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on heart  
disease

# Focus on Heart Failure:



**10 recommendations to improve  
care and transform lives**

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## Foreword

**Heart failure can be a debilitating condition that has a considerable impact on the lives of patients, their families and carers, and often results in unnecessary early death. It is also an increasingly common and costly condition for the NHS.**

There is currently no cure for heart failure. But thanks to comprehensive clinical guidelines we know how people should be diagnosed, treated and managed to significantly improve their outcomes and experience.

Many people with heart failure receive excellent care, and there is much good practice and service innovation. But this is not happening consistently across the country. The APPG undertook this inquiry to understand what the key issues are, and what needs to happen to address them.

I would like to thank all of those who took the time to provide evidence to the inquiry – whether it was in writing, at one of the sessions in Parliament, or through one of the focus groups that we held – and in particular the patients who were kind enough to share with us their personal experiences of living with heart failure.

I would also like to thank our Advisory Panel, which included individuals and representatives from organisations with expertise in heart failure, for their advice and guidance during the course of the inquiry.

The recommendations in this report will help to improve the outcomes and experience of people living with heart failure. They will also help the Government and NHS to meet some of their objectives around, for example, improving out-of-hospital care and reducing unplanned admissions, as well as improving the cost-effective use of resources at a time when these are tighter than ever.

The APPG and the members of the Advisory Panel are keen to work collaboratively with the Government and NHS to help implement these recommendations, and make a tangible difference to the lives of people with heart failure, and their families and carers.

**Stuart Andrew MP**

Chair, All-Party Parliamentary Group on Heart Disease

## Advisory Panel

### Jennifer Bayly

Kent Surrey Sussex Academic Health Science Network

### Prof Andrew Clark

British Society for Heart Failure (co-Chair)

### Richard Corder

Heart failure patient, Cardiovascular Care Partnership

### Prof Martin Cowie

Cardiologist, Imperial College London

### Angela Graves

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### Jacqui Hunt

British Association for Nursing in Cardiovascular Care

### Dr Mike Knapton

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### Dr Jim Moore

GP with a special interest in heart failure

### Joel Rose

Cardiomyopathy UK

### Dr Rick Steeds

British Society of Echocardiography



### What is heart failure?

**Heart failure is a complex clinical syndrome of signs and symptoms that suggest the heart is not pumping blood around the body as efficiently as it should. It is most commonly caused by damage to the heart muscle, for example as the result of a heart attack, cardiomyopathy or related to high blood pressure. It can also be caused by heart valve problems, congenital heart disease, a viral infection affecting the heart muscle, an abnormal heart rhythm and some types of cancer treatment such as chemotherapy.**

**Symptoms include breathlessness, fatigue and swelling as a result of fluid retention. Heart failure can be chronic, meaning the signs and symptoms develop gradually over time; or acute, meaning the signs and symptoms develop suddenly. Someone with chronic heart failure may also have episodes of acute heart failure.**

## Summary of Recommendations

- 1.** Health Education England should support heart failure specialist teams to **improve awareness, knowledge and understanding of the condition** in general medical colleagues, including GPs. This should cover the need to consider the history of heart disease in the patient, and their family.
- 2.** All Clinical Commissioning Groups (CCGs) should **commission cost-effective NTproBNP testing** to support the diagnosis of heart failure. NHS England should consider how CCGs can be incentivised to do this.
- 3.** NHS England and Health Education England should take urgent action to implement the recommendations in the Strategic Review of Cardiac Physiology Services on meeting workforce challenges, to ensure that demand for echocardiography can be met.
- 4.** Clinicians should ensure that when patients are diagnosed they are provided with information about heart failure, how it may impact on their lives, and how they can help manage this, in a form that is suitable for them. Patients should also be provided with a single point of contact for any questions and concerns.
- 5.** All patients admitted to hospital for heart failure should **receive early specialist input to their care**. NHS England and NHS Improvement should seek improvements in the percentage of patients receiving specialist input through the Best Practice Tariff for heart failure and expand it to include other measures such as follow up from the multidisciplinary team (MDT).
- 6.** Health Education England should work with the Royal College of Nursing, Nursing and Midwifery Council and others to build a picture of the number, location and qualifications of heart failure specialist nurses (HFSNs) and other cardiac nurses treating people with heart failure; and urgently develop plans to ensure that the workforce is sufficient to meet demand.
- 7.** All CCGs should commission heart failure services centred on MDTs including HFSNs, to provide an integrated approach to care. NHS England should consider how CCGs can be incentivised to do this.
- 8.** All CCGs should **commission exercise-based cardiac rehabilitation programmes** suitable for heart failure patients and increase referrals to them. NHS England and NHS Improvement should expand their proposal for a Best Practice Tariff for cardiac rehabilitation to include appropriate patients with heart failure.
- 9.** As part of the Government's commitment to offer people approaching the end of life honest discussions, Health Education England should work with professional bodies to ensure all those caring for heart failure patients receive training in advanced communication skills.
- 10.** As part of the Government's commitment to offer this opportunity to everyone approaching the end of life, CCGs and providers should ensure that all heart failure patients can make informed personalised decisions about their care using advanced care planning.

## Introduction

Over 400,000 people in England have been diagnosed with heart failure<sup>1</sup> and there are likely to be many more undiagnosed cases. Its prevalence is likely to increase with the combined effect of an ageing population and improved survival from heart attacks. Many people with heart failure are older and will be living with multiple long term conditions. However, the inquiry also heard from younger people with heart failure, including those that developed the condition as a result of cardiomyopathy, congenital heart disease and chemotherapy.

Heart failure is a progressive condition for which there is currently no cure. Mortality rates are high. Nearly ten per cent of patients admitted to hospital for heart failure die in hospital, and nearly 30 per cent die within a year of being discharged.<sup>2</sup> Premature mortality from heart disease more widely is higher in areas of social deprivation and health inequalities.<sup>3</sup> Heart failure can also have a significant effect on the quality of life of patients, their families and carers. As well as physical limitations, heart failure has an emotional, social and economic impact on those that live with it. Alongside health services - including psychological support - patients may also need to access other help, for example social support.

*'I have days when I get extremely fatigued for no apparent reason... it's as though someone has pulled a plug'*

**Jennifer, 80,**  
developed heart failure following a heart attack.

*'Emotionally, I found it difficult to come to terms with the real truth that I would perhaps have a shortened life.'*

**Ross, 65,**  
developed heart failure as a result of dilated cardiomyopathy.

*'In order to do my job I needed to not work one day in six... 50 per cent of that time in a whole year I had to take as unpaid leave.'*

**Doug, 66,**  
developed heart failure as a result of heart valve problems.

In addition to the personal cost, heart failure is also costly to the NHS. It accounts for around two per cent of the total NHS budget – estimated at about £2 billion<sup>4</sup> - and one million patient bed days, each year.<sup>5</sup> Heart failure was the cause of over 63,000 emergency admissions in 2014/15.<sup>6</sup> It is the most common cause of admission in people over 65.<sup>7</sup> The number of admissions for heart failure is predicted to continue to rise with an ageing population.<sup>8</sup>

However, with the right treatment and care, the outcomes and experience of people living with heart failure can be significantly improved. The cost to the NHS associated with unplanned hospital admissions can also

be reduced. The National Institute for Health and Care Excellence (NICE) has developed evidence-based guidelines that set out how heart failure should be diagnosed, treated and managed.<sup>9</sup> But whilst many people with heart failure receive excellent care, many do not receive care that meets these guidelines.

*'What we can do for heart failure patients now at least doubles life expectancy, and in many patients' cases it restores a degree of normality to life... treatment is relatively simple, relatively cheap, and has a dramatic impact on outcomes'*

**Prof Andrew Clark,**  
Chair of Clinical Cardiology and Consultant Cardiologist, Hull University.

The health and care system currently faces huge financial challenges.<sup>10</sup> NHS England has identified a number of clinical priorities for the NHS, including cancer, mental health, diabetes, dementia, learning disabilities and maternity.<sup>11</sup> Forty-four local health and care systems are working together to identify and address the health priorities in their communities through Sustainability and Transformation Plans (STPs). Some, for example in Greater Manchester, have been given more devolved powers from Government and are integrating health and social care, including budgets. New models of care are being developed to support improvement and integration of services. All of this presents both challenges and opportunities to improve services for heart failure, and the outcomes and experience of patients. The 44 areas that have developed STPs should take account of the recommendations in this report in implementing their plans.

This inquiry was launched in March 2016. It has looked at diagnosis, treatment and care – both in hospital and the community – and palliative care for people living with heart failure. It focussed on heart failure in adults. It did not cover the specific process and issues around transplantation. Evidence on the issues and solutions in these areas was received from a wide range of organisations and individuals with an interest and expertise in heart failure including patients and their families and carers, clinicians and commissioners. Twenty-five pieces of written evidence were submitted, four evidence sessions were held in Parliament and two focus groups were held with patients. This evidence forms the basis of this report and its recommendations.



## Diagnosis

The main steps in diagnosing someone with the signs and symptoms of heart failure are:

- taking a medical history, performing a clinical exam and other standard investigations such as a chest x-ray, blood tests, an electrocardiogram (ECG) which looks at the rhythm and electrical activity of the heart, and tests to check how well the lungs are working;
- testing the level of natriuretic peptides in the blood; and if these are raised
- performing an echocardiogram.

People are often diagnosed with heart failure in hospital after an acute episode, whilst others are diagnosed by their GP, or as a result of referral by their GP.

### Diagnosis and mis-diagnosis

Early and accurate diagnosis is vital for ensuring that people with heart failure get the treatment and care that they need. However, heart failure can be difficult to diagnose as the signs and symptoms can be caused by a number of conditions. Diagnosis can also be complicated by the fact that patients will often have other long term conditions. Nearly a third of patients admitted to hospital for heart failure have diabetes, and just under 20 per cent have chronic obstructive pulmonary disease (COPD).<sup>12</sup> Many of the patients that the inquiry heard from told us they were initially mis-diagnosed with other conditions, such as chest infections, asthma, anxiety and stress.

Many patients are also not asked about their own, or their families', history of heart disease. Family history is particularly important for those with inherited conditions such as some cardiomyopathies. Thirty-eight per cent of respondents to a survey conducted by Cardiomyopathy UK said they were initially treated for other conditions, and 43 per cent said that they were not asked by their GP about any family history of heart disease.<sup>13</sup> This can be a particular issue for younger patients who may be less obvious candidates for heart failure. Respondents also said that their experience of being diagnosed affected their ability to cope psychologically with the diagnosis, and how they felt about their subsequent treatment and care.

**1** Health Education England should support heart failure specialist teams to improve awareness, knowledge and understanding of the condition in general medical colleagues, including GPs. This should cover the need to consider the history of heart disease in the patient, and their family.



## Sharon Barnes' Story

**I was diagnosed with asthma when I had heart failure.**

"I started feeling unwell in August four years ago. But it took five months for me to get the right diagnosis of heart failure - and the right treatment. The shortness of breath was the most obvious thing. The GP thought it was asthma and gave me inhalers. I went to A&E with palpitations but they thought that was caused by the inhalers.

I began feeling nauseous too. I was given medicine for reflux but later found out it was caused by my liver becoming enlarged. Once when my palpitations and breathlessness were very bad I dialled 999 but the paramedics said it was a panic attack. By November I wasn't any better. I went on to the NHS Direct website and used the symptom checker. It flashed up 'dial 999 now'. I was taken to hospital where a chest x-ray showed my heart was enlarged. I was diagnosed with heart failure. It was such a relief finally to begin the right treatment."



### NTproBNP testing

Natriuretic peptides are hormones that are made by the heart. Raised levels of natriuretic peptides in the blood can indicate that someone has heart failure. A simple test can measure the level of natriuretic peptides in the blood. Where levels are normal, heart failure can be ruled out. The degree to which natriuretic peptide levels are raised can also indicate the severity of heart failure. NICE guidelines recommend measuring natriuretic peptide levels in patients with suspected heart failure.<sup>14</sup> There are two types of natriuretic peptide that can be measured: testing for N-terminal proB-type natriuretic peptide (NTproBNP) is considered to be more reliable.

This is relatively inexpensive, costing under £28 per test, although the cost per test should decrease as the number of tests performed increases.<sup>15</sup> In one particular area, NTproBNP testing in primary care reduced the number of echocardiograms and referrals by about 50 per cent.<sup>16</sup> It is estimated that implementing natriuretic peptide testing in primary care in line with NICE guidelines could save £3.8 million.<sup>17</sup>

However, access to natriuretic peptide testing is variable across the country. The inquiry was told that in some areas it is not commissioned at all, while in others it is available in hospitals but not to GPs. Estimates suggest that up to a third of GPs and a third of hospital trusts do not have access to natriuretic peptide testing.<sup>18,19</sup>



**All Clinical Commissioning Groups (CCGs) should commission cost-effective NTproBNP testing to support the diagnosis of heart failure. NHS England should consider how CCGs can be incentivised to do this.**

**Implementing natriuretic peptide testing in primary care could save £3.8 million a year.**

**£3.8m**

### Echocardiography

If a NTproBNP test shows that a patient has raised levels of natriuretic peptide in their blood then NICE guidelines recommend that they be referred for an echocardiogram, performed on high resolution equipment by experienced operators trained to the relevant professional standards.<sup>20</sup>

An echocardiogram is an ultrasound of the heart. It is essential in confirming a diagnosis of heart failure, as well as its cause and the prospects of the patient. The timescales for referral depend on the degree to which levels of natriuretic peptides are raised.<sup>21</sup>

There has been an average increase of three to four per cent a year in demand for echocardiography across the UK,<sup>22</sup> and it is anticipated that demand will continue to grow as a result of the ageing population. However, there is a serious shortage of staff to meet this demand. The vast majority of echocardiography is carried out by cardiac physiologists. Their exact number is not known as they are not coded separately to other scientific staff in the NHS. The Department

of Health commissioned a Strategic Review of Cardiac Physiology Services in England which projected a shortage of 663 whole time equivalent posts out of 3650 total potential posts by 2018.<sup>23</sup> Over 85 per cent of departments offering cardiac physiology services report difficulties in recruiting qualified staff.<sup>24</sup>

To qualify as an echocardiographer, NHS England currently requires entry into the Scientist Training Programme. Following the introduction of the programme, the increase in people specifically training in echocardiography has been small. In 2016/17 there were 36 training posts on the Scientist Training Programme for cardiac science - however, based on previous years only about half of these students will train in echocardiography.<sup>25</sup>

As a result of the gap between demand and supply, waiting times for both urgent outpatient and inpatient echocardiography are frequently longer than recommended by NICE.<sup>26</sup> In order to address this, real progress needs to be made in tackling the shortage in the echocardiography workforce.



**NHS England and Health Education England should take urgent action to implement the recommendations in the Strategic Review of Cardiac Physiology Services on meeting workforce challenges, to ensure that demand for echocardiography can be met.**

### Patient information

Many of the patients that the inquiry heard from said that no one had explained what having heart failure actually meant, and how it would impact on their lives. In some cases, they had not explicitly been told they had heart failure. NICE guidelines stress the importance of providing patients with information about their condition, treatment and outlook that is tailored to their needs and in a way they can understand.<sup>27</sup>

“It is all very well being given a diagnosis, but at that moment, your world is turned upside down, so whatever anyone says to you, you might not remember in half an hour’s time. You have many questions, but they do not always arrive at the right time either.”

Sam, 43, developed heart failure after a heart attack.

Many patients praised the information provided by organisations such as the Pumping Marvellous Foundation, Cardiomyopathy UK and the British Heart Foundation. They also praised the peer support groups they provided that helped them deal with the emotional and psychological impact of being diagnosed with heart failure, and with managing their condition. However, they often had to find information for themselves.



**Clinicians should ensure that when patients are diagnosed they are provided with information about heart failure, how it may impact on their lives, and how they can help manage this, in a form that is suitable for them. Patients should also be provided with a single point of contact for any questions and concerns.**

## Treatment & Care

**Getting the right treatment and care is crucial to improving outcomes and quality of life for people with heart failure, as well as helping to reduce hospital admissions and the associated costs to the NHS.**

Patients will receive treatment and care in different places at different times. Patients diagnosed in hospital will receive treatment there before being discharged, and will then be cared for primarily in the community. Those diagnosed by their GP, or as a result of referral by their GP, will be cared for primarily in the community. In both cases patients may be admitted to hospital for treatment of acute episodes, or other interventions, such as having a device implanted in their chest to control their heart rhythm. This highlights the importance of, and need for, integration between primary and secondary care.

### Specialist input in hospital

Eighty per cent of patients admitted to hospital for heart failure are seen by a heart failure specialist – a consultant cardiologist, another consultant with a specialist heart failure interest, or a heart failure specialist nurse (HFSN). This figure has changed little over the last few years.<sup>28</sup>

Patients seen by a heart failure specialist or treated on a cardiology ward are more likely to receive treatment and care that meets guidelines, for example being discharged on all three medicines recommended for managing heart failure, and receiving follow-up from the heart failure multidisciplinary team (MDT). Mortality rates for patients treated on cardiology wards are lower: 7.1 per cent die in hospital compared to 10.4 per cent

of those treated on general medical wards; and 25 per cent die within a year of being discharged, compared to 33 per cent for general medical wards.<sup>29</sup>

‘My want is that care across the country is just more consistent. I have friends that... have the same history and see a specialist every time they go to hospital. Lots of people...do not.’

Annette, developed heart failure as a result of cardiomyopathy.

A Best Practice Tariff for heart failure was introduced in 2016/17 that provides a higher payment for heart failure care in hospitals where at least 60 per cent of patients receive specialist input.<sup>30</sup>



**All patients admitted to hospital for heart failure should receive early specialist input to their care. NHS England and NHS Improvement should seek improvements in the percentage of patients receiving specialist input through the Best Practice Tariff for heart failure and expand it to include other measures such as follow up from the MDT.**

### Meeting guidelines on community care

The Heart Failure Audit only covers care provided when a patient is admitted to hospital for heart failure. There is no national audit of the heart failure care provided in the community, although some areas do their own audit, often facilitated by HFSNs. Anecdotal evidence suggests that not all patients are receiving care outside of hospital that meets NICE standards – for example several patients that the inquiry heard from said that they did not have a review of their condition every six months.

The National Institute of Cardiovascular Outcomes Research (NICOR), which undertakes the Heart Failure Audit, is considering extending it to primary care, and a pilot project is underway. Extending the Heart Failure Audit in this way would provide valuable information about how the care people with heart failure receive in the community could be improved. Patient outcomes and experience measures for heart failure developed by the International Consortium for Health Outcome Measures (ICHOM) are also being considered for future inclusion in the Heart Failure Audit.<sup>31</sup>


### Heart failure specialist nurses (HFSNs)

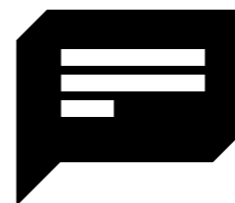
HFSNs help patients to manage their condition, including assistance with their medication, providing education on lifestyle changes such as diet and

exercise, and providing psychological support. They also co-ordinate patients' care, helping them to access other services to meet their needs. Their role is often extended to include activities such as undertaking physical examinations, prescribing, and palliative care. Evidence shows that HFSNs can reduce hospital admissions and costs to the NHS, and improve patients' quality of life, as well as facilitating better communication across primary, secondary and community care.<sup>32</sup>

The patients that the inquiry heard from spoke highly of their HFSN, highlighting the importance of having someone that understands them and their condition and supports them to manage it, as well as arranging other services and helping them navigate the health and care system.

However, the inquiry heard that access to HFSNs is variable across the country. Anecdotal evidence suggests that some services are being decommissioned, and other posts are being lost as nurses retire and are not replaced. Currently there is no national definition of a HFSN, and the skills and experience that are required, although this may be happening locally: the inquiry heard that a skills framework had been developed in Cheshire and Merseyside. The exact number of HFSNs, where they are located, and their skill levels, is not known. In Scotland this information is available through the Scottish Heart Failure Nurse Forum, which monitors HFSN posts against the ratio of one HFSN per 100,000 of the population recommended by the European Society of Cardiology.<sup>33</sup>

**6**  **Health Education England should work with the Royal College of Nursing, Nursing and Midwifery Council and others to build a picture of the number, location and qualifications of HFSNs and other cardiac nurses treating people with heart failure; and urgently develop plans to ensure that the workforce is sufficient to meet demand.**



## Julie Bartlett's story

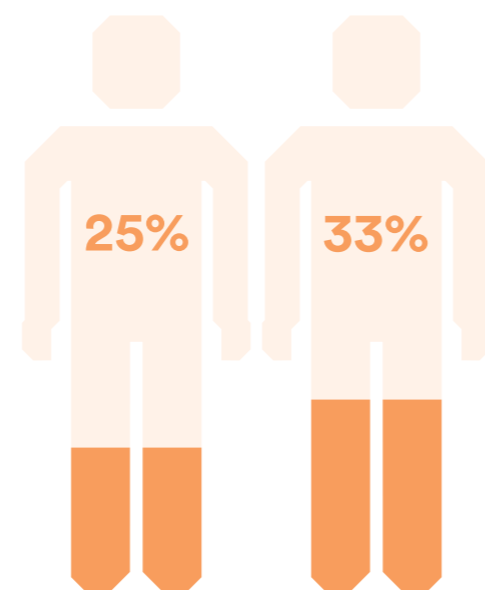
**I think of my heart failure nurse as a really good friend.**

“I'm really lucky to have someone as wonderful as Bethan. She's a life saver. She keeps a really close eye on me. For example my kidneys aren't working too well at the moment because my heart doesn't work properly. She can prescribe and she can adjust my medication - the right balance of medication is critical to the way you feel when you have heart failure.

I have a cardiology appointment every three months but she is there in between. Without her I would need more visits to my GP, or more hospital admissions. But I can avoid that because she is looking after me on a very regular basis. I consider her to be someone I can talk to and trust. I was completely shocked to find out that not everyone with heart failure who needs a specialist nurse has one. Because I just couldn't manage without Bethan.”



**A quarter of heart failure patients treated on a cardiology ward will die within a year of being discharged from hospital, compared to a third of patients treated on a general medical ward.**



#### **Multidisciplinary heart failure teams (MDTs)**

Many people with heart failure will need to access other services to help them manage their condition and its impact on their life. The patients that the inquiry heard from spoke in particular about the need for support to manage the emotional and psychological impacts of heart failure. Some had been referred to psychological services, some had received this support from their HFSN, others had accessed peer support services provided by organisations such as the Pumping Marvellous Foundation, Cardiomyopathy UK, and the British Heart Foundation, whilst some relied on their carer. Few patients had received psychological support through cardiac rehabilitation. Some patients said they had not received any such support.

*'My feeling from reflecting upon the experience I have had as a heart failure patient in both hospital and the community is a lack of acknowledgement of the psychological aspects of the disease and how this then impacts on the physical progression of the disease.'*

**Maya, 49,**  
developed heart failure following a heart attack.

NICE guidelines recommend that heart failure care should be delivered by an MDT with an integrated approach across the healthcare community.<sup>34</sup> This should ensure that the wider needs of patients with heart failure are addressed.



**All CCGs should commission heart failure services centred on MDTs, which include HFSNs, to provide an integrated approach to care. NHS England should consider how CCGs can be incentivised to do this.**

#### **Community heart failure service, Rotherham**

In Rotherham, the HFSNs in the team have extended roles and responsibilities. They refer patients for a range of tests and procedures, diagnose heart failure and initiate treatment. Patients are triaged as green, amber or red. 'Green' patients are discharged to the care of their GP with a management plan. All discharged patients receive three monthly text reminders about self-monitoring and contacting the service if symptoms deteriorate. 'Amber' and 'red' patients are cared for by the team in clinics or at home. Patients are offered a heart failure education and learning programme, heart support group, heart failure exercise programme and encouraged to make use of resources provided by other organisations. 'Amber' patients are also offered telehealth, which includes a 12 week electronic education programme. The HFSNs are also trained in palliative care.

The inquiry heard about several service innovations that have helped to improve patient outcomes and experience, whilst reducing hospital admissions and costs to the NHS. However, the APPG was concerned to hear that the cardiovascular Strategic Clinical Networks (SCNs) will no longer be supported by funding from NHS England. Some excellent work has been undertaken by the cardiovascular SCNs, which have acted as catalysts for

service improvement across their area. Continuation of work on cardiovascular issues that are not covered by urgent and emergency care networks, or diabetes networks, will depend on the resource that can be found for this by the 12 regional networks. However, in some areas, such as Kent, Surrey and Sussex, the Academic Health Science Network (AHSN) is undertaking work on some cardiac issues, including heart failure.<sup>35</sup> We welcome this.

#### **IV Diuretics in alternative settings**

When a patient's fluid retention becomes severe and problematic a course of intravenous (IV) diuretics may be needed, which usually requires admission to hospital.

The British Heart Foundation funded a two-year project in ten NHS organisations across the UK to explore the potential for specialist nurses working in heart failure teams to deliver IV diuretics in the home or in a day care setting. Hospital admission was avoided in 79 per cent of interventions, saving a total of 1040 bed days. The approximate cost of delivery was £793 per intervention, compared to £3,796 in hospital, leading to net savings of £162,740. All patients and 93 per cent of carers preferred home based treatment to hospital admission.<sup>36</sup>

The Royal Berkshire NHS Foundation Trust set up a day care heart failure unit based within the cardiology ward at the Royal Berkshire hospital in Reading. This is available seven days a week and is run by a specialist nurse with daily consultant cardiologist supervision. It offers patients the opportunity to receive IV diuretics by attending as a day case. Patients can now be referred to the service from primary care and ambulances services, as well the hospital and community heart failure service. During the first 12 months of the service, 1024 bed days were saved, and all patients were satisfied with the service.

### Cardiac rehabilitation

Patients that the inquiry heard from that had attended cardiac rehabilitation spoke of its benefits. Cardiac rehabilitation generally offers physical activity such as exercise classes, lifestyle advice and support such as dietary guidance and smoking cessation, and education about heart disease, to help people manage their condition and reduce their risk of associated heart events. They should also offer other services such as psychological support, although psychologists are involved in only 19 per cent of cardiac rehabilitation programmes.<sup>37</sup> Evidence shows that cardiac rehabilitation can help to reduce mortality and hospital admissions.<sup>38</sup>

*'They offered me cardiac rehab where I had my ICD fitted, but I didn't want to do that because it meant travelling. Someone at my GP practice said I could do it close to where I live. They had exactly the same type of talks and dietary advice and exercise advice. I just thought it was brilliant. They give all sorts of information.'*

**Barry, 57,**  
developed heart failure as a result of cardiomyopathy.

NICE guidelines recommend that patients are offered a supervised group exercise-based rehabilitation programme designed for patients with heart failure, where they are stable and do not have a condition or device that would rule this out.<sup>39</sup> Despite this, fewer than 20 per cent of patients admitted to hospital for their heart failure are referred for cardiac rehabilitation<sup>40</sup> – although others may be referred from the community - and some programmes still do not offer cardiac rehabilitation to patients with heart failure.<sup>41</sup>

NHS England and NHS Improvement recently consulted on a Best Practice Tariff that would provide a higher payment to hospitals that referred at least 45 per cent of appropriate patients that have a heart attack for cardiac rehabilitation.<sup>42</sup>



**All CCGs should commission exercise-based cardiac rehabilitation programmes suitable for heart failure patients and increase referrals to them. NHS England and NHS Improvement should expand their proposal for a Best Practice Tariff for cardiac rehabilitation to include appropriate patients with heart failure.**

## Palliative Care

**Palliative care helps people with conditions from which they will not recover, and their loved ones, to achieve the best quality of life. It treats or manages people's pain and the other physical symptoms of their condition, and should also provide psychological, spiritual and social support. End of life care is an important part of palliative care for those approaching the end of life and should ensure that people die with dignity and are cared for, and die, in the place of their choice. People are generally considered to be approaching the end of life if they are likely to die within the next 12 months.**<sup>43</sup>

Relatively few people with heart failure are referred for palliative care, and for those that are referred it is often too late to be of benefit. Only four per cent of those admitted to hospital for heart failure were referred to specialist palliative care services.<sup>44</sup> One study found that the average time from referral to palliative care to death for people with heart failure was just 21 days.<sup>45</sup> However, as the inquiry heard, palliative care need not always come from palliative care specialists: some heart failure specialist nurses (HFSNs) are trained in palliative care, and others, such as GPs, may also be involved.

*'Palliative and end of life care for people with heart failure still is not happening in the way that it should be.'*

**Simon Chapman,**  
Director of Policy and External Affairs, the National Council for Palliative Care.

The course of heart failure is unpredictable. Some people's condition worsens continually over time, but others have repeated severe episodes that respond well to treatment. This can make it difficult for clinicians to know when to refer someone for palliative care, and also make them reluctant to discuss this with their patients. As a result, many people with heart failure may not understand the seriousness of their condition, and may not have their physical, mental and spiritual needs and preferences met as their condition progresses and they approach the end of life.

*'At no stage during his illness had I considered it was palliative. Nobody had said those words to us, and it was quite shocking'*

**Caroline,**  
whose husband Les developed heart failure as a result of dilated cardiomyopathy.

### Linking cardiology & palliative care

The inquiry heard about examples of cardiology and palliative care teams working closely together. This has enabled patients' needs to be dealt with as they arise, and can help to overcome the difficulties associated with pinpointing when someone with heart failure is approaching the end of life. Surveys of HFSNs undertaken in 2005 and 2010 suggest that there is a growing relationship with palliative care.<sup>46</sup> However, the inquiry was told that progress is slow and inconsistent across the country.

*'If we get palliative care - problem based care - right, end of life care flows out of that naturally into care for the dying and support for the bereaved.'*

**Miriam Johnson,**  
Professor of Palliative Medicine,  
Hull University.

### Communication skills

The ability to have honest and sensitive conversations with heart failure patients is crucial to ensuring that they receive the palliative and end of life care that they need. Yet the inquiry heard that training in advanced communications skills is not provided to all staff caring for people with heart failure. The lack of systematic training in these skills for cardiologists was highlighted as a particular concern. Training in advanced communication skills was rolled out for professionals working with people with cancer, including oncologists, following the publication of the NHS Cancer Plan in 2000.<sup>47</sup>



**As part of the Government's commitment to offer people approaching the end of life honest discussions, Health Education England should work with professional bodies to ensure all those caring for heart failure patients receive training in advanced communication skills.**

#### Integrated heart failure and palliative care team, Scarborough

There has been an integrated palliative and heart failure service in Scarborough, based in St Catherine's Hospice since 2000. Once or twice a month a multidisciplinary team (MDT) from cardiology and palliative care meet to discuss patients, and decide who is best placed to manage the issues they are having. The MDT also acts as mutual support and identifies areas for training - advanced communication skills for the cardiologists and heart failure specialist nurses, and diuretic management, heart failure medication dose adjustments, and identification of patients that would benefit from a cardiology review for the palliative care team. Joint visits are organised as necessary at the hospice, on the hospital ward or at the patient's home. Many palliative issues are managed by the patient's usual care team, with the palliative care team directly involved mostly in complex or persistent issues.

### Advance care planning

Advance care planning (also known as anticipatory care planning) is a process of discussion between an individual and those providing their care, which can help ensure their preferences and wishes for end of life care are met. It can cover issues

such as where the person would like to be cared for, where they would like to be at the end of life, who they would like with them, and any spiritual or religious beliefs they would like taken into account.<sup>48</sup> This may also cover the deactivation of any device implanted to control their heart rhythm.



**As part of the Government's commitment to offer this opportunity to everyone approaching the end of life, CCGs and providers should ensure that all heart failure patients can make informed personalised decisions about their care using advanced care planning.**

#### Caring Together, Glasgow

The Caring Together Heart Failure Supportive Palliative Care Programme showcases partnership working between the British Heart Foundation, Marie Curie and NHS Greater Glasgow and Clyde. It uses a person centred approach to ensure that care for people living with and dying from heart failure is responsive to their needs and preferences. It integrates core components including earlier identification of patients using defined criterion, comprehensive cardiological and holistic assessment, anticipatory care planning, and wider multidisciplinary working to ensure that needs and preferences can be realised. The outcomes from these components are documented in a medical anticipatory care plan and communicated to all involved in the patient's care, including unscheduled care providers. Delivery of these outcomes is supported by greater partnership working, shared management, improved communication across disciplines and care boundaries, and educating and upskilling a wide range of professionals.

The service model is transferrable across the UK.

## Government's response to the Choice Review

The Government's response to the Review of Choice in End of Life Care, published in July 2016, made a number of welcome commitments to people approaching the end of life. These include that they should be given the opportunity and support to:

- have honest discussions about their needs and preferences for physical, mental and spiritual wellbeing so they can live well until they die;
- make informed choices about their care supported by clear and accessible information;
- develop and document personalised care plans that are shared with their care professionals;
- involve their family, carers and those important to them in discussion about and delivery of their care to the extent that they wish; and
- know who to contact for help and advice at any time.

These commitments are supported by a wide range of actions, including that all staff responsible for the care of people approaching end of life receive training to support the difficult and sensitive conversations they will need to have with people. Health Education England is taking this forward.<sup>49</sup>

These commitments address some of the key issues highlighted by the inquiry and have the potential to make a positive difference to people living with heart failure. The Government has said that it expects improving end of life care to run as a thread through relevant major programmes and national initiatives spearheaded by NHS England to the Sustainability and Transformation Plans being developed by local health and care systems. The Government will hold NHS England to account through its annual Mandate to the organisation. As part of implementation of the response, the Government, NHS England and all those involved in providing end of life care need to ensure that this care is improved across the breadth of conditions to which it is relevant, including heart failure.

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