

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



**Marie Curie Cancer Care, British Heart Foundation Scotland and NHS Greater Glasgow and Clyde are working in partnership in the Caring Together programme. Our programme aims to improve the quality of palliative care for patients in the advanced stages of heart failure. We also aim to improve these patients' access to palliative care.**

Through the Caring Together programme, we are working with care professionals in different care settings to help patients with advanced heart failure to live more comfortably with their illness and have a better quality of life. We also aim to enable choice in the place of care.

Our programme has developed innovative models of delivering palliative care for patients with advanced heart failure. We are now piloting these care models in North East Glasgow, South West Glasgow and Inverclyde.

Since June 2011, more than 150 patients with advanced heart failure have been referred to our programme for assessment

and care. These patients have benefited from the programme's comprehensive assessments of their care needs; advance planning of their care; and support from their dedicated care managers (usually their heart failure nurse).

So far, patients who are supported with our programme's multidisciplinary approach and key components are more likely to remain in their preferred place of care.

## **Benefits our programme is delivering to patients and carers**

- Improved access to palliative care services for patients with advanced heart failure in hospital and hospices, at home and in care homes
- Better coordination and provision of care, enabling choice in place of care for patients
- 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

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





## An improved approach to care

The Caring Together programme is piloting integrated care models in North East Glasgow, South West Glasgow and Inverclyde to improve the provision of palliative and supportive care for heart failure patients in all care settings – hospital, home, hospice and care home.

The three pilot areas were identified as representative of the differing populations with a range of particular needs which our programme aims to address.

Our programme's integrated care models have been developed in collaboration with stakeholders and representatives from a wide range of local services. They included heart failure specialist nurses, community nurses and other professionals working in cardiology, palliative care and the managed clinical networks.

The care model for each area is designed to meet the needs of local patients, demographics, healthcare infrastructure and resources. As part of these care models, we have developed and introduced a number of key components.

### Key components of the Caring Together programme

#### Clear and concise referral criteria and pathways

Patients are referred to our programme if they meet the following criteria:

- Have advanced heart failure (New York Heart Association classification categories 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
- Are registered with a GP in North East Glasgow, Inverclyde or South West Glasgow

#### Comprehensive assessment of identified patients

Patients who meet our referral criteria receive:

- a cardiological review in outpatient or in-patient settings as appropriate
- a holistic assessment which looks at the physical, social, psychological and spiritual aspects of their needs so that these needs can be addressed



### Allocation of a care manager who leads and coordinates care

Each patient in our programme is assigned to a care manager, who will act as their main point of contact for information and support. The care manager, who could be their heart failure nurse, district nurse or GP, works closely with the wider multidisciplinary team to ensure that the patients and their carers receive the care and support that they need.

### Individualised anticipatory care management plan

Our programme has developed a medical anticipatory care plan to meet patients' care needs and national guidelines. The care plan is completed by the patient's cardiologist and includes concise information on the patient's medical and palliative care needs.

### An approach to multidisciplinary working and joint learning

Our programme's multidisciplinary approach across the acute, community and out-of-hours care teams enables us to deliver consistent and coordinated services to patients and their carers in all care settings. We also support joint learning between palliative care and cardiology teams in the acute and community settings.

### Programme objectives

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

- meet the needs of patients and 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 of place of care for patients
- improve coordination of care among stakeholders

“Knowing your likely outcome influences where you want to go for care.”

Patient with heart failure

## About the Caring Together programme

Our five-year programme covers a population of 1.2 million people across a large and diverse geographical area of Greater Glasgow and Clyde. Since June 2011, our programme has been piloting new integrated care models in North East Glasgow, South West Glasgow and Inverclyde.

We are commissioning a robust, independent evaluation of our programme. This will contribute additional learning to the evidence base regarding the palliative care needs of patients in the advanced stages of heart failure and their carers.

In the final phase of the programme, we plan to share our learning and support the roll out of our integrated care models across other areas in Greater Glasgow and Clyde. We will also consider opportunities for the application of our care models elsewhere in Scotland and the UK.

Our programme supports the Scottish Government's action plan for palliative care services, *Living and Dying Well*, which calls for a more equitable provision of end of life care services for patients with any advanced, progressive or incurable condition across all care settings.

Our programme also supports the Scottish Government's action plan for heart disease, *Better Heart Disease and Stroke Care Action Plan* and more specifically Standard 18 of the *NHS Quality Improvement Scotland Clinical Standards for Heart Disease* (2010) which requires "patients with heart disease, particularly heart failure, who remain symptomatic despite optimal treatment, to have access to supportive and palliative care according to their needs".

## Facts about heart failure

- Compared with most cancer patients, people with heart failure often have poorer symptom control and quality of life; limited access to palliative and social care services; and lack of choice in place of care and death.
- In most cases, heart failure is incurable.
- The disease progression and prognosis for patients with heart failure vary significantly. This makes it more challenging to diagnose patients as nearing the end of life and ensuring that their care needs are met.
- Heart failure is one of the most prevalent conditions in Scotland, with an estimated 100,000 people currently living with it.

## For more information

Phone: 0141 557 7551

Email: [caringtogether@mariecurie.org.uk](mailto:caringtogether@mariecurie.org.uk)

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

[www.bhf.org.uk/caringtogether](http://www.bhf.org.uk/caringtogether)

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

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

Marie Curie Cancer Care. Charity reg no. 207994 (England & Wales), SC038731 (Scotland) Q833

British Heart Foundation. Registered as a charity in Scotland (no. SC039426) and in England and Wales (no. 225971)

