Meeting the psychological needs of people with cardiomyopathy and those supporting them - a public survey of people affected by cardiomyopathy

Cardiomyopathy UK has been providing information and support services for people with, and affected by, cardiomyopathy since 1989.

We know from discussions with individuals, family members and professionals that the emotional impact of having a diagnosis of cardiomyopathy and subsequently living with the condition can be significant. However, this is something for which there is currently little support available.

In order to understand more about the experiences of people with cardiomyopathy, and those close to and supporting them, we created two surveys to focus on the experiences, needs and wishes of people with cardiomyopathy and family, friends and carers of people with cardiomyopathy.

Surveys
We created two separate surveys: for people with the condition and for people supporting someone with the condition (family, friends and carers). This allowed us to compare the results from the two different groups and to look at each group separately, to use wording appropriate to each separate group, and to ensure that we considered the specific and distinct needs of people with the condition and that of family, friends and carers separately.

The surveys were available online and in print, and promoted primarily through the charity’s website, online and social media channels during August 2016. 385 people with cardiomyopathy and 70 family, friends and carers completed the surveys.

Key findings
The following highlights the key findings from both groups.

- Most people preferred the term ‘emotional wellbeing’ to any other term for mental health issues.

Preferred terminology for ‘mental health’
Most people said that having cardiomyopathy affects their mental health to some degree, with the largest group being those that are affected ‘some of the time’. Very few people said that it didn’t affect them in this way (8% of people with the condition, 3% of family, friends and carers). The greatest response to how it affects people was that it makes ‘certain parts of life more challenging’ (27% and 36% respectively).

The impact on mental health and emotional wellbeing

People with cardiomyopathy said
1) something informal such as a chat with someone with similar experiences (41%);
2) sharing experiences in a group (30%);
3) meeting face-to-face informally (24%); and
4) online support such as social media groups (21%).

These are services that Cardiomyopathy UK provides through support volunteers, support groups, information days, a forum and a closed Facebook group.

Family, friends and carers preferred:
1) something informal such as a chat with someone with similar experiences (45%);
2) meeting face-to-face informally (25%);
3) attending a course such as mindfulness or peer support (25%); and
4) meeting someone face to face such as a counsellor (25%).
• Looking further into what type of support is preferred at different stages of someone’s condition, from the first onset of symptoms onwards, both people with the condition and those supporting them showed a preference for chatting with someone with similar experiences, sharing experiences in groups (support groups), and meeting someone formally face-to-face (such as a counsellor).

• Around half of people with cardiomyopathy (47%) and the majority of family, friends and carers (70%) have never started a conversation with a healthcare professional about their mental health. Of those that have started a conversation, most respondents with the condition have spoken to their GP (39%) in preference to other healthcare professionals (nurse or cardiologist).

• We looked at why people may not feel able to bring up the subject of mental health with their healthcare professionals, particularly when they want to. For both groups, the largest response was that people hadn’t wanted to bring up the subject of their mental health with a healthcare professional because it hadn’t occurred to them or because they didn’t want to bring it up.

The people with cardiomyopathy who had wanted to bring up the subject, didn’t do so mainly because their appointments are too short and they felt embarrassed. For the family, friends and carers who had wanted to bring up the subject, the main reasons for not doing so were because they feel guilty as it is not them with the condition and they don’t want to bring up the subject in front of the person with cardiomyopathy.

• When asked if their healthcare professional brought up the subject of their mental health, the majority of people said that no one had brought the subject up (62% people with cardiomyopathy, 82% of family, friends and carers). Of healthcare professionals who have raised the subject, the GP was the most common.

• When asked who they think should bring up the subject of mental health, people with cardiomyopathy (53%) think that their GP should ask them about their mental health ‘every so often’, and 37% think that their cardiologist should ask about it every so often. This shows that people with the condition think that the subject should be brought up, and by the healthcare professional. However, 40% also think that they should bring it up if it is affecting them. For family, friends and carers, the majority (54%) think that someone involved in the care of their loved one with cardiomyopathy should ask about their mental health. However, 44% think that they should bring the subject up if there is a need.
When asked if people start a conversation with their family and friends about mental health, the majority of people with cardiomyopathy (53%) have started a conversation with their partner or spouse, and 34% with friends. In the family, friends and carers group, 40% have started a conversation with friends, and 37% with partners or spouses. Almost a third in both groups have never started a conversation with anyone on this issue (28% and 29% respectively).

Looking at the barriers to bringing up a conversation with family and friends, most people who haven’t brought up the conversation haven’t because they haven’t wanted to (38% people with the condition and 29% of family, friends and carers) or it hasn’t occurred to them to bring it up (29% of family, friends and carers). Of those who have wanted to bring it up, the most common reason for not doing so for people with cardiomyopathy was because they feel embarrassed, and for family, friends and carers is that they don’t know how to bring up the subject.

Looking at the levels of awareness of different types of support and services available, in general services were well known about but not used. The best known service was use of medication, followed by support groups. The most used by people with cardiomyopathy is medication (39%) and by family, friends and carers is support groups (26%). The least well-known services in both groups are talking therapies (37% in both groups) and mindfulness (37% and 34% respectively).
In terms of looking for services and support, the majority of people (in both groups) would ask their GP or look on the cardiomyopathy UK website for information.

The survey results suggest that people are more likely to start a conversation with their family and friends than they are with healthcare professionals.

Family, friends and carers were asked whether anyone had spoken to them about what help may be available to people in a ‘caring role’. Although around a third of respondents did not feel that this applied to them, over half reported that no one had brought this up with them although they would like someone to. This shows an interest in knowing what services are available to them, but that this is not routinely offered to people potentially in a caring role.

Has anyone spoken to you about being a carer?
• When addressing the subject of stigma, more people feel that there is or may be a stigma around mental health (100 people) than there is no, or less, stigma (24 people).

![Stigma around mental health pie chart](image)

Is there a stigma around mental health?

• In a final summary, people feel that emotional and mental health should be mainstream or part of all services, that there are not enough services, that services don’t have enough time, and that the emotional impact of cardiomyopathy can be greater than the physical one.

**Conclusions**

Cardiomyopathy UK provides many of the services that people with the condition, and those supporting them, identify as being a preferred type of help and support for their emotional wellbeing. Many of these services meet the need for support, but are not necessarily promoted as supporting the emotional wellbeing needs of people with the condition, and those supporting them. This could be addressed by improving the materials that promote these services.

Families, friends and carers are in as much need, and show preferences, for accessing support services for themselves, as people with the condition. However, they appear to put their needs secondary to that of those they support. Identifying that families, friends and carers have support needs themselves may help people to identify the need within themselves and therefore feel more able to reach out to services for support.

Many people, in both groups, haven’t brought up the subject of their mental health with their healthcare professional. This was often because they felt that their appointments were too short, or they were embarrassed (people with the condition) or because they felt guilty focusing on their health needs or didn’t want to bring it up in front of the person with the condition (family, friends and carers). Coupled with the preference people showed for healthcare professionals being the initiators of a conversation about the issue, these results suggest that appointments in which to discuss this issue could be initiated by the healthcare professional and could be made specifically to talk about this (or separate appointments made to discuss this issue). Also, the results highlight that families, friends and carers are giving their needs a lower priority than that of those they support.
The results indicate that the subject of mental health is *not* routinely addressed by healthcare professionals. Of those who do, most are GPs (over nurses or cardiologists). Further, most people with the condition feel that a healthcare professional should take responsibility for initiating the conversation (either the GP or cardiologist for people with the condition, or someone involved in the care of the person they support for family, friends and carers). However, people also feel that they should bring up the conversation if they feel a need.

Most people in both groups are comfortable starting a conversation with partners/spouses and with friends. However, almost a third of both groups don’t feel able to bring up the conversation with anyone.

Looking at the barriers to bringing up a conversation with family and friends, most people who haven’t brought up the conversation because they haven’t wanted to or it hasn’t occurred to them to bring it up. Of those who have wanted to bring it up, the most common reason for not doing so for people with cardiomyopathy was because they feel embarrassed, and for family, friends and carers is that they don’t know how to bring up the subject. This suggests that greater understanding and awareness of the potential impact of cardiomyopathy on mental health may help the subject to become more acknowledged and more talked-about. Which may help to reduce potential stigma around the condition, making it more accessible. People are more likely to start a conversation with their family and friends than they are with healthcare professionals. Whilst it is positive that both groups are able to initiate a conversation with family and friends and therefore benefit from this support, these results suggest that people are potentially missing out on other services that may be available through their healthcare professionals. These results also give a rationale for efforts going into informing healthcare professionals about the need to raise this issue.

Looking at the levels of awareness of different types of support and services available, in general services were well known about but not used. This suggests that there is a good level of awareness of different types of support/intervention (which may imply good promotion), but also suggests that people are not routinely accessing them. There may be many reasons for this, and understanding these limitations may help to identify ways to encourage and increase use of services.

In terms of looking for services and support, the majority of people (in both groups) would ask their GP or look on the cardiomyopathy UK website for information. This suggests that the Cardiomyopathy UK website is considered a good source of information to both groups, and also suggests that it is important to ensure that GPs (and primary care) are aware of sources of support so that they can appropriately signpost people when they ask.

Overall, more people feel that there is a stigma around mental health than think there is no stigma. People feel that emotional and mental health should be mainstream or part of all services, but that there are not enough services, that services don’t have enough time. By highlighting this issue through this survey and the subsequent work we intend to do around this subject, we are starting to open up a conversation on the topic, and hope that this will be a starting point to develop further services and widen access to support. Ultimately we want to be starting the conversation about this subject so that more people feel able to discuss it and make it an integral part of their condition management.
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- Looking at the barriers to bringing up a conversation with family and friends, most people who haven’t brought up the conversation haven’t do so because they haven’t wanted to or it hasn’t occurred to them to bring it up.
- Of those who have wanted to bring it up, the most common reason for not doing so for people with cardiomyopathy was because they felt embarrassed, and for family, friends and carers, they don’t know how to bring up the subject.

People are more likely to start a conversation with their family and friends than with their healthcare professionals. While it is positive that both groups are able to initiate a conversation with family and friends and therefore benefit from this support, these results suggest that people are potentially missing out on knowing and accessing other services which may be available through their healthcare professionals. These results also give a rationale for informing healthcare professionals about the need to raise this issue.

Looking at the level of awareness of different types of support and services available, in general services were well-known about but under used. This shows a good level of awareness of different types of support/intervention and therefore suggests good promotion of them, but also suggests that people are not routinely accessing them. There may be many reasons for this, and understanding these limitations may help to identify ways to encourage and increase use of services in the future.

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Overall, more people feel that there is a stigma around mental health than think there is no stigma. People also feel that emotional and mental health should be mainstream or part of all services, that there are not enough services, and that services don’t have enough time. By highlighting this issue through this survey and the subsequent work we intend to do around this subject, we are starting to open up a conversation on the subject, and hope that this will be a starting point to develop further services and widen access to support. Ultimately we want to start the conversation about this subject so that more people feel able to discuss it and make it an integral part of their condition management.

These results suggest that greater understanding and awareness of the potential impact of cardiomyopathy on mental health may:
- reduce potential stigma around the condition;
- reduce reluctance to engage with services;
- encourage people to talk about the issue;
- encourage greater engagement with services; and
- be a driver of making services for mental health be seen as more ‘mainstream’ in healthcare services (rather than add-on or side-line services).
How we will use these results to inform our work

At Cardiomyopathy UK we have been providing services for people affected by cardiomyopathy since 1989. This includes a range of direct services to provide information, advice and peer support to individuals and those supporting them.

The results of the surveys demonstrate that a diagnosis of cardiomyopathy can have a significant impact on mental health and emotional wellbeing, and that this impact can be as significant on the family, friends and carers as it is on the individual with the diagnosis.

The results also suggest that many of the services we currently provide give support and help in the way that people prefer to receive them: through peer support offered as an informal chat with someone with shared experiences, through support groups, and through information days (which combine medical presentations from professionals with opportunities to meet and share experiences with other people).

However, the results also show that the issue of mental health appears to be little talked about with healthcare professionals, despite a desire for this from individuals. While individuals will raise the issue with family and friends, there is reluctance to raise the issue with their healthcare professionals. This is matched by an apparent reluctance on the part of healthcare professionals to raise the issue.

It appears that the demand for support for emotional wellbeing and the impact of the condition is not met by a supply of services.

At Cardiomyopathy UK we feel that the impact of the condition on the individual, and those supporting them, is of paramount importance to an individuals wellbeing, and their ability to best manage their condition holistically. More could and should be done to recognise this impact, and provide services to support individuals. Appropriate support and interventions may significantly improve an individual’s ability to take control of, and manage, their condition. The first step to realising this is to recognise and raise the profile of this issue.

These surveys fulfilled two important aims: to start the conversation about cardiomyopathy and mental health (and therefore bring it into the open); and to gather insights from people with lived experience so that we can understand and represent the needs of individuals affected by the condition, and develop services to better meet these needs.

Meeting the psychological needs of people with cardiomyopathy - round-table meeting
The results from the surveys will be shared with a group of healthcare professionals and lay representatives at a round-table meeting in October 2016.

This meeting, entitled ‘Meeting the psychological needs of people with cardiomyopathy’, will bring together professionals with expertise in cardiomyopathy and mental health to work with the charity and people with lived experience to discuss these issues, share best practice and identify potential for development of services. It will focus on how best to meet the psychological needs of people with cardiomyopathy and those supporting them, and how this potentially can be developed and delivered. Specifically, it will also seek to identify how Cardiomyopathy UK can develop its services to meet these needs so that people are better able to manage the impact of the condition on their emotional wellbeing.
Knowing more, living better: 2016 Cardiomyopathy UK National conference
Cardiomyopathy UK is holding its first national conference in November 2016 for people with cardiomyopathy and those supporting them.

The programme for the conference was developed from feedback from previous information-giving events, and from insights into the topics of interest and importance to individuals with cardiomyopathy. Importantly, it also took into account the reported needs of the family, friends and carers of people with the condition. The programme balances clinical information on cardiomyopathy with topics around lifestyle and the emotional wellbeing and psychological impact of the condition. Throughout the day, sessions combine insights from people with lived experience with input from relevant professionals, and encourage involvement and interaction from those attending.

The programme for the conference include several sessions specifically on mental health and emotional wellbeing:
• coping with the emotional impact of cardiomyopathy - for people with the condition;
• coping with the emotional impact of cardiomyopathy on you - for family and carers;
• supporting a young person with cardiomyopathy; and
• self-management and goal setting.

By including sessions on these topics we are demonstrating the importance of the topic while encouraging people to engage with the subject and share experiences. We also hope that the experiences shared will give us further insights into the view, needs and experiences of people which can be used to inform how we develop our services into the future.

Hearts and minds: a new resource on cardiomyopathy and emotional wellbeing
Cardiomyopathy UK currently does not have a specific information resource on mental health and emotional wellbeing.

Using the results from these surveys, the outcomes from the round-table meeting and the national conference, and further engaging with people with the condition and those supporting them, we hope to develop a new resource specifically on this subject. This resource would combine insights from the surveys, and personal experiences of people who have used support services for their psychological health. It would also include valuable information on the various types of support available, what they do, and how to access them. We would also seek to involve people in the development of the resource to ensure it is as relevant as possible.