Better Together
An end of life initiative for patients with heart failure and their families

Executive summary
10 reasons to provide supportive and palliative care for patients with heart failure

1. Heart failure is a serious condition with poor prognosis; this is often not realised by patients, and their families, who may have previously recovered from a life threatening acute event.

2. People with heart failure have a significant burden of symptoms, and elderly patients may also have several co-morbidities, leading to inability to function normally, poor quality of life and considerable distress.

3. Patients who have received supportive and palliative care and ultimately been able to die in their place of choice, have highly valued the care.

4. Carers benefit from the early supportive care. This enables some much needed time off so they can cope with their caring role the rest of the time, and also gain comfort and confidence of knowing they will be supported in caring for their loved one as death approaches.

5. Death can be from either worsening heart failure or sudden cardiac death from arrhythmia, so patients are not sure when or how they will die; this can engender anxiety and affect quality of life.

6. Heart failure is increasing in prevalence and is a frequent cause of hospital admission and readmission, especially in the last year of life.

7. Most people with advanced heart failure die in hospital. Although some younger patients may wish to go to hospital for life preserving treatment, many older patients would prefer to remain in their own home for symptom relief and comfort care.

8. Clinicians may overestimate prognosis which can result in a lack of advance care planning, and more life-sustaining treatments and devices just before death.

9. Using a flexible mix of disease-treating and symptom-relieving measures that evolve as heart failure advances, and can be provided concurrently in a seamless continuum, can improve end of life for patients and their families.

10. Evidence suggests that a systems based approach to palliative care, with good channels of communication, may keep patients out of hospital and be cost effective.
Better Together: A study of the development and impact of the British Heart Foundation (BHF) and Marie Curie Cancer Care (MCCC) supportive and palliative care initiative for patients with heart failure and their families.

Executive Summary June 2010

Jill Pattenden       Anne Mason

Acknowledgments

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Jill F Pattenden
Given that two of the defining characteristics of charities are their independence – born of a desire to produce change – and their passion for what they do, it is probably not surprising that they do not always find it easy to work together.

We are delighted that the British Heart Foundation (BHF) and Marie Curie Cancer Care (MCCC) – both at least as passionate as others in the sector – have been able to prove exceptions to the general rule. The two charities have shown that by joining forces in a well-defined area of activity with a very clear objective, and with organisational values which match perfectly, a huge amount can be achieved.

Many of those reaching the end of their lives as the result of heart failure have hitherto failed to receive the type of care to which the two charities believe they should be entitled. The BHF and MCCC saw, three years ago, that by combining the BHF’s understanding of heart failure with MCCC’s extraordinary knowledge of providing end of life care, there was a wonderful opportunity to produce change. The Better Together project was conceived to show what could be done and we are delighted that it has been such a success, with four out of five patients dying in their preferred place of care. Not only did the project succeed in its principal objectives, but it also gave the two organisations huge opportunities to learn from one another, as well as the satisfaction of working co-operatively between two like-minded organisations.

As a result of the project, MCCC and the BHF are continuing to work together to establish what we believe will be a world leading centre in Glasgow, developing the practice of providing end of life care for those dying of heart disease.

We are immensely proud of what we have achieved together, both for its own sake and for the example we believe it provides in how two proud and successful charities can work together.

Peter Hollins
Chief Executive
British Heart Foundation

Thomas Hughes-Hallett
Chief Executive
Marie Curie Cancer Care
Better Together

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The BHF and MCCC are committed to working together to enhance care for heart patients with palliative care needs, alongside other community, secondary and tertiary care staff. Better Together was a two year pilot project in two areas of England, which aimed to provide a service joining the expertise of BHF heart failure specialist nurses (HFSNs) with Marie Curie Nurses (MCNs) and healthcare assistants (MCHCAs) to help with the provision of hands-on care at home for patients estimated to be approaching end of life.

HFSNs, district nurses, community matrons and GPs could refer patients to the service. Clear referral guidelines were provided and it was made clear that patients should be referred according to need. This could be:

- irregularly – when extra support is needed to avoid readmission
- regularly – for respite or last weeks of care
- as a one-off – before the patient is then discharged from the service.

Patients were eligible for the service if:

- they came under New York Heart Association (NYHA) classification III or IV. These are likely to be associated with repeated hospital admissions and difficult physical/psychological symptoms despite optimal therapy
- referring staff would not be surprised if the patient were to die in the next year
- the patient had palliative needs involving extra care or support
- patients were willing to have the service.

Prior to the start of the service, HFSNs and MCNs attended a three day training course to extend their skills in the palliative management of this patient group, with MCHCAs attending the first day due to their narrower role. This training was deemed essential to ensure both groups of nurses had adequate skills to assess, support and care for these patients and their families in their last year of life.

The system of referral to the service, and requests for day or night shifts for patients, can be seen in the flowchart (Flowchart 1).
Flowchart 1: Referral via the DN and the BHF HFSN

DN/BHF HFSN assesses patient

Patient asked if they would like to have a MCN/HCA, if one is available, and role of MCN/HCA is explained.

Grade of nursing staff and amount of care required is decided in conjunction with the MCNTM as appropriate (essential for complex cases).

DN/BHF HFSN calls the MCNRC to place their referral. If a “cut off” time for allocating the shift is required, the referrer needs to identify it to the referral centre at this point.

If a MCN/HCA is available at time of referral the DN/BHF HFSN is told the visit will be filled and the co-ordinator contacts the MCN/HCA.

The MCNRC co-ordinator calls the patient and informs them of the MCN/HCA’s name and when to expect them.

The MCNRC co-ordinator telephones the referrer to confirm the booking and give the name and telephone number of the MCN/HCA.

DN/BHF HFSN calls the MCN/HCA to give verbal handover.

MCN/HCA telephones the patient an hour before the visit starts.

MCN/HCA completes visit.

MCN/HCA give verbal handover to DN/BHF HFSN if there were any problems during the visit.

If no MCN/HCA is available at the time the referral is placed, the MCNRC co-ordinator will continue to search for availability of nursing staff until the cut-off time agreed with the referrer. If successful, they will allocate the MCN/HCA to care for the patient and will confirm the shift with them.

The MCNRC co-ordinators are unable to allocate a MCN/HCA to care for the patient.

The MCNRC calls DN/BHF HFSN to inform them that they are unable to cover referral.

DN/BHF HFSN informs patient that no-one is available for the visit requested.

DN/BHF HFSN informs patient that no-one is available for the visit requested.

Key

MCNTM – Marie Curie Nurse Team Manager

MCNRC – Marie Curie Nursing Referral Centre
Methods

The intervention was evaluated in a pilot prospective cohort study involving 99 patients. Multiple data sources were used:

- The nurses’ training was observed and evaluated by questionnaire at the end of each day.
- Nurse reflective diaries were collected and analysed throughout the period of the evaluation.
- A sample of patients and carers were interviewed to gain their views of the service.
- Clinical and demographic data, referral history, readmissions to hospital and length of stay, cause and place of death were obtained from the HFSNs and entered into SPSS (Statistical Package for Social Sciences Version 15).
- As the pilot did not include a control group, historical control groups were selected for the economic analysis as convenience samples from specialist nurse caseloads in Bradford and Poole PCTs. In total, there were 98 patients in the control group. Costs included the costs of the intervention and inpatient care. Training costs were also estimated, but not included in the main analysis. Benefits included ‘death in preferred place of care’ (PPC: available only for the intervention groups) and ‘inpatient admissions averted’.
Results

1. Service delivery

- Joint training and joint working were beneficial to HFSNs, MCNs and MCHCAs, and enabled provision of a more comprehensive end of life care package, with individualised, tailored services to better meet the needs of patients and carers. The cost of training course attendance by nurses and care assistants was £11,310 (for both sites).

- HFSNs mostly referred patients to Better Together at an appropriate time, when respite for carers and supportive or palliative care for patients was needed. However, there is room for improvement in getting patients help earlier rather than for just the last weeks of life.

- MCNs learned to manage heart failure symptoms with confidence. They also had to learn to deal with a different frame of mind in these patients than they had encountered before, as some patients wish to be resuscitated. Although patients may be aware that there is no cure for their heart failure, they may have recovered from acute episodes before, and in order to cope on a day-to-day basis may choose to focus on the life they have, rather than think about death.

- HFSNs developed a more holistic approach to care, and were able to co-ordinate end of life care. Knowing they would get assessment and follow-up phone calls from MCNs, who provided care for their patients, meant they could make fewer visits.

- Frequent communication between HFSNs, MCNs, district nurses, Social Services, patients and carers is needed in order to get the correct level of care, ideally with one person acting as the care co-ordinator.

- The issue of sudden death and living with uncertainty, as well as the approaching end of life, is relevant to all patients and, as such, HFSNs need high level communication skills to enable them to discuss these sensitive topics.

- There needs to be further clarification about ‘do not resuscitate’ (DNR) status and this being discussed and documented at an appropriate time. Currently there is variation in who is permitted to carry out this task. A discussion about preferred place of choice (PPC) should also take place as early as possible after diagnosis.

- There should be a national policy for deactivation of ICDs in end of life heart failure patients.

- Out of hours (OOH) services need to improve to support home care at end of life.

- Over the past two years, national strategies have led to an increase in new palliative care services for non cancer patients. Thus, any new service for patients with heart failure will need careful planning to ensure it dovetails with other services in the locality and avoids problems of duplication and poor communication.
2. Provision of supportive and palliative care

- Research literature suggests about 10% of patients in a HFSN caseload have palliative care needs. In Better Together, nurses considered between 13% and 17% of their caseload as being suitable for end of life care. The increase in numbers eligible shows an increased awareness by nurses of carers’ needs for respite, and early supportive care for patients, with high numbers of requests for day care shifts, as well as hands-on nursing care in the last days of life.

- As with some cancer patients, some families were unsure about accepting this new service. Up to 50% of those offered Better Together declined initially, not feeling it was needed at the time. Some of these concerns may be helped by information from district nurses and HFSNs earlier in care, and joint visits with a MCN. This uncertainty may well decrease over time.

- The slow uptake of the service resulted in fewer patients being referred than anticipated, and the pilot study was extended from one to two years.

- Ninety-nine patients were referred to Better Together with requests for day and night shifts. Eighty of these patients (81%) actually received Better Together shifts. Four patients needed care rapidly and it was unavailable, resulting in an admission to a palliative care bed or hospital, two moved into nursing homes. Six patients changed their minds about receiving the service and seven had unexpected sudden cardiac death between referral and their allocated shift.

- Seventy-four patients died; of these, 39 (53%) died within one month of referral to the service. All patients referred (bar one who had declined the service and three who had one-off sessions) died within a year of referral. Referring HFSNs and district nurses are clearly able to predict the deterioration towards death in heart failure patients.

- Numbers referred by HFSNs and community staff have not been unmanageable.

- Provision of MCN services to cancer patients has not been affected.

- Different referral patterns were required for heart failure patients compared to cancer patients, with more day care requested for both respite and early supportive care.

- Long-term patients having supportive day care can be resource heavy, and it has similarities with personal and social care. Social service/agency staff are not equipped to deal with the complex physical needs of heart failure patients.

- The importance of continuity of care where possible, has been raised by staff and carers, especially in the last weeks of life, as there is less need for repetition of information and familiarising staff with the patient's home. However, many patients do not seem to mind having a variety of MCNs.

- There is a need for care at short notice, to avoid hospital admissions in this patient group due to rapid deterioration, or a reluctance to accept the service until crisis point is reached.

- As MCN shifts were allocated on a ‘first come, first served’ basis, having a nurse co-ordinator to juggle the MCN allocation locally helped enormously, enabling those with critical needs to be prioritised. Prioritisation of care has now been introduced into the MCCC referral centre.

- HFSNs appear to be good at knowing which patients need extra support to enable them and their families to have a better quality of life in the last months of life. This respite care can be provided by MCHCAs. District nurses and HFSNs also seem able to assess those patients who are in the last days of life and needing more hands-on overnight nursing care, at which the MCNs are very skilled.

- Better Together, alongside the primary care team, supported families in caring for the person with heart failure at home, only involving specialist palliative care for the most complex problems. Where day care or in-patient hospice beds were available, these were considered invaluable when patients needed intravenous diuretics to remove fluid build-up but did not wish to go into hospital.
3. Emergency admissions and place of death; economic effects

- It is difficult to assess hospital admissions avoided in any robust way. But by nurse reports, at least 47% of Better Together patients were kept at home by the service. Nurses also reported a reduction of heart failure related deaths in hospital, due to input from Better Together and other services already in place.

- Nurses reported that the introduction of the Better Together project has kept some patients alive longer than expected, as acute exacerbations were avoided due to the extra care. The service also improved the ability to carry out daily living activities of other patients, due to the early supportive care received, which gave them confidence and motivated them to be more active.

- Some admissions may have been avoided if intravenous/subcutaneous diuretics were able to be administered in the community.

- Of the 99 patients referred to Better Together, 74 died. Of these 74, 55 (74%) did so in their PPC. This includes those 19 who did not actually have MCC shifts as they were re-hospitalised before a shift was available, changed their mind about receiving the service, or had an unexpected sudden cardiac death (See Flowcharts 2 and 3).

Table 1 below shows place of death by study group compared to national average statistics.

![Table 1 showing place of death by study group compared to national average statistics.](image)

- The total cost of the intervention was £44,537 in Bradford and £20,908 in Poole. In Bradford, the total cost of care was significantly lower in the intervention group; in Poole, there was a trend for lower costs in the intervention group, but this was not statistically significant. In both groups, rates of home deaths were higher in the intervention group. In Bradford, PPC was 70%, and in Poole, the corresponding figure was 77%. The estimated numbers of hospital admissions averted for heart failure were 14 in Bradford and 18 in Poole. The cost per heart failure admission averted was £1,529 in Bradford. In Poole, these averted admissions were estimated to be cost saving.
Flowchart 2: Bradford patients

Bradford – 62 patients referred

49 had MCN shifts

17 alive at end of study

32 died

13 did not have any MCN shifts

1 alive at end of study

5 in PPC

5 in PPC

1 PPC not known

1 alive at end of study

12 died

27 in PPC

5 not in PPC

4 at home

1 in hospice

1 in hospital

3 in nursing home

1 in hospice

1 in hospital

Altogether 32 patients died in their PPC

Flowchart 3: Poole patients

Poole – 37 patients referred

31 had MCN shifts

6 alive at end of study

25 died

19 in PPC

6 not in PPC

15 at home

2 in nursing home

1 in hospice

1 in hospital

6 in hospital

6 did not have any MCN shifts

1 alive at end of study

5 died

4 in PPC

4 at home

1 not in PPC

1 in hospital

Altogether 23 patients died in their PPC
4. Impact of the service on users

• Ten patients and 14 carers were interviewed to gain their views of the service.

• Patients reported having great confidence in the new service as they felt they benefitted from the extra care from MCNs whilst still having regular input from their HFSN.

• Some patients didn’t see themselves as ill enough to accept the service but did so as respite for their carers.

• Patients feel isolated once their physical function limits their ability to go out. The company provided by MCNs lifted mood, and quality of life was much improved by a reduction in anxiety, with patients and carers having the opportunity to build a trusting relationship with one or more nurse.

• Patients reported reassurance and a better quality of life by having MCN day or night hands-on care to help with breathlessness and anxiety, in addition to their HFSNs. One patient, who had repeated re-admissions and regularly received day care, and knew night care was available as his health deteriorated, said:

“She said our idea is to get you looked after in your home and that’s what I want. I told my son that I don’t want to go into any home, I’d rather die at home, I don’t want to go. Provided I’m getting the care I’m getting at home now, I can manage without going anyway, that’s what I want”. (Pt 4)

• Many patients had discussed DNR issues with their HFSN. The majority did not wish to be resuscitated in the case of sudden cardiac death as they had a fear of being a burden, or “a vegetable with a long, lingering death” (Pt 9). Others, many of whom had previously had a cardiac arrest and recovered, were not ready to discuss it, preferring to get on with life and not dwell on death, or place of death. However, most were clear that they did not wish to die in hospital.

• Carers appreciated the service, both to provide a needed break from 24 hour caring for patients, and the opportunity for their spouse/relative to be cared for and to die at home.

• Most carers reported being able to face the death of a loved one at home knowing they would get adequate support. For some carers, this supportive service, after years of coping alone, has been invaluable, and donations to both BHF and MCCC have been requested at funerals by the families.

Summary

• 99 patients were referred to Better Together.

• Most patients were elderly, a mean age of 81 (Range 39-104).

• 61% of patients were male.

• 90% of patients were white.

• 74 patients died, 53% within a month of referral. Median time to death 31 days, mean 80 days.

• 55 (74%) died in their PPC.

• 7160 hours of MCN care were provided to 80 patients; patients received a mean of 71 hours of care (median 24). However, this ranged from 3 to 642 hours.
Conclusion

An unpredictable prognosis need not be seen as a barrier to provision of End of Life services for people with heart failure. It is possible to provide care at an appropriate time within the last year of life, but some patients will die suddenly and unexpectedly. Collaborative working across acute and community settings is essential, with extra training for the generalist community staff providing the service. In order for people to be cared for, and die, in their place of choice, there needs to be improvement in the provision of:

- discussions around do not resuscitate orders and preferred place of care
- intravenous diuretics
- out of hours services.

The Better Together intervention was associated with an overall reduction in the costs of care and increased likelihood of death at home.
What people said…

**Patient:** You all worked selflessly, sympathetically with the upmost care and respect to tend my own and my family’s needs whilst I endured the final stages of chronic heart failure.

In doing so you allowed me to remain out of hospital and be with my nearest and dearest without any compromise on the quality of medical care received.

In particular we single out [nurse name] - her demeanour, behaviour, interpersonal skills and awareness of others needs touched me in particular. She always held my hand, sat on the floor besides me (after asking permission) and, though often my son had to translate, she always talked to me. She especially listened. What an individual, what an ambassador for BHF heart failure nurses! Both the BHF and [nurse name] need to be recognised and congratulated. If the BHF can replicate her – then you will touch, support and help so many others who find themselves in our situation.

Before all this, palliative care were just words – the family quickly realised that this is something so special, words do not exist to describe it justly. This goes equally for the staff involved, their attitudes, their understanding, patience and care. You care for the whole person (physical and mental) and the whole family (patient, carers and relatives). We cannot thank you enough for the help you so kindly gave.

Your partnership with the NHS and Marie Curie – Bradford was and is an initiative that is priceless and so much in need. Heart failure is a terrible condition that afflicts so many yet unlike cancer it is not so readily recognised nor supported. I am so grateful that you are helping to address this.

**Wife of heart failure patient:** A very deep and heartfelt thank you for putting [nurse name], the heart failure nurse, in touch with us over a year ago, I can’t begin to express the difference she made to our life in the last year.

I think without her we probably would not have coped, and we would not have had the quality of life we did achieve, very poorly though he was at the end. [Nurse name] gave us huge support and comfort all the way through and her visits to us were always a joy. [Patient name] was so fond of her and it all gave me great confidence. She was always so approachable and contactable.

I am sure without her I would have crumbled but as a family we were able to nurse him at home until he died as peacefully as is possible.

As a system it worked and I hope it was as good for the NHS as it undoubtedly was for the patient and family. That we achieved his remaining at home is a great comfort to me at the moment as I go through this dark tunnel of bereavement.

References:


10 things to consider in setting up a supportive and palliative care service for people with heart failure

1. Due to the uncertainty of when someone may die, all people with advanced heart failure need to be offered supportive and palliative care to improve quality of life for them and their carers.

2. As both patient and family may only recognise the patient is dying late in the dying process, when it may be too late to experience much benefit, care needs to be taken that the subject is sensitively introduced before end-stage disease. Heart failure specialist nurses (HFSNs) may be the best people to introduce this discussion, supported by the GP and cardiologist/physician.

3. There are different types and levels of care needed according to individual preference, age and family circumstances. Care needs may differ between younger people and the very elderly, whose thoughts on death, desire for treatment and spirituality may lead to differing preferences.

4. Setting up supportive and palliative care in the patients’ home is complex and requires good communication between the multi-disciplinary team to ensure the care is there when needed. This requires one key co-ordinator of care.

5. HFSNs can act as the key worker to co-ordinate multi-disciplinary care for patients with advanced heart failure. The nurses may have built up a relationship with the patient over some years and have a good understanding of their health and social care needs. Mostly patients can be supported at home by their HFSN and the primary care team, only involving specialist palliative care for the most complex problems.

6. Written records and care plans need to improve to ensure all health and social care professionals understand the patients’ wishes about DNR orders and advance care plans. There needs to be a policy for the discussion and deactivation of ICDs in patients nearing end of life.

7. Messages about hope and prognosis need to be consistent and cardiologists, geriatricians, renal physicians, GPs and heart failure specialist nurses need to agree on when to start using a supportive and palliative care approach, and when to change the proportions of life preserving treatment to symptom relief and comfort measures.

8. Out of hours services need to improve to support home care at end of life.

9. Rapid response services are required in order to avoid hospital admissions and keep people at home.

10. More supportive day care may be needed to provide respite for families who may have been providing care for many years. Although this has similarities with personal and social care, staff in the organisations that provide those services may not be equipped to deal with the complex physical and emotional needs of people with advanced heart failure.