

# Better palliative care for heart failure patients

## The Caring Together programme

British Heart Foundation, Marie Curie Cancer Care and NHS Greater Glasgow and Clyde are working together to provide better palliative care for heart failure patients.

Heart failure is a life-limiting condition affecting up to 100,000 people in Scotland<sup>1</sup>. Compared with many cancer patients, heart failure patients have a worse prognosis, poorer quality of life, and limited access to social services and palliative care<sup>2,3</sup>.

The Caring Together programme is a five-year programme which aims to improve the quality of and access to palliative care for any patients in the advanced stages of heart failure across NHS Greater Glasgow and Clyde.

Through partnership working, we are developing an innovative approach to delivering palliative care for these patients in all care settings – in hospital, hospice, care home and at home.

### What we want to achieve

Caring Together is developing pioneering models of palliative care for patients in the advanced stages of heart failure which:

- Meet the needs of patients and their carers
- Complement the optimal management of heart failure (and other diagnosed conditions)
- Promote equity of access to palliative care for heart failure patients
- Acknowledge the patient's preferences in place of care, including home
- Enable increased choice in place of care for patients
- Improve coordination of care among stakeholders

Our programme will commission a robust, independent evaluation of the project to contribute to the evidence base on the palliative care needs of patients in the advanced stages of heart failure.

We will also consider the opportunities for application of the model elsewhere in Scotland as well as the rest of the UK.

### Our core components

Following initial engagement with key stakeholders (including healthcare professionals, patients, carers and bereaved carers), we have developed integrated models which include our programme's six core components. To date, we have focused on the design and development of models for patients with left ventricular systolic dysfunction (LVSD).

Our programme's six core components:

1. **Referral criteria** for Caring Together (primarily LVSD patients)
  - a. a diagnosis of heart failure (NYHA stage III or IV)
  - b. progressive distressing or debilitating symptoms despite optimal cardiological therapy (identified by increased or changing needs)

2. **A comprehensive assessment** of identified patients including a cardiological review, holistic needs assessment and anticipatory care planning (where appropriate).
3. **Identification of an appropriate care manager**, who takes a key role in managing, directing and coordinating the care of an individual patient.
4. **Training and education** of professionals involved in the care of these patients.
5. **An approach to multidisciplinary working** to ensure coordinated planning and delivery of care.
6. **Joint working and professional development** across palliative care and cardiology teams, in both the acute and community settings.

### Integrated care models

The Caring Together integrated models have been designed and developed with the full participation of key local stakeholders. Local facilitation groups have taken the core components of the programme and facilitated the redesign of services by integrating these components into the local delivery.

The local facilitation groups focused on:

- Developing and implementing an integrated care model for heart failure patients with palliative care needs that is appropriate to local needs, facilities, systems and staffing
- Raising awareness of the role of the different teams and professionals involved
- Improving the communication between hospital professional groups, community care staff (including staff in nursing homes and at hospices), and patients and their carers
- Improving the current processes for arranging care packages and accessing services, and the continuity of care during the transition from hospital to the community

Three pilot sites in Greater Glasgow and Clyde were chosen to represent differing demographic profiles and healthcare structure:

- **north east Glasgow** with a population of 224,000 people
- **Inverclyde** with a population of 81,000 people
- **south west Glasgow** with a population of 117,000 people

The Caring Together holistic assessment tool has been specifically designed to support healthcare professionals and care managers in the identification of the unmet supportive and palliative care needs of patients with advancing heart failure.



The physical, social, psychological and spiritual aspects of care needs of each patient are appraised and addressed where possible through a multidisciplinary approach.

### Implementing and refining our models

Between June and November 2011, the three pilot sites implemented the first iteration of the integrated models. These sites have identified patients that fit the criteria of Caring Together, completed assessments, assigned care managers and are co-ordinating the care of these patients.

In the first five months, 55 patients across the three pilot sites met the Caring Together criteria. A heart failure nurse was the care manager for the majority of patients. 12 holistic assessments were completed and a further 35 partially completed for this group of patients.

Information gathered as part of this process on patient preferences and symptom burden were communicated to appropriate healthcare professionals and care providers. This information enabled appropriate care planning and management, and the completion of the electronic palliative care summary by the GP. Nine patients died during this period, with the majority dying at home – their preferred place of care.

We have appointed an action research partner to support the refinement of the models in each of the three pilot sites. Together with the local facilitation groups, we are refining the care models for the second and third iterations during 2012, with the view of implementing the final version in 2013.

### Benefits to patients and carers

- Improved access to palliative care services in hospital and at hospices, at home and in care homes
- Better coordination and provision of care, enabling choice in the place of care for patients who expressed their preference
- Increased support provided to families and carers including information about heart failure and how it affects the patient, and how they can get help when needed or referral to other services

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### References

- 1 CHD Statistics Scotland [www.heartstats.org](http://www.heartstats.org), 2007
- 2 Scottish Partnership for Palliative Care. Living and dying with advanced heart failure: a palliative care approach, March 2008.
- 3 Review of palliative care services in Scotland. Audit Scotland, August 2008.

[www.mariecurie.org.uk](http://www.mariecurie.org.uk)

