

# Using patient and carer experience to improve palliative care for patients in the advanced stages of heart failure

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## Aims

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>.

**Caring Together** is a five-year collaborative programme between Marie Curie Cancer Care, the British Heart Foundation and NHS Greater Glasgow and Clyde. The programme aims to improve palliative care for patients in the advanced stages of heart failure across NHS Greater Glasgow and Clyde.

Caring Together will develop a pioneering model of palliative care for patients in the advanced stages of heart failure in Greater Glasgow and Clyde which:

- Meets the needs of patients and carers
- Complements the optimal management of heart failure (and other diagnosed conditions)
- Promotes equity of access to palliative care for heart failure patients
- Acknowledges the patient's preferences in place of care, including home
- Enables increased choice of place of care for patients
- Improves coordination of care among stakeholders

Caring Together will also contribute additional learning to the evidence base on the palliative care needs of patients in the advanced stages of heart failure by commissioning a robust, independent evaluation of the project.

Marie Curie Cancer Care and the British Heart Foundation will consider the opportunities for application of the model elsewhere in Scotland as well as the rest of the UK.

To help guide the development of the programme, we invited patients, carers and bereaved carers to share their experiences of services and care.

## Methodology

Graphically recorded focus groups were used as a method of involving patients, carers and bereaved carers. A graphic recorder participated in the session, creating a frieze during the session to capture words and images which reflect people's experiences.

## 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.
- 4 Millerick Y. Integrating palliative care recommendations into clinical practice for chronic heart failure. *British Journal of Cardiac Nursing* 2008; 3(12): 579-585.

## Benefits of this approach include:

- ✓ Images help stimulate discussion and overcome literacy issues
- ✓ An experiential picture is created; showing linkages in the patient journey
- ✓ The flow of discussion is captured in one place
- ✓ The frieze is gradually created throughout the session and is responsive to what people are saying
- ✓ The frieze reflects views and experiences

Fourteen patients, carers and bereaved carers participated in three sessions. Patients in the advanced stages of heart failure with palliative care needs were identified from an existing heart failure liaison nurse service database<sup>4</sup>.

## Outcomes

Each session focused on broad, open questions regarding the experience of care. Three locations of care – hospital, home and hospice – became the key themes which the friezes were developed around.

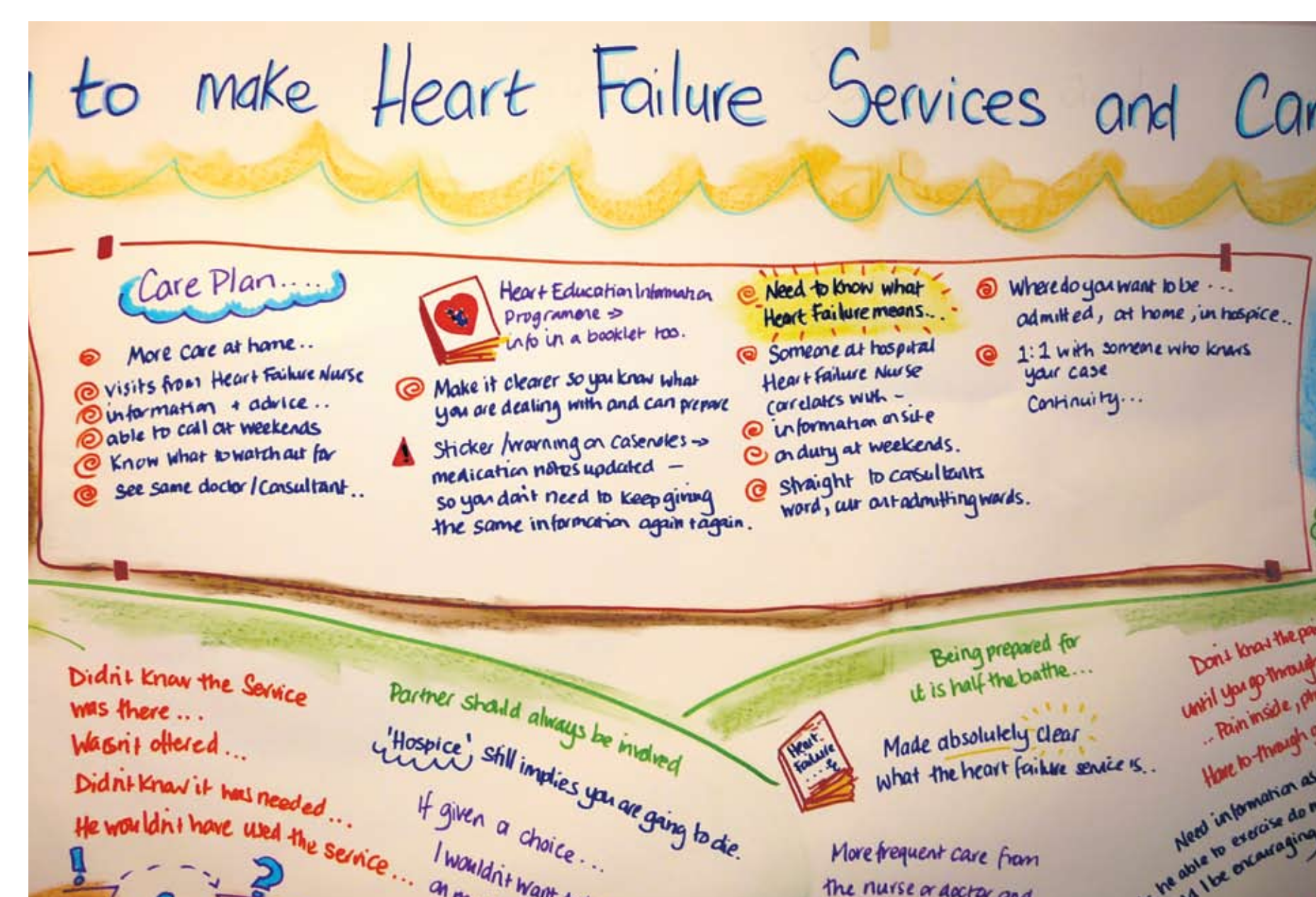
From these key themes, a range of comments emerged including:

- A lack of understanding of the life-limiting nature of heart failure
- Praise for heart failure liaison nurse service and the support they provide
- Acknowledgement that hospital is an appropriate setting during acute episodes
- Patients would have preferred to be cared for at home but for this to happen, they and their carers would need the right tools and support
- Hospices have negative connotations; however, patients who had been introduced to hospice day care by their heart failure nurse benefited significantly from the experience of the services and the social interaction with other patients

## Conclusion

Patient experience has informed the development of the Caring Together programme. The programme will develop information, tools and services which address the comments raised in all sessions.

An improved approach for patients with left ventricular systolic dysfunction will be in place in three pilot sites across NHS Greater Glasgow and Clyde in January 2011.



Comments from bereaved carers on care and information needs



Comments from patients and carers on care provision in hospitals



Comments from bereaved carers on care provision at home



Comments from patients and carers on care provision in hospices

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