happen in terms of cardiac rehab and if there was anything I got anxious about I could ring her and she said ‘look I’ll try and find out for you’. Pretty much like the Macmillan nurses for cancer patients. I’ve dealt with quite a lot of Macmillan nurses and they’ll do anything and become like the hub of information and support and that’s what she was, she was like that she became the conduit to lots of other things and we could always go to her. (Male, DCM, suggestion related to early days after discharge).

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<sup>3</sup> The availability of cardiology specialist nurses varies greatly across the region and nationally. Some secondary and tertiary cardiology centres have generalised cardiology specialist nurses, who work alongside cardiologists, providing support to patients with various cardiac conditions. Other cardiology specialist nurses are more specialised, working with specific groups of cardiology patients, e.g. device nurses, arrhythmia nurses, cardiomyopathy nurses, transplant nurses, heart failure nurses, cardiac rehabilitation nurses and inherited cardiac conditions nurses. Some of the nurses working within these sub-specialties are supported by the British Heart Foundation. Funding for such posts is usually for a 3 year period, when costs are handed over to the host Trust. They usually continue to work under the badge of BHF, as their continuing professional development is supported by BHF.

Community cardiology specialist nurses work with patients once they have left hospital. Many of these nurses are heart failure specialists and their job is to manage and support patients with heart failure. They manage and prescribe doses of medications, so that the optimal dose is given for the individual, they educate and support patients from diagnosis through to palliative care. Many of them have been supported by BHF, as posts were created when evidence became available that this was a cost-effective and valuable way to keep patients out of hospital and cared for in the comfort of their own homes. Some of these nurses work across the primary / secondary / tertiary boundaries.

Other patients who attended a secondary care hospital also described their positive experiences of being able to ask questions and get timely support from the heart nurses.

I hadn't heard of it [cardiomyopathy] before ... [my knowledge] was in large part down to the heart nurse I got from the secondary care hospital – she was fantastic. They've got a great education programme across there. The support you get from the heart nurses – they're BHF supported – they do a fantastic job ... I think [there is a need for] a cardiomyopathy nurse rather than just a device nurse, but she could take in devices. That would be an excellent idea. You've got the clinical side and you get the support group and they do a fantastic job but I having had the support of the heart nurses at a secondary care hospital and what they do is to bridge the gap... It is that sort of bridge and you get the diagnosis thinking the worst and living with it and learning to live with it. I found that very useful when they led you through that process and any kind of concerns you had, you just pick up the phone – I still do. (Male, LVNC)

The heart nurse used to come at first to see me, when I was first diagnosed, when I was say more poorly maybe, I don't know what with, which was champion, because it saved me going to the GP for blood tests and what not ... the person I spoke to the most was the heart community nurse. (Male, DCM)

Another patient described how a 'specialist nurse' at the tertiary care hospital went beyond her role as a genetics nurse to reassure and answer questions that the patient had not had answered. The patient's sister also valued the service provided by this specialist nurse.

It's actually a specialist nurse who does certain work because I have a son and I was obviously worried whether...because he had a heart problem when he was younger. She was really good and went through the whole procedure and explained everything perfectly and she even answered questions that we had been asking the doctor I suppose. Well my sister went in. My sister's one who likes to write everything down, with her notebook and her questions and I think she really had a lot to ask [genetics nurse] and it wasn't really her place to answer them but she was there for genetic testing sort of thing, but my sister came away and said 'I feel like I know everything now'...she was just great. And with her letters and her correspondence she came back to us and said we're not going to have to do this but can you send us death certificates and things. She's very on the ball and very efficient. (Female, DCM)

Carers also described how they valued specialist nurses for both information and support

We were given a cardiac nurse at the secondary care hospital who was very, very good. He used to come out to the house as well sometimes. Yes, he was very good. He kept an eye on the medication and everything, yes, he was very good. My husband didn't respond to some of the medication, he came out in a rash and it wasn't until I mentioned, he said, 'oh, that could be a side effect of one of the pills'. (Female carer of male with LVNC then transplant)

It was after the operation, on the Friday when he was going home, a specialist nurse came in to see us about the genetics and she was very good. She told us all about the genetics side and made an appointment to see us properly after.... we saw the specialist nurse about a week and half after my husband's discharge and she explained some of that to us and that was very helpful. Although we were there about the genetics but we were obviously very

concerned and just blurted all of this out. So she helped a bit there. But still whenever this is happening my heart sinks that this is still going on ....if I really needed some support, the person I would think of there would be [the genetics nurse] (Female carer of male with HCM)

I think the best source of information for us was the genetic lady, at the tertiary hospital, who looked in to see if there was a family history of cardiomyopathy with my wife. I know it wasn't her job but she was a source of loads of information. She was more interested in finding out the problem with the genes, but we could ask her questions and she was a source of a huge amount of information... It was just the ability to ask questions and get almost a layperson's reply from her in terms of bringing it down to our level, and use terminology we could understand and think about. We just found her very approachable. (Male carer of female with DCM)

It appears that specialist nurses, such as the genetics nurse described above, may play a much wider role in informing and supporting patients than just dealing with the family implications. However this role may not be sustainable in the clinic time available and under current budget constraints.

[The] specialist nurse, she was a bit of a rock as well when I was going through the worst moments. I know how much pressure she is under and how little funding she gets. She certainly goes out of her way (Male, LVNC)

However, in stark contrast to the positive accolades above, one respondent was not happy with the care that they received from their specialist nurse at their secondary care hospital and, as a result, asked to be transferred to a tertiary hospital. In this instance, the specialist nurse did not appear to be a source of information or reassurance and the respondent did not build up any rapport with them.

When I used to see a specialist nurse every so often at the secondary care hospital, it was a case of take your blood pressure, take your weight, up your medications and away you go. There wasn't an opportunity to have a proper conversation...I wasn't very keen on the specialist nurse at the secondary care hospital....The cardiac nurse once told me when I rang her 'I don't know why that's happening – go and see your GP'. The GP couldn't believe it and that's when I transferred over to the tertiary care hospital ... I had [an episode] where I had a lot of breathlessness and pain and a lot of water retention and I actually went to see my GP because I didn't feel I could talk to the specialist nurse. (Female, DCM)

This respondent and her carer both recounted an incident where a medication had been continually increased which made the patient increasingly poorly. It was the carer who made the link about what was happening and raised it with the nurse.

At one of those meetings, they were still trying to triangulate my wife's meds and one of her symptoms was increasing every time she went, I think it was tightness of the chest, and in the end I said to me, from a lay person, it seems linked to the fact you are increasing this particular medication, I forget the name of it, and the light seemed to come on with the nurse, making the link between increasing that med is making that symptom worse and that's kind of, 'oh yes we'll stop doing that we'll knock it back a notch'. They did and it worked, my wife stopped having those particular problems which were pains in her chest. I thought 'well that can't be right'. That came from me. It just seemed to be a leap of logic. If you are doing that, that's the problem so stop doing that and that'll stop the problem and it happened, it worked, and I thought hang on that doesn't seem good. That was kind of the straw that broke the camel's back (Male carer of female with DCM, above)

Recounting this experience serves as a reminder of the difference one medic can make to a patient's perception of their care. It also emphasises the importance of being able to talk to medics about concerns and anxieties and how having confidence in a medic's expertise can reassure a patient and make their journey more tolerable.

However, as stated previously, all other experiences around specialist nurses were positive. Some patients who had not had a specialist nurse also thought that having 'someone' like this would have helped improve their care. Those respondents who suggested that having a specialist nurse would improve the patient experience made suggestions as to how this service might possibly work: some suggested that being able to make contact by phone would suffice.

Yes, just somebody you could contact, just on the phone. Not necessarily a consultation. Get reassurance about the things that were happening or if they were serious, whether to go to the secondary care hospital, what to do, that would have been particularly helpful and particularly for that first 3 months. (Male, HCM)

That's why a specialist nurse would be great. If there was a specialist nurse available I'd just phone them up and ask them [questions]...You could phone her up and then it would be up to the nurse to suggest well you can come in and we can have a chat ...For me, having a focal point-a specialised nurse. And I can't understand why they haven't got them, because they have them for other things. (Male, HCM)

I think the big thing would be to be able to speak to somebody a week or so after the diagnosis. To get the information I needed then I could pass it on to my son and my sisters. It

would have saved a lot of worry for everybody. Like a specialist nurse, say. To chat on the phone, not necessarily seeing face to face. (Female, DCM)

I think definitely a phone call from somebody who knows this particular situation and who can discuss it with me properly over a 15 or 20 minutes time period...someone who knew what had happened with me and could give me 20 minutes of their time.... You know like you have the specialist nurse for cancer? Have a specialist nurse for cardiomyopathy. (Male, HCM)

The last quotation raises the idea that whoever was contacted should have some knowledge of the patient, so they had the context in which to address concerns. This suggests that personalised support is important. Some patients suggest that the 'specialist nurse' could contact them occasionally, just to see how they are doing and to see if any questions have arisen.

And the other thing, some kind of follow up, maybe pastoral, after maybe 12 months. It's like any sort of bereavement really, you get loads of care in the initial stage and then sometimes 12 months later people crash. I'm aware of that possibility, I mean I'm dealing with it myself, I've got a counsellor etc., but even just a call to say 'just wondering how things are' so at least there was something and if there was a real need it might get flagged up. (Male, DCM)

By having this contact, continuity of care would be maintained during the first year which is a time when patients are coming to terms with the changes that their diagnosis brings. Patients would be able to have questions answered and concerns allayed which would help make their journey more manageable.

## **Conclusion**

It has been strongly suggested by our respondents that having 'someone' to contact is invaluable in guiding them through the maze. Respondents who have experience of specialist nurses have, in the main, found them an important source of information and support. Some were aware that individual specialist nurses sometimes went 'above and beyond' to provide an excellent level of care. Those who were not allocated a specialist nurse believe that such a person would have been able to offer the information and support they were seeking around everyday issues, and also in relation to devices and family screening. The idea of a 'MacMillan nurse for cardiomyopathy' was suggested. Being given the opportunity to access psychological support was also suggested as a way of improving

care. The few respondents who had direct experience of the Transplant Unit held the holistic approach to patient care in high regard. Finally, some respondents described the value they placed on the local support group.

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### **Summary – The Need for Support**

- The value of having a ‘someone’ to go to with questions and concerns, for carers as well as patients, was highlighted.
- Questions often arose in the early days and weeks after a diagnosis, after or between consultations or when ‘changes’ and ‘events’ occurred.
- Respondents wanted to know what a diagnosis of cardiomyopathy meant – what they could expect and what might happen in the future. These questions arose around the time of diagnosis.
- Respondents also had questions around living with a device. The Rhythm Management Team work office hours so were not always available to answer concerns at the time they arose.
- Some respondents suggested that family screening was an area where better information and support were needed, particularly around how to broach the subject with relatives.
- Those who had met with a specialist Genetics Nurse described this experience as extremely helpful.
- The majority of respondents who had experience of a specialist nurse described how they valued them for both information and support.
- The suggestion of a ‘specialist nurse for cardiomyopathy’ or a ‘MacMillan nurse for cardiomyopathy’ loomed large.
- Being able to contact ‘someone’ by phone when queries arose would be helpful.
- Personalised support was also raised as important – respondents would like to know the person they are contacting and would like to be known to them.
- Respondents highlighted the psychological impact a diagnosis of cardiomyopathy can have.



- Very few respondents had accessed psychological support; those who had found it helpful. However, respondents were often unaware of the availability of psychological support services.
- The Transplant Institute was described as providing 'holistic' care and this was something valued by patients and cares alike and described as a model of good practice.
- Respondents found the local cardiomyopathy support group helpful and suggested clinicians should promote it more amongst their patients.

## 11

### North East England Cardiomyopathy Support Group

#### What do members value about their group?

Cathy Stark

##### Introduction

Three members of the North East England Cardiomyopathy Support Group<sup>1</sup>, supported by Julie Goodfellow<sup>2</sup>, BHF Cardiac Genetics Nurse, have undertaken research to examine patients' experiences of cardiac care services in the North East region. Twenty-one members of the local Cardiomyopathy Support Group (16 patients and 5 carers) were interviewed in September 2015, using a semi structured interview schedule and the interviews were transcribed and analysed thematically.

During the interviews, respondents were asked what, if anything, they had found useful on their journey through cardiomyopathy. Many people mentioned the local Cardiomyopathy Support Group. Obviously as this is a sample drawn from the support group, it is to be expected that members find it a useful resource, but we have obtained an understanding of how and why members find the support group useful and it is those findings which are presented here.

##### Shared experience

Not surprisingly, people appreciated talking to others who had cardiomyopathy. This helped reduce feelings of isolation. Often people attending the support group for the first time have never met anyone else with the condition.

It's nice, I did get comfort from knowing that you're not the only one. (Male, HCM)

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<sup>1</sup> Ian Mackersie, Vera Mackersie & Cathy Stark

<sup>2</sup> Julie Goodfellow, BHF Cardiac Genetics Nurse, Freeman Hospital, Newcastle-upon-Tyne

It was the first time I'd spoken to someone, yes, when I rang you up [about the group].  
(Male, HCM)

I think people get confidence from knowing that somebody else has this. (Female, HCM)

Respondents felt someone else with the condition understood how they felt and could empathise.

Yes. And I mean sitting having a coffee with someone and talking about what is happening to me or them and being able to say that is happening to me too, it's a problem shared. You halve the problem. (Male, DCM)

...meeting other people who have got a similar condition and talking to them and listening to them, all that reassures you and builds your confidence. (Male, DCM)

I think it's good to have a conversation with people who have got the same thing. (Female, HCM)

I felt great when I left it, I really did. I just felt it was good to be amongst people who are experiencing the same problems and to listen to them talk... we met a lovely couple. We felt really uplifted when we left. (Male, HCM)

## Peer support

Members of the group are both givers and receivers of support and information. Initially people may come to gain information and support. Some members who have lived with the condition for many years come primarily to offer support. However, roles can shift as the condition changes. Through sharing experiences, members find that they can support and learn at the same time.

It's the same as when [X] came and I first talked to him. I was telling him what could happen and that little bit of experience when you talk to somebody and being able to share that experience is a good thing ... but to me it is absolutely brilliant. It's not only good for me but it's good for my wife because she is obviously involved as well. I can honestly say that every time you come and there is a speaker on, you learn something new. There is always something there. You can sit and talk to different people. (Male, DCM)

Well I've only been to a meeting once but I did find extremely helpful because there are people there and you talk to your peers about their experiences and you learn a bit more. (Male, HCM)

People attending the group sometimes have particular concerns. Being able to talk to someone who has already experienced this can be comforting.

The local support group has been fantastic, as a resource for people with cardiomyopathy it's been... it's nice to sit down with people with the same condition. And it's been nice to go back post-transplant because I'm still part of the support group. It's nice to talk to people

from the perspective of having a transplant as well. There are some people in the group that worry will it come to them. I think it's been reassuring for them, especially the lad who's on the list now. My wife and I, without us he would have struggled. He got himself very depressed. He says it's been nice to talk to somebody who has gone through it and come through the other end and doing so well on it. (Male, post- transplant)

It's helped a lot. It's calmed me down a lot. (Male, HCM)

## Normalising the condition

People also find it helpful to compare themselves to others with cardiomyopathy. This can help put the condition into perspective. It appears to be particularly comforting for newly diagnosed people to meet others who have lived with the condition for many years. It helps them realise that cardiomyopathy is not a death sentence but rather something that can be lived with.

It was interesting for her, I was able to tell her things she didn't know because I have had it for so many years. And I think that was good for her to know as well that I was still around. (Female, HCM)

...it was interesting talking to them about their experiences. I mean there were people there in their 70s which is good because maybe that means I'm not going to die tomorrow. I think that was probably the best part out of it. (Male, HCM)

Realising that other people share similar symptoms and problems can help 'normalise' the condition, and hearing 'good news' stories from other members can boost morale.

And it was so reassuring to know that things like pains in the legs and things like that, which the cardio nurse would say like 'I don't know why you're getting them'. Lots of people have them and it wasn't just me. And things like that were confirmed at the [tertiary care] hospital – they are symptoms – we don't know why you are getting them - but they are symptoms. But just talking to the people in here [support group] it's just all part of the symptoms. Everybody's getting them and it's nothing to be totally worried about. It was such a big relief. (Female, DCM)

I think the first avenue for people with cardiomyopathy or heart problems is to be given, like we have our group, if somebody comes in with heart problems they should be told that there is this group that meets every so often and we will let you know when the next meeting is and you should go and talk to these people. Because everybody in that room is going through the same type of thing that I am and if that was set in motion right from the outset...well the first thing they tell you on the internet is that if you have any pain at all go to A&E. But you would be down there every week. But now if you were given a piece of paper that says forget about the internet and go and talk to these people. (Male, DCM)

It's nice as well, I met a girl at one of the meetings who had an ICD fitted, improved and they took it out. They actually removed it. I think she had it in 4 or 5 years. It's just nice to hear good news stories. You don't get many. (Male, HCM)

## Getting information

Many people who valued the support group did so because it was a source of information. The support group has booklets and information from Cardiomyopathy UK. It also invites speakers to talk about 'health related topics'. In addition to Robert Hall from Cardiomyopathy UK talking specifically about the condition, topics have included: diet, exercise, psychological wellbeing and support, genetics and the family, medicines, devices, support for carers, local Healthwatch services, transplant experiences, sharing personal experiences and first aid training.

And the lecture on the stuff like the healthy eating was good too. I mean I know all that but it is good to hear it again and to have it verified. (Male, HCM)

I've been to about 2 or 3 of the meetings, I don't go to all of them. I normally see what's on the agenda and think I'll get something from that one. ....But I do know when I was away there was a meeting I was meaning to get to and it was about exercise and that. (Male, HCM)

Well, lately just I asked you for it [information] and I looked on the internet for information but there wasn't a great deal on that either. There was some, more than what I had. When I found out about you and I started to get information, now I've got more and more. (Male, HCM)

The local support group is part of Cardiomyopathy UK. Some people come to the group having been referred through the charity. Those who discover the local support group through other channels are encouraged to contact Cardiomyopathy UK if they have not already done so. The local support group promotes the charity's regional Information Days. Together, the support group and the charity provide much needed information.

I got more information off you [local group & Cardiomyopathy UK] than I ever got off anybody else. (Male, HCM)

I found out there was a Cardiomyopathy UK meeting at the Holiday Inn when they had got Dr Perry [Elliott], he was there and the head of Cardiomyopathy UK so I went to that first and listened to that and thought they seemed to know their stuff, so I then came to the support meeting and it's nice that you can talk to the people here but you can also ring Cardiomyopathy UK and they've got nurses and they've even helped me with work issues as well. (Female, DCM)

They've [Cardiomyopathy UK] been very useful actually, over stages. We've been having some concerns about my youngest daughter at the moment and they've been very helpful

with phone calls. And the Information Days as well, I've been to a couple. I talked to Perry [Elliott] – a mine of information as well. (Female, HCM)

It is also noteworthy that some people wished that they had found out about the support group earlier as they believed it could have helped them cope better. This reinforces that access to timely information is important.

I just didn't know anything other than I had a heart problem. But going there...I came out walking tall after a lot of time feeling very, very black about it. I think if I'd had that at the very beginning, I wouldn't have wasted months of my life. I do feel 18 months were wasted in a dark, depressing place and I'm sure that I wasn't a very nice person to be around at that point because I was so down in the dumps. But yes, if I had picked up that brochure the day I was diagnosed and thought I will go to one of those straight away, I would have felt much better about things. (Male, HCM)

But as I say, it all goes back to when you are first diagnosed. If someone points you in the right direction to talk to somebody, or if the doctor says if you would like to talk to somebody, this group of people are there and you can give them a ring. (Male, DCM)

Oh yes [the group leaders] have been brilliant because when I think about the time I first made contact it was probably about the time I was diagnosed and [group leader] was brilliant and I was getting quite a lot of tachycardia episodes which had been quite scary and we exchanged quite a lot of emails and phone calls. I got a lot of support. (Female, HCM)

First of all it still comes up to the group. That little poster you have should be downstairs. It shouldn't be a little poster, it should be a big poster and patients should be directed to it. They should be told that if you have a problem, go and talk and listen. (Male, DCM)

## Accessing the group

Having a support group that is 'local' is important. Some people with cardiomyopathy can find travelling difficult. A support group which is 'nearby' is a plus. The North East England Cardiomyopathy Support Group meets at the tertiary care hospital in Newcastle. The catchment area for the group is large and members come not only from Newcastle, but also from Teesside, Darlington, Durham, Sunderland, North & South Tyneside, Northumberland and even Yorkshire. Therefore the group cannot be 'local' to everyone.

I went to a meeting down Teesside [from Newcastle]. It took me ages to get down there and get back. I was completely shattered when I got back about 6 o'clock at night on the Saturday. A couple of years after that these two young lassies started one up here. (Male, DCM)

It's just along the road from where I live. (Male, DCM)

Well just you [support group] and I prefer that because you are on the doorstep. I prefer that, being able to get in touch with somebody. (Male, HCM)

And sometimes you don't know what you don't know, and you don't know what's realistic, and that's where a cardiomyopathy support group would be really helpful, to regularly meet with people, somewhere where you could have conversations to hear how other people are getting on, you know, 12 months on.....I do feel quite isolated. There's nothing in [my area]. You're the nearest group by a long way. (Male, DCM)

Having a group that specifically focuses on cardiomyopathy was felt to be more useful than generalised 'heart support' groups.

We used to go to [heart support group] once a month. But there were only three people there with cardiomyopathy. It was all heart attacks and things like that (Male, DCM).

## **Carers' perspectives**

The support group is aimed at people with cardiomyopathy but most people attend with a spouse or partner. Bringing family members and friends is encouraged. Five 'carers' were interviewed, and although the interviews did not specifically focus on the role of the support group, some helpful feedback was obtained.

Carers valued the group as a source of support for both the person they were caring for and for themselves. As above, sharing experience is valued by carers.

We find the support group really, really useful. Just being able to chat to other people about the kinds of problems you've got and how you are feeling. Just for the lads to sort of say how you feeling? Or even the girls [carers] because there are quite a few women [carers] that come along to the group as well. But I think that it is a very useful thing and it should be made more public that it's available. (Female carer of male with HCM)

For my wife and for me I suppose it was kind of, she had a list of symptoms and we didn't know if those symptoms were linked to the condition and that was the norm or was this something different. It wasn't until we got involved with the Cardiomyopathy Association that, when she was talking to the rest of the people that they said that happened to me, the tiredness, the pains in the legs, things like that, that's what you would expect. In all this experience of the past couple of years that's the darkest space, that's the original trying to get your hands on as much information to understand it. That's my overriding feeling of this whole thing that was the bad part. Then when we met up with these guys in the Cardiomyopathy Association it improved... (Male carer of female with DCM)

I read up on it and thought it is quite serious and quite frightening. But then we had no support group then. Then they started the support group and we could see we were in the same boat as other people and they looked well, but not being well, because everybody looks at you and thinks there is nothing wrong with you. That's the worst part of it because

he does look well..... I mean we've never missed a meeting yet since it started and it'll be coming up to 3 years in February. We've always tried, and if we've got anything on we'll always try and say no, we've got our meeting because it's been such a big help for us.  
(Female carer of male with DCM)

Two of the carers described how friendships made at the group led to people supporting each other between meetings.

We've got a friend who has had a heart transplant. We've got a friend who is on the heart transplant list and we only met these people through the support group. We just support each other because they are people who understand what it is all about, whereas other friends sort of down play it. (Female carer of male with HCM)

...we've made some nice friends and we've been out with a couple we [first] met in the defib clinic. They don't live very far from us so we've been out a couple of times with them, we've been out for a run, we've been out for a meal. Then our other friends who've had the heart transplant, we supported him at the transplant games, he's having a fundraising event in September which we are helping him out with that, so it's really brought us together with other people and it's been nice... As I say the couple who've had the heart transplant, his wife's been brilliant for me because she's been where I am now so I know that when my husband was in hospital awaiting his transplant [assessment] she was very feisty, come on you've got to do this....so she's there for me. So we have got some lovely friendships out of the support group so in that way our support group is helpful. It's not a carer's group but I suppose in that group we will find people that you can latch on to for the other side of it as well. We all know we are in the same boat, we are all sort of there to help each other and if somebody's not well. (Female carer of male with DCM)

This fact that the group is not specifically for carers, was mentioned again by this carer later in the interview.

But there again, it is mainly for them and not for the carers. The carers go with you and you get the love from them but it's still them that gets the support because they're getting the support through the group, but it's a big help to you because you know everybody in that room and we've made some lovely friendships, we've got some lovely friends from it, you know. (Female carer of male with DCM, above)

This does raise the question whether separate groups should be available for carers, or whether during the meeting carers could gather separately to support each other and express their concerns. This is something that can be explored further with the support group.

It was acknowledged by one of the carers that other general support groups were available for carers to attend without their spouses. However, she had not found them helpful and preferred to be in a group specifically for cardiomyopathy.



...they have support groups as well, like for carers, but it tends to be older people who've got relatives with dementia or you might have a younger one that's got arthritis, but I've been down that one as well so I know what that one's like. So to me that support group wasn't helpful. Then I'm in the Carers UK that's online and I joined that and I went on the forum and there again it's a lot of people looking after their elder relatives with dementia. There's nobody in the same boat as you are so it was nice when the local cardiomyopathy support group was set up as you are in a support group where everybody is in the same boat. (Female carer of male with DCM)

Providing information is an important aspect of the support group. Being able to access information was valued by carers. Again, the overlap between the support group and Cardiomyopathy UK is apparent.

...we ended up going to the first cardiomyopathy meeting in Newcastle at the Holiday Inn, and that's when more information started coming to us. You kind of don't know what you don't know. We were talking to the guys [support group members] and talking to the people who were speaking and they were asking my wife what is your refraction rate [ejection fraction]. We said we don't know, we don't even know if we should know what that is. We don't know, we've never had that type of conversation. Do we need to know? What is it? It turns out it is apparently the rate the blood is pumped out of the heart and round the body. Alright we'll have to look into it and we started talking to other people. That's just an example of the information we didn't know. We started talking to the people in the Cardiomyopathy Association and that's where we got more information. More information from that Association than really we got from the hospital. (Male carer of female with DCM)

My daughter and son-in-law came with us on the very first occasion that we came along to the group, and she was gobsmacked just meeting people who'd had transplants and listening to people talking about it and I think that she gained more information there than anywhere else. (Female carer of male with HCM)

I suppose just knowing the support is there via the support group if you need it, because you can't get hold of cardiologists if you have any questions. You need to wait until your next appointment. Which could be too late for some people. (Female carer of male with HCM, above)

We've got one daughter. She is 27. When we found out that my husband had cardiomyopathy, one of the things we found out at the group was to have her tested as well. (Female carer of male with HCM, above)

However, one carer did express concern that the support group may not always be a positive experience. Getting information and sharing experiences may raise new concerns.

Sometimes I think in these situations it can make it worse if you speak to somebody that has had a terrible time of it and it makes you think 'oh could that happen?' So there are pros and cons ..... We have only been to one meeting so we haven't really got into the group that well and spoken to many people. We did speak to one or two that day and it is nice to see people who are fit and healthy and getting on with their lives. It is nice to see that...On the whole I think it is a good thing to have the support group there. (Female carer of male with HCM)

Carers who were keen to promote the support group, described what they had done to 'spread the word'.

. ...and I am sure that there are lots of people who have it but are not aware that there are support groups available and I think that a lot more people would benefit if they knew what was available. So I just take all the information I can get from the group back to our GP surgery. (Female carer of male with HCM)

...we were sitting in the defibrillation clinic one day and there was this young couple and he was waiting to have his defibrillator checked, so we said do you know there is a support group so a couple weeks later the person who runs the group said I think it must have been you two who was talking to someone in the defibrillator clinic and we've now got a couple of new members coming. So it was nice to think we'd been able to pass on the information. We're waving the banner for cardiomyopathy. (Female carer of male with DCM)

...as I said before it was just luck that we happened to be at the clinic when some other cardiomyopathy support group members were there who had been coming to the meetings, and we just got chatting to them in the waiting room and they invited us to come along to the meetings They gave me [group leader's] phone number and I got in touch with her and she said this is when the next one is just come along and we did. (Female carer of male with HCM).

However, this 'lucky' approach is obviously too ad hoc to reach people who may benefit from the group. Posters are regularly put up in clinics at local hospitals that cardiomyopathy patients attend – echo and ECG clinics, device clinics and outpatients – but the group has limited control over how long these remain in place. Carers suggested that medics could play a more active role in promoting the group.

Yes and I think maybe even the consultants who are dealing with people with these problems should actually tell them that we have this support group at the [tertiary care] hospital...I know it's not for everybody but you might catch one person out of five and that to me would be a huge result...Like I've just said, they don't know about the support groups and they need to be aware of them, because yes it is not for everybody but if you can get one person out of five to come along to a support group then I think you are winning because the word will spread. (Female carer of male with HCM)

I think having some information available so you can give them a pack, you know like we have the packs here at the group. Why can't those be readily available at the hospital because you can get things like living with cardiomyopathy, the treatments and there are just all sorts of different leaflets that we have now that we didn't before. I think they can be more readily available within the cardio units within the hospital. (Female carer of male with HCM, above)

You can give all the information you want in leaflet form on day one, it probably takes 2/3 days for you to absorb that, go back and read it again and that'll give you some information but you just want to be able to have a conversation with somebody about what's gone on. And then if they could put you straight in contact with an association like the local cardiomyopathy group, people with the similar problems, same diagnosis, so you can take

the weight off the doctors and go to talk to other people and you know what they're feeling. You can speak to somebody who has actually got it and you start building an understanding of what to expect. So it's all round information something from the NHS, from the hospital or links straight into, well actually these people are an association of people with a similar problem, go and talk to them. Go and talk to them and put you straight in contact. (Male carer of female with DCM)

## **Conclusion**

Although this research did not set out to examine or evaluate the North East England Cardiomyopathy Support Group, some insights have been gained into what people value about their group: sharing experiences; being able to both give and receive support; getting information through speakers, Cardiomyopathy UK and other members; being able to normalise the condition through learning from others. These findings will be helpful in planning the future of the group (which has been running since February 2013).

Carers valued the support provided by other carers. Consideration will be given to how support for carers can best be provided by the group in the future.

Promotion of the local support group needs improving. Group members appear keen to help publicise the group and this enthusiasm could be harnessed. Despite the fact that the support group meets at the tertiary care hospital, patients who attend this hospital are not always informed about the support group. This suggests that it is important to promote the group amongst hospital clinicians and encourage them to signpost patients.

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## **Summary**

### **North East England Cardiomyopathy Support Group**

- The support group provides a forum where people with cardiomyopathy and their families can talk to others with the same condition.
- Often people attending the support group for the first time have never met anyone else with the condition. Respondents appreciate talking to others who have cardiomyopathy. This may help reduce feelings of isolation.
- Respondents felt someone else with the condition understands how they feel and can empathise.

- Comparing themselves to others with cardiomyopathy can help put the condition into perspective.
- Meeting others who have lived with cardiomyopathy for many years reassures the newly diagnosed that it is not a death sentence.
- Realising that other people share similar symptoms and problems helps 'normalise' the condition.
- Hearing 'good news' stories from other members can boost morale. Conversely, hearing 'bad news' stories may cause anxiety.
- Some people wished they had found out about the group earlier as they felt it would have helped them cope in the early days.
- Members of the group are both givers and receivers of support and information. Initially people may come to gain information and support. Some members who have lived with the condition for many years come primarily to offer support. Roles can shift over time.
- People value the support group as a source of information. The support group provides booklets and information from Cardiomyopathy UK and invites speakers to talk about 'health related topics'.
- Having a support group that is 'local' is important. Some people with cardiomyopathy can find travelling difficult.
- Having a group that specifically focuses on cardiomyopathy was considered more useful than a general heart support group.
- Carers valued the group as a source of support for both the person they were caring for and for themselves. Some carers supported each other outside the group.
- The fact that the group is not specifically for carers was mentioned by the carers. This raises the question whether separate groups should be available for carers.
- Patients and carers felt that more could be done to inform new patients about the existence of the group, possibly being directed to it by their clinicians. Some members were active in spreading the word themselves on clinic visits.

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