



Heart Failure Patients End of Life Baseline Assessment Evaluation Report – One Year On

Introduction

The End of life Care Programme (EoL) is a National agenda set up to improve care at the end of life and provide information by sharing good practice and resources. Their main objective being “to provide sensitive, quality care for all dying patients, across all diseases, in all settings, so that more people receive their choice of care and die in their chosen place”.

The National clinical heart failure guidelines⁹ produced by the National Institute for Clinical Excellence (NICE) and Chapter 6¹ of the National Service Frameworks (NSF) for heart failure included clear standards regarding palliative care with chronic heart failure patients. Both documents outline the main areas of need as good symptom control, psychological support and open communication about disease outcomes. The opportunity to discuss these issues, including planning for the future and end of life care should be made available and discussed at all stages of care.

In support of the EoL Care Programme, the publications of ‘Building on the Best, Choice Responsiveness and Equity in the NHS’⁴, which identified that patients and carers, want choice over care at the end of life, the white paper ‘Our Health, our care, our say’³ and recently the ‘Healthcare For London: A Framework For Action’⁸ both reinforce that services should focus on individual needs enabling patients to feel in control of their care and be able to make informed choices to suit their personal requirements. The government has recognised the need for additional investment to improve EoL care and the need for proper resources to be able to look after dying patients and their carers as illustrated in the document ‘Supportive and Palliative Care for Advanced Heart Failure’⁷ which outlines the core elements required to improve EoL services.

This report outlines the findings of end of life services for heart failure patients one year on from the baseline assessment undertaken in 2006. The findings provide an overview of developments and the progression made so far in implementing the end of life programme within each locality across the North West London sector.

Methodology

The baseline assessment was based on the evaluation framework developed by the Heart Improvement Team to assist cardiac networks in measuring the impact of developing EoL care within heart failure services and links in with 'The Supportive and Palliative Care for Advanced Heart Failure'⁷ document. The framework suggested twelve sections for developing and improving service provision, for this project it was adjusted to eleven. Overall assessment is evaluated by using the traffic light system and to measure progress as follows:

No service	Very little provision	Evidence of some service provision	Evidence of significant service provision
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Each locality was assessed using the following indicators:

1. Co-ordination of care
2. User involvement in planning, delivering and evaluating services
3. Face-to-face communication
4. Information
5. Psychological assessment and support
6. Social support services
7. General palliative care services, including care of dying patients
8. Specialist palliative care
9. Rehabilitation services
10. Complementary therapy
11. Family/carer bereavement support

A template (appendix 1), which outlined each indicator, was sent to all heart failure nurses to complete in October 2006 and again a year later in October 2007.

Each template was transferred onto the evaluation framework to depict a before and after assessment of services (appendix 2).

Background

An EoL cardiac workshop was set up for key stakeholders from across the NW London sector in June 2006. This provided a platform to highlight gaps in the service relating to the provision of EoL for heart failure patients and provide a networking opportunity to share existing care models.

The heart failure nurses forum was utilised to discuss the results of the workshop and prioritise EoL areas that impacted on their services the most. It was agreed that evaluating the services would provide a clearer view on what was happening within each locality and these were defined by the following aims and outcomes:

Aims – Evaluate end of life care for heart failure patients within NW London, identify gaps within each heart failure service and address inequalities within each service.

Outcomes – Identified areas of good practice for sharing and benchmarking, identified specific gaps in service provision for organisations to plan local delivery, measurable progress of service, provide evidence of levers for change as outlined in the ‘Supportive and palliative care for advanced heart failure’¹⁷ guide which drew on the NICE guidelines for adults with cancer.

The following areas were identified as a priority by the heart failure nurses and have been or are to be developed:

- Advanced communication skills – set up and delivered by Hatfield University in 2007, possibility of running another course in 2008
- Study Days – seven 1-day heart failure and EoL workshops were run across NW London targeting community matrons, district nurses, hospices and care homes
- Preferred place of care – already in place in two localities, to be rolled out across NW London
- Generic heart failure palliation pathway – developed
- ICD deactivation – guidelines developed, implementation being rolled out
- Symptom control guidelines – guidelines developed
- Service Directory – developed and accessible on NW London Cardiac Networks website

Continued EoL workshops and the development of the above EoL documents and tools have helped to increase the knowledge and awareness of EoL within cardiac services.

Findings

The initial assessment of the baseline in 2006 showed a lot of variation of service provision between organisations. It was acknowledged that EoL service provision was mostly available only to cancer patients and the provision of these services limited to non-malignant diseases. It was agreed that being able to link into these already available resources would provide greater access to EoL services for heart failure patients but would require established collaboration with palliative care and related services across secondary and primary care.

The updated evaluation framework (appendix 2) has shown a vast improvement for heart failure patients within each locality, representing the collaboration and spread of EoL knowledge that has gone on in the past year.

Where some organisations are blank depicting no service, this indicates that no heart failure nurses were in post and consultant led heart failure services were being provided. Other areas of concern are in the community where there are no community heart failure nurses, which would indicate unmet need for end stage heart failure patients.

This project assumes that heart failure nurses are pivotal to end stage heart failure patients receiving EoL care, as they appear to be the link in referring patients as appropriate.

The following gives a detailed analysis of the gaps in the service and where improvements have been made:

- EPCT, HHNT and H&FPCT – as indicated before there have been no heart failure nurses to co-ordinate care. This doesn't mean that there is no EoL service available but that there is no one to link or instigate EoL care for the heart failure patient.

The impact here is that often patients wishes and preferences will not have been realised. Limited support within the community due to the lack of heart failure expertise and inappropriate discharge assessments, which often lead to failed discharges could all result in frequent readmissions.

- Rehabilitation – there was little improvement in rehabilitation and it was felt that funding and limited resources were an issue.

The growing evidence⁷ is that this group of patients can still benefit from participation in similar comprehensive rehabilitation offered to patients recovering from acute myocardial infarction or following revascularisation. Support from allied health professionals and involvement with multi-disciplinary teams will be essential to provide delivery of a comprehensive rehabilitation service for chronic heart failure patients.

- Complementary therapy – these services were available albeit limited across the sector and restrictions applied. The following outlines who has access:
 - Patients who were known to palliative care teams
 - PCT services run by hospices – referred patients only
 - Hospital services – limited to cancer patients only
- Bereavement support – all palliative care teams have bereavement teams to follow up with families/carers indicating that all patients referred to palliative care will get follow-up. There was some availability to cardiac patients but very basic with no formal arrangements.

This area of the evaluation was particularly limited and it will be essential to address these limitations by including this service for heart failure patients to meet the proper standards as outlined in the National Bereavement Consortium⁷.

- WMUH and Hillingdon – provided a good example of working across boundaries, indicating the link between primary and secondary care was well supported as shown by matching columns (Appendix 2) between the hospital and community.

To ensure the patient receives a seamless service along their EoL care pathway it will be vital to have good co-ordinated care throughout the patient's journey. Communication between all health care professionals involved and acknowledging the needs of the patient will be an essential component of the pathway.

Summary

Overall, NW London has shown an increase in EoL development within each locality and this is being seen as an evolving process. The development of EoL steering groups has expedited the delivery of EoL with the delivery of the Gold Standards Framework⁵ in the community and the Liverpool Care Pathway⁶ (or Care of the Dying Pathway) in acute care both acknowledging non-malignant disease groups.

To ensure that chronic heart failure patients receive appropriate end of life care in NW London the following points outline recommendations that should be addressed as identified by the assessment framework:

- Better access to resources in particular:
 - Bereavement services
 - Rehabilitation
 - Complementary therapies
- Training and education – this was highlighted as an important and necessary part of the delivery of EoL care. The recent study days conducted by a heart failure nurse and a palliative care nurse where they presented case studies to community matrons, district nurses, hospice and care home staff was extremely well received by all the attendees. Providing a better understanding of symptom control, basic heart failure knowledge and confidence in dealing with heart failure patients in particular end stage heart failure patients.

Other training issues were advanced communication skills and this was highlighted across the board in community and acute settings. Development of MDT EoL education days for community and acute staff will help establish the acknowledgement required for appropriate referrals.

- Referral links are vital to get patients on the EoL pathway at the right time. Establishing these links with key health care professionals throughout each organisation and across secondary and primary care will provide a continued care process allowing the wishes and preferences of patients to be realised. The use of the generic palliation pathway for end-stage heart failure patients will assist in referring patients for initiating the PPC, particularly in collaboration with the LCP, allowing patients to be referred appropriately and avoiding unnecessary hospital admissions and readmissions. Attending MDT's or other appropriate meetings will assist in identifying patients for referral.

The Network will continue to support EoL care and collaborate with organisations to establish and maintain an EoL care programme within heart failure services across the sector.

Temo Donovan
Senior Project Manager
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Appendix 1

Name of Organisation:

Do patients with advanced heart failure have a key worker who will assess their needs for information, involvement in decision-making, control of symptoms, psychological support, rehab and complementary therapies?	
Who is this person?	
What evidence is there of this?	
Is there an 'Out of Hours' service available?	
What evidence is there of this?	
Is there a local directory of services, which those key workers can use to signpost patients to appropriate support once the patients needs have been assessed?	
Who else is providing nursing care for HF patients in the area?	
What roles are being covered by these staff?	
What are the gaps in service provision?	
Is there evidence of user involvement in the planning, delivering and review of services for people with advanced HF?	
What evidence is there of this?	
Is there any training available locally to address advanced communication skills and spiritual care?	
What evidence is there of this?	
Do patients with advanced HF have the information they need? This will include brief introductory information, general health information and information specific to their condition (preferably written)	

What evidence can be found to suggest that this happens?						
Do patients with advanced HF have their needs for psychological support addressed? Is a tool for the assessment of anxiety and depression used? Do providers have access to psychological support such as counselling and complimentary therapies?						
What evidence is there of this?						
Do patients with advanced HF have the social support they need?						
What evidence is there of the assessment of social support?						
What evidence is there that HF services are collaborating with services providing financial, social and carer support?						
Are HF patients having their care managed by the following programmes:						
GSF		LCP		PPC		ACP
If not, when will they be implemented (if known)?						
What evidence is there of collaboration between local specialists palliative care services and services for HF patients?						
Are there referral guidelines, symptom control guidelines that are relevant to advanced HF? Joint visits to assess patients? Any evidence of specialist palliative care services helping with the most complex cases?						

<p>What evidence is there that patients with advanced HF are accessing rehab services?</p>	
<p>What evidence is there that complementary therapy services are available to patients with advanced HF?</p>	
<p>What information about the availability of complementary therapies is there for patients with advanced HF?</p>	
<p>What evidence is there of local coordination of bereavement services? This may be a coordinator and or a directory of services.</p>	
<p>Are the bereaved from heart disease included in this provision?</p>	
<p>Where such services do not exist, is there a plan to create such services?</p>	

Appendix 2

		Brent PCT		CMH		Ealing PCT		EHT		H&F PCT		HHNT		Harrow PCT		NPH		Hounslow PCT		WMUH		Hillingdon PCT		Hillingdon		K&C PCT		RB&H		C&W		Westminster PCT		SMH	
		B	A	B	A	B	A	B	A	B	A	B	A	B	A	B	A	B	A	B	A	B	A	B	A	B	A	B	A	B	A	B	A		
1	Co-ordination of care	Red	Yellow	Yellow	Yellow			Yellow	Green					Yellow	Green			Yellow	Green			Green	Yellow	Green		Yellow	Green	Green	Green			Green	Yellow	Green	
2	User involvement in planning, delivering and evaluating services	Yellow	Green	Yellow	Yellow			Yellow	Green					Yellow	Green	Yellow	Yellow	Yellow	Red	Yellow			Yellow	Yellow	Yellow	Red	Green	Green		Yellow		Red	Yellow	Yellow	
3	Face-to-face communication		Yellow		Yellow				Green					Red	Green			Yellow	Red	Yellow			Red	Yellow	Red	Red	Yellow	Yellow		Yellow	Yellow	Yellow	Yellow		
4	Information	Red	Yellow		Yellow				Green					Green	Yellow	Green			Yellow	Green			Green	Yellow	Green	Green	Green	Green		Green	Yellow	Green	Yellow		
5	Psychological assessment and support		Yellow	Red	Yellow			Red	Green					Red	Green			Yellow	Green	Yellow	Yellow			Yellow	Yellow	Red	Red	Yellow	Yellow	Red	Red	Yellow	Red	Yellow	
6	Social support services		Red	Red	Yellow			Red	Yellow					Red	Yellow			Yellow	Yellow	Yellow	Yellow			Yellow	Red	Red	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	
7	General palliative care services, including care of dying patients	Red	Yellow	Yellow	Yellow			Red	Yellow					Yellow	Green			Yellow	Red	Yellow			Green	Red	Green	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	
8	Specialist palliative care	Red	Yellow	Red	Yellow			Yellow	Green					Green	Green			Yellow	Red	Yellow			Green	Green	Red	Green	Yellow	Yellow	Yellow	Red	Yellow	Red	Yellow	Yellow	
9	Rehabilitation services		Red	Red	Red			Red	Yellow					Green	Green	Red							Yellow	Red	Yellow						Red	Yellow	Yellow	Yellow	
10	Complementary therapy														Yellow								Red	Red	Red	Red	Red	Red			Red	Red	Red	Red	Red
11	Family/carer bereavement support		Red												Yellow				Red	Red	Red			Red	Red	Red			Red	Red	Red	Red	Red	Red	Red

B = before
A = after

No service	Very little provision	Evidence of some service provision	Evidence of significant service provision
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References

1. Commission for Healthcare Audit and Inspection (2005) 'Getting to the heart of it: Coronary heart disease in England: A review of progress towards the national standards'. London.
2. Department of Health (2000) National Service Framework for Coronary Heart Disease: Heart Failure Chapter 6. London.
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