



Better palliative and end of life care for patients with advanced heart failure

The Caring Together programme

Marie Curie, the British Heart Foundation and NHS Greater Glasgow and Clyde are working in partnership to improve the quality of palliative and end of life care for patients in the advanced stages of heart failure.

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Caring Together is a programme jointly funded by British Heart Foundation and Marie Curie.



An improved approach to care for advanced heart failure patients at the end of life

Launched in March 2011, our partnership programme piloted new integrated care models in Greater Glasgow and Clyde to help people with advanced heart failure live more comfortably with their illness and have a better quality of life.

The aim of the Caring Together programme was to develop pioneering models of palliative care for patients in the advanced stages of heart failure which:

- met the needs of patients and carers
- complemented the optimal management of heart failure (and other diagnosed long-term conditions)
- promoted equity of access to palliative care for heart failure patients
- acknowledged the patient's preferences in place of care, including home
- enabled increased choice of place of care for patients
- improved co-ordination of care among stakeholders.

About heart failure

Over half a million people live with heart failure in the UK. It is one of the most prevalent conditions in Scotland, with an estimated 100,000 people currently living with it. Of people diagnosed with heart failure, 30-40% die within one year¹. Disease progression is likely to follow the pattern below²:

- New York Heart Association (NYHA – the most commonly used classification system) Stage I: No limitation of physical activity – ordinary physical exercise does not cause undue fatigue, dyspnoea or palpitations.
- NYHA Stage II: Slight limitation of physical activity – comfortable at rest but ordinary activity results in fatigue, palpitations or dyspnoea.
- NYHA Stage III: Marked limitation of physical activity – comfortable at rest

but less than ordinary activity results in symptoms

- NYHA Stage IV: Unable to carry out any physical activity without discomfort – symptoms of heart failure are present even at rest with increased discomfort with any physical activity.

Patients at stage III and IV can be characterised as in advanced heart failure and are likely to have supportive and palliative care needs.

The disease progression and prognosis for patients with heart failure is unpredictable, but it is a life-limiting condition. This prognostic uncertainty is due to the fact that cardiac events which commonly lead to hospitalisation, such as myocardial infarction, unstable angina and atrial

¹ Powell et al. (2015). Putting palliative care on the global health agenda. *Lancet Oncology* 16, 131-3.

² The Criteria Committee of the New York Heart Association. (1994). *Nomenclature and Criteria for Diagnosis of Diseases of the Heart and Great Vessels*. (9th ed.). Boston: Little, Brown & Co. pp.253-256.

fibrillation, can occur at any time and sudden death may occur at any point in the disease trajectory.

This makes it more difficult to diagnose patients as nearing the end of life and ensuring that their care needs are met.

Compared with most cancer patients, people with heart failure often have poorer symptom control and quality of life, face limited access to palliative care services, and lack choice in place of care and death.

“You want to get them to begin to appreciate that... there aren't any more things we can do physically but we are not writing patients off. We are there really to support them and to manage their symptoms, to feel as well as they can for as long, and as good quality of life as we can get.”

Heart failure liaison nurse

How the models were developed: listening to patients, carers and professionals

Marie Curie and the British Heart Foundation funded the University of Glasgow to undertake a detailed study examining perceptions of advanced heart failure from patients, carers and professionals, and barriers and facilitators to improving care in Greater Glasgow and Clyde. This informed the development of the Caring Together models³.

Patient and carer perspectives

Patients raised how difficult it was to make sense of their illness and the processes of care.

“No, they don't really tell you what the problem is, they just say your heart is bad and that's it, you are getting treatment for your heart. No, no, no, they don't even say to you take it easy or that. When you go in there you are just a clinical case, they give you the treatment, whatever it is they've decided, but as far as you're concerned they don't really tell you anything.”



Katie Hyams/Marie Curie

They seldom described themselves as having 'heart failure'. Those who did mention the term heart failure thought that it was too extreme a term for their illness, highlighting a lack of appreciation of their poor prognosis. Instead, patients described long histories of managing heart 'problems'.

³ Browne, S., May, C.; Macleod and Mair, F. (2012). Patient, Carer and Clinician Experience of the Palliative Care for Patients in the Advanced Stages of Heart Failure. mariecurie.org.uk/caringtogether

Perhaps because of their poor understanding of their diagnosis, some patients had **failed to recognise the deterioration of their condition** or weren't fully aware of its terminal nature. What patients were very clear about was the degree to which their illness limited their ability to live 'normal lives'.

People with heart failure frequently have **a number of other long-term conditions**, and these co-morbid conditions added a further layer of complexity, making it more challenging for individuals to understand their diagnoses and to accurately understand their symptoms. The co-morbid nature of heart failure also impacts on quality of life. Descriptions of discussions with health professionals about diagnosis and prognosis suggested a lack of frankness that led to uncertainty among patients about why they were becoming progressively unwell.

“The left ventricle isn't working properly. When I had the heart attack it damaged it a bit so that is what I was told, that is all I know.”*

Making sense of their illness and the processes of care, in an environment in which relations with healthcare providers were often fragmented and intermittent, was a great challenge. Patients needed to work through the different roles, responsibilities and limitations of the numerous health professionals who organised their care, including GPs, heart failure liaison nurses (HFLNs), cardiologists, and hospice staff. They also expended a great deal of effort negotiating help with a wide range of friends, family and outside agencies.

Patients' accounts conveyed **discomfort at having to work to distribute the burdens of their care**, such as collecting repeat prescriptions and helping them manage at home, and an important subtext is anxiety about whether or not others would accept these burdens. Patients said that others sometimes failed to grasp how unwell they were, and felt that their requests for help were therefore illegitimate.



Layton Thompson/Marie Curie

Continuity of care was valued by patients and some spoke of regret that they didn't have their 'own' doctor, either GP or specialist.

“And it's the same nurse more or less you get every time you go up. Well, she has been to the house, she has spoken to us, she gets to know you. You don't feel you are just a number.”*

The volume and complexity of medications and treatments

potentially available to advanced heart failure patients were daunting, and new treatments for heart failure, such as implantable cardiac defibrillators (ICDs), posed particular challenges. Difficulty adhering to complex treatment regimens was seen as a cause of emergency admissions to hospital, which were often underpinned by patients' uncertainty about their illness.

The experiences of **acute admissions to hospital were uniformly described as extremely unsatisfactory**, both in terms of the process of getting admitted and their in-patient stay. Consequently, patients tended not to seek help, for fear of being admitted, until their situation became desperate. Patients and carers seemed **unable to identify suitable emergency care plans**, and the lack of support outside of office hours was unhelpful.



Simon Rawles/Marie Curie

Health professional perspectives

Professionals felt that **patients' understanding of their condition was poor** and some had unrealistic expectations regarding their illness and its implications. Poor patient understanding of diagnosis and prognosis also meant it was **difficult to introduce the subject of palliative care**.

“They will say ‘oh, at least I haven’t got cancer.’”

*Heart failure liaison nurse**



Layton Thompson/Marie Curie

Professionals felt that **current service configurations acted as a barrier** to the delivery of optimal care. Short appointment times and lack of continuity of care did not allow professionals to have the involved, ongoing conversations required to improve patients' understanding of their illness.

Healthcare systems, as currently configured, did not promote integrated care and did not accommodate the communication required between disciplines and between health and social care, which was found lacking at key points.

Unclear pathways led to patients having unscheduled admissions, often out of hours via A&E, universally deemed to be inappropriate. Inflexible systems prevented direct access to cardiology. Direct admissions (“back door” arrangements) were seen as the optimal way to deal with those needing admission. If advanced heart failure patients phoned a GP in an emergency it was likely they would have

been advised to phone an ambulance, leading to an admission via A&E. Once admitted, cardiologists often focused on dealing with the immediate needs of the patient during an acute admission and failed to recognise the pattern of deterioration and the need to consider palliative care.

“You really don’t need to have them lying around an emergency department. It provides no safety for these people because some other individuals in there have very challenging behaviour. It provides absolutely no privacy and no dignity at all so these people are coming in who are in their last days or weeks of life and we are throwing them into the mix of undifferentiated presentations and it is unacceptable, and frankly appalling.”

*A&E consultant**

GPs, district nurses and palliative care professionals described **minimal experience of advanced heart failure patients** and some HFLNs did not consider palliative care to be a part of their remit. Professionals also described the difficulties of deciding upon a prognosis and ways of identifying transition to palliative care as a barrier initiating supportive and palliative care discussions.

A lack of ‘ownership’ of advanced heart failure patients was also evident. Professionals were asked who would

be the most appropriate key worker for a patient suffering from acute heart failure. HFLNs were thought to be the best candidate but supported with multidisciplinary team input to guide them on more complex issues. Some GPs felt they were in the best position to be a ‘key worker’ because they had the best knowledge of patients’ psychosocial situation, but felt they would need help in identifying when individuals should be considered ‘end stage’. Generalists often felt that they would need specialist advice and support to identify when patients were entering a terminal phase. No professional group identified themselves as being fully able to fulfil this role without additional support mechanisms being put in place.

Professionals raised the inequity of access to services for patients suffering heart failure caused by right ventricular dysfunction. These patients do not have access to the heart failure liaison service that sees only patients with heart failure caused by left ventricular dysfunction.

“If they have right-sided heart problems they don’t have access to these specialist nurses... I generally find that these people with right-sided heart failure, they see their GP very infrequently, they have no contact with the district nurse so with regards to their heart failure they have minimum contact with a health care professional.”

*Palliative nurse**

* All quotes: Browne, S., May, C.; Macleod and Mair, F. (2012). Patient, Carer and Clinician Experience of the Palliative Care for Patients in the Advanced Stages of Heart Failure. mariecurie.org.uk/caringtogether

The core components of Caring Together: a shared approach to care

The cornerstones of the Caring Together Models are five core components that identify and appropriately assess patients, and co-ordinate patient-centred holistic care. These core components were defined by clinical knowledge from both cardiology and palliative care, listening to the needs and wishes of patients and carers, and the experience and knowledge of a variety of care professionals.

I – Patient identification and referral

- Have a diagnosis of advanced heart failure (NYHA III or IV).
- Have distressing or debilitating symptoms despite optimal medical therapy.
- Have supportive or palliative care needs that may include a combination of physical, social, emotional, spiritual or psychological needs.

II – Holistic assessment of patient

- Cardiology review: this could be outpatient/in-patient as appropriate.
- Holistic assessment: review with patient the physical, social, psychological and spiritual aspects of their needs to identify appropriate solutions. The **Caring Together holistic assessment tool (HAT)** provides prompts and supports the holistic assessment of both patients and carers.
- Caring Together has developed a **medical anticipatory care plan (MACP)**. The care plan is completed by the patient's cardiologist and includes concise information on the patient's medical and palliative care needs, their understanding of their condition and prognosis, and their place of care and Do-Not-Attempt-Cardiopulmonary-Resuscitation preferences. The care plan is shared with the wider multidisciplinary team (and the patient if requested) to ensure that all are aware of the patient's condition and preferences of care.

III – Care management and co-ordination

- The patient is assigned a care manager (usually a heart failure nurse specialist), acting as the main point of contact for care management, information, advice and support.

IV – Training and education

- Training and shared learning between specialities (palliative care/cardiology and service delivery settings, community/acute care).

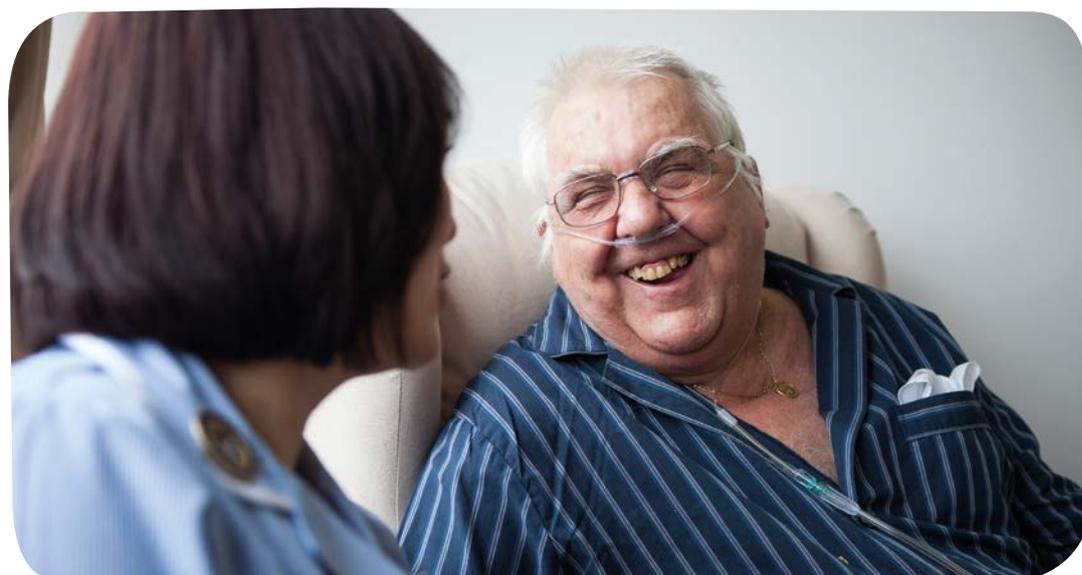
V – Multidisciplinary work and joint working

- Joint working and care co-ordination across teams (community, out-of-hours care and acute care).
- Care manager co-ordinates care with the multidisciplinary team and can action additional referrals if required.
- A care plan is devised with patients to fulfil personalised medical and palliative care needs.

Local implementation of the core components

Based on the core components, local models were developed in north-east Glasgow, Inverclyde and south-west Glasgow to improve palliative care for people with heart failure.

These local models were designed by local facilitation groups made up of hospital, hospice and community professionals. Together, they tailored the core components to meet local needs and demand for existing services and making the best use of existing resources.



Simon Rawles/Marie Curie

North-east Glasgow: an urban area with a population of 224,000

Using the identification criteria, patients are referred to the Heart Function and Supportive Care Clinic at Glasgow Royal Infirmary. This is an outpatient clinic staffed by a consultant cardiologist with special interest in palliative care and heart failure, as well as a heart failure nurse who is trained in palliative care.

The clinic operates weekly. Patients are seen for cardiological assessment, optimisation of therapy, assessment of palliative care needs and generalist palliative care interventions and support. Where appropriate, a medical anticipatory care plan (MACP) is produced by the cardiologist. A holistic assessment is undertaken by the nurse using the Caring Together

holistic assessment tool. The outcome of the outpatient consultation is communicated to the patient's GP, district nurse and other healthcare professionals, either via circulation of the MACP or standard format letter. This initial communication specifically states that this heart failure patient has supportive and palliative care needs and should be added to the palliative care register in primary care. A care manager, usually the clinic nurse or another heart failure nurse, is allocated to co-ordinate the care of the patient. A weekly multidisciplinary team (MDT) meeting takes place within the hospital to help discuss and plan care with the whole team.

Inverclyde: a mainly rural area with a population of 81,000

Patients that fit the identification criteria are reviewed in the existing Heart Failure Clinic at the Inverclyde Royal Hospital. The clinic operates monthly and is staffed by a consultant cardiologist and a heart failure specialist nurse (HFSN). A cardiological assessment is undertaken and optimisation of therapy where appropriate. Due to the small size of the hospital, most cases are known to the cardiologist prior to consultation. The cardiologist does not address palliative care needs. The HFSN in

the clinic undertakes the holistic assessment and advice on palliative care interventions and support. A care manager, usually the clinic nurse or another heart failure nurse is allocated to co-ordinate the care of the patient. The outcome of the outpatient consultation is communicated to the patient's GP, district nurse and other healthcare professionals. A monthly MDT meeting is held to discuss patients with a palliative care consultant and palliative care nurse present.



Kieran Dodds/Marie Curie

South-west Glasgow: a mainly urban area with a population of 117,000

Patients that fit the identification criteria are reviewed in the existing Heart Failure Clinic at the Southern General Hospital (now Queen Elizabeth University Hospital). The clinic operates weekly and is staffed by a consultant cardiologist and a HFSN. A cardiological assessment is undertaken and optimisation of tolerated therapy where appropriate. This ensures patients are on the optimal medication for their condition and that there is no further appropriate surgery or treatment to

improve their symptoms. The cardiologist does not address palliative care needs. The HFSN in the clinic undertakes the holistic assessment and advice on palliative care interventions and support. A care manager, usually the clinic nurse or another heart failure nurse is allocated to co-ordinate the care of the patient. The outcome of the outpatient consultation is communicated to the patient's GP, district nurse and other healthcare professionals.

Evidence and findings

After four years of implementing the local models, Marie Curie and the British Heart Foundation funded the University of Glasgow to undertake a detailed study. The study's aims were to define and manualise the models developed in the three areas, identify components that could be transferred to other areas of the UK and other disease groups, and undertake a scoping review comparing the components with those of other initiatives in the UK and internationally⁴.

Key conclusions

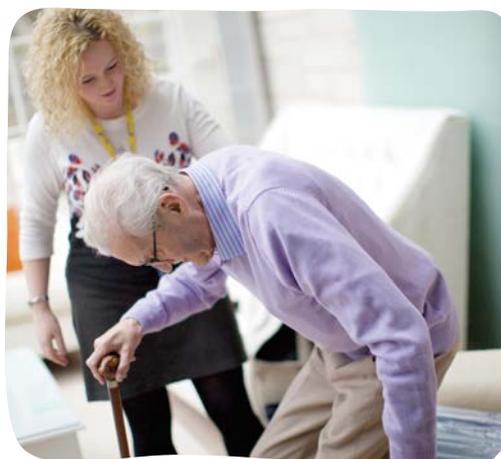
- The main elements identified in the review of the other integrated palliative care models were similar to the core components of Caring Together, suggesting that the **transferability and integration of these core components to other care settings is likely to be high.**
- The programme has enabled the implementation of a **system for identifying and referring patients**, promoted **joint working** between different health professionals, and placed greater emphasis on **anticipatory care planning** for people reaching the end of their lives.
- By transforming informal and ad-hoc practices into **formalised and systematic ways of working**, such as through the standard holistic assessment and documentation processes, patients were able to **access advice and services** they wouldn't necessarily be aware of, for example information on social care and benefits. **Professionals were also supported to think more broadly** about the care they provide to patients with advanced heart failure.
- The Caring Together programme addressed an important gap in the care provided to people with advanced heart failure, by working to **redress inequalities** in access to care, **tackle unmet needs** and **improve quality of life.**



Simon Rawles/Marie Curie

“I think it has been identified over a number of years that the palliative care offered to patients always focussed around cancer patients but heart failure patients quite often have actually a more troublesome time, symptom-wise, towards the end and it was a big gap.”

Healthcare professional



Kieran Dodds/Marie Curie

⁴ Bouamrane, M-M; Saunderson, K. and Mair, F. (2014). Manualisation of models of Caring Together in NHS Greater Glasgow and Clyde. mariecurie.org.uk/caringtogether



McAteer Photograph/Marie Curie

“The heart failure patients were so obviously a group of patients that you need to have palliative care and it’s something that you know we have known for a long, long time but we hadn’t physically sort of done anything about it. You know they have a poor prognosis. They tend to have ongoing symptoms despite their treatments and... their prognosis is similar to many common cancers. Their symptom burden is similar to patients with cancer, sometimes worse, but they don’t have access to palliative care.”

Healthcare professional

- Above all, the Caring Together programme has highlighted the need for **patient-centred co-ordinated care** for people living with advanced heart failure. It has helped them **express where they would like to be cared for** in their final days, as well as providing and co-ordinating bereavement support for their carers and families.



Kieran Dodds/Marie Curie

“I think because she has a plan sort of arranged, you know, you would just be admitted straight to the Royal without this furore of going through Accident and Emergency and hanging in there feeling terrible for hours. You would just go straight to, I think that is what part of the plan is about to relieve a lot of that. A lot of that yuk.”

Relative of a patient with advanced heart failure

Outcomes for patients

Marie Curie and the British Heart Foundation funded the University of York to undertake a prospective comparative exploratory study to compare heart failure patients that attended the north-east Glasgow Caring Together model with patients that attended a local heart failure liaison service⁵. The study measured the following outcomes:

- Symptoms.
- Health-related quality of life (HRQoL) – the impact on a person’s physical, mental, emotional and social functioning.
- Performance status – a measure of a person’s general wellbeing and activities of daily life.
- Understanding of disease.
- Evidence of anticipatory care planning.
- Health service utilisation.
- Survival.

Outcomes were measured at baseline, after two months and four months in both groups.

Upon referral, the study found that Caring Together patients had worse symptoms and quality of life than patients referred to the heart failure service. After receiving care in the Caring Together clinic, patients:

- had a better understanding of their condition
- were much more likely to have anticipatory care plan discussions which were documented in their clinical record
- received systematic advance care planning
- spent fewer days in hospital
- an average cost saving of £785 per patient, despite them being more unwell and the Caring Together model deliberately aiming to increase use of the multidisciplinary team.

This evidence supports that the Caring Together programme improves symptoms and quality of life, provides individual patient planning and reduces hospital admissions and healthcare costs.

Patients themselves highlighted the excellent co-ordination between the Caring Together clinic and community services, and continuity of care. They felt known by the Caring Together team and that their care was tailored to them as individuals.

⁵ Johnson, M.; McSkimming, P.; Hogg, K.; Briggs, A.; Millerick, Y.; Geue, C. and McConnachie, A., 2017. The feasibility of a randomised-controlled trial to compare the cost-effectiveness of palliative cardiology or usual care in people with advanced heart failure: two exploratory prospective cohorts. mariecurie.org.uk/caringtogether

Key learnings

Several factors contributed to the success of the Caring Together programme. These include the flexible approach to implementation permitting three different models to be deployed, the presence of local management support, an enabling local and national policy environment, dedicated and enthusiastic champions, clinical

leadership, the presence of IT systems to help facilitate information sharing, up-skilling and training of professionals and a very active awareness raising and engagement campaign. There is much to be learned from the positive experiences of implementation of the different models, but also from the challenges faced.



McAteer Photograph/Marie Curie

Improving identification and continuing with training and up-skilling professionals

We understand that clinicians may struggle to recognise people with heart failure who may benefit from palliative care. One of the challenges is putting in place a robust system that can systematically identify patients that are

entering a palliative phase. In addition, there is a need for ongoing training and up-skilling of professionals, bridging medical specialisms and supporting sharing of information and knowledge.

Leadership and champions

Identifying champions has been central to the success of the Caring Together programme, and will be vital to the successful implementation of the Caring Together programme in other areas. Such champions need to be influential individuals with the enthusiasm to sustain their involvement.

Facilitation groups proved to be a crucial factor in implementing the Caring Together programme. They considered local needs and priorities and allowed implementation of the programme into the existing structure and services. Tailoring services to the local environment was key to the successful development of the models.

Time and resources

The Caring Together programme was initially designed to operate within existing resources and many of the stakeholders acknowledged this. One of the main resources used in the programme that many stakeholders identified a further need for was time. Many acknowledged that the Caring Together patients required more time and that this was a major resource demand. However, providing adequate

resources to carry out the holistic assessment of patients' needs, such as dedicated consultation time at weekly clinics, was seen as very important in transforming the way patients were managed. Time in clinics has been offset by the reduced time patients with heart failure spend in hospital in the last year of life, better quality of life at end of life and more patients dying in their preferred place of care.



Katie Hyams/Marie Curie

Education

The Caring Together programme has improved the knowledge and understanding of healthcare professionals in both palliative care and cardiology. The British Heart Foundation and Marie Curie, in partnership with the Scottish Government and Glasgow Caledonian University, have continued to support the spread and adoption of the Caring Together approach

across Scotland. Funded by the British Heart Foundation and the Scottish Government, multidisciplinary teams from each health board are being supported by the lead cardiologist and nurse consultant for the programme through clinician teaching and shadowing to implement the Caring Together approach.

The Caring Together programme has developed pioneering models of palliative care for patients in the advanced stages of heart failure, highlighted the need for co-ordinated patient-centred care, helped patients live more comfortably with their illness and have a better quality of life.



For more information on the
Caring Together programme, visit
mariecurie.org.uk/caringtogether
bhf.org.uk/healthcare-professionals/best-practice

All images used in this report are illustrative and do not reflect the people quoted therein

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