

Launch of publication: *Living and dying with advanced heart failure: a palliative care approach - notes from presentation/discussion*
Wednesday 12 June 2008

Andy Carver, Prevention and Care Advisor at British Heart Foundation (BHF) Scotland, thanked the Scottish Partnership for Palliative Care for the opportunity to participate in that night's meeting.

He went on to report that whilst premature mortality from heart disease was falling, survival from heart attacks was rising, leading to increased demands on health services. Those surviving patients had a debilitating and life-threatening condition for which there was no cure and BHF Scotland felt very strongly that such patients deserved the highest level possible of treatment and care. The launch of the heart failure report provided a significant opportunity for the Scottish Government and NHS Scotland to begin to tackle the needs of these patients.

In the foreword of the report, the Chief Medical Officer for Scotland, Dr Harry Burns acknowledged that SIGN Guideline 95 on the management of chronic heart failure had a section on palliative care that included a clear recommendation that a palliative care approach should be adopted by clinicians in the early stages of the disease. This report was a milestone towards delivering on that recommendation for all heart failure patients. Other important milestones included the publication over the next few months of the Scottish Government's palliative care strategy where it was hoped that a strong focus on non-cancer conditions such as advanced heart failure would be included. The CMO had suggested that the essence of the recommendations in the heart failure report would be incorporated in the imminent refreshed version of the CHD and Stoke Strategy.

The heart failure report highlighted the importance of joint working, especially between generalist palliative care staff and health professionals working with heart patients, and also between NHS Boards and palliative and CHD managed clinical networks across the country. BHF Scotland was committed to working with the Scottish Government, NHS Scotland, and the Scottish Partnership for Palliative Care to ensure these objectives were delivered upon. BHF Scotland was also in particular looking forward to the proposed work which would be carried out by NHSQIS on new standards in heart disease and for advanced heart failure.

Professor Henry J Dargie, Director, Scottish Advanced Heart Failure Service, Golden Jubilee National Hospital, Glasgow explained that at the hospital there was a specialist unit and heart failure team working in a multi-disciplinary environment that could assess the most severe forms of heart conditions. Once a patient was diagnosed and assessed an advanced care plan including agreed goals and priorities of care was prepared. Heart failure patients at the end of life benefitted from the co-ordinated and continuity of care that inter-professional working provided at the hospital.

Heart failure was a more common cause for admission to hospital than heart attacks. Of those patients admitted to hospital with advanced heart failure, it was expected that 50% of them would die within a year of being diagnosed and 50% of the remainder would die within 5 years. It was difficult to predict individual prognosis because some heart failure patients died suddenly and unexpectedly. The care available for most heart failure patients was not as good as in other conditions and in some acute hospitals these patients had a poorer quality of life than cancer patients with little or no access to palliative care. There was often a lack of robust systems in place in the acute sector to support a palliative care approach. The correct approach - a palliative care approach - to the management of advanced heart failure should be adopted by all clinicians to improve the quality of life for patients.

Professor Dargie welcomed and endorsed the recommendations made in the heart failure report.

Dr Chris Ward, Honorary Consultant Cardiologist, Ninewells Hospital, Dundee gave a presentation *a palliative care approach to the management of advanced heart failure.*

Dr Ward explained that heart failure occurred when the heart was damaged and no longer able to pump sufficient blood for the other organs and tissues of the body to function normally. The great majority of heart failure cases were caused by heart attacks or high blood pressure.

Usual symptoms of heart failure included breathlessness on exertion, swelling of the ankles and legs and fatigue which in this context was not just feeling tired after a hard day at the office – it might be feeling totally exhausted after for example, making a cup of tea. Symptoms improved with treatment, stabilised for a while enabling many patients to return to some level of normal activity for months or even years but then the symptoms would return and worsen.

The illness trajectory for heart failure showed long term limitations with intermittent serious episodes sometimes resulting in emergency hospital admission to sort out certain cardiac events such as unstable angina. In addition up to 50% of heart failure patients died suddenly and unexpectedly.

Heart failure was mainly a disease of older people and affected approximately 10% of 80 year-olds. It was almost always fatal and in severe cases the annual mortality was 50%.

In Scotland:

- 85% of patients were aged over 65
- up to 10,000 new cases were identified annually
- the total number of cases recorded annually was over 90,000
- there were probably between 4,000 and 5000 deaths each year attribute to heart failure.

Those living with heart failure reported a greater reduction in quality of life than those with any other long-term illness, and had a worse prognosis than that for most forms of cancer. Most patients also had at least two or three other serious medical conditions such as anaemia or diabetes, which made their already poor prognosis and quality of life even worse.

One main objective for writing the heart failure report was to highlight that, for one reason or another current standard treatment strategies did not address many of the needs of these patients. Throughout the illness there was poor communication: about the diagnosis, prognosis treatment options and other 'important issues'. Patients often had financial problems or marital problems. Older patients were often socially isolated, and questions such as 'why me?' were frequently asked, as were questions about religion. Patients' views should be paramount and their needs fully discussed with key issues as resuscitation status, preferred location for end of life and withdrawing or withholding treatment included in the discussion. Major concerns of patients were often unaddressed and wishes ignored.

Many of these patients had poor symptom control and a limited prognosis despite optimum medication. The evidence base to support symptom control remained poor.

The following phrase from American comedienne Lilly Tomlin very neatly summed up the plight of the average heart failure patient:

'Things are going to get a lot worse before they get worse.'

Recurrent problems during the last year of life included:

- poor communication between primary and secondary care teams
- unco-ordinated out of hours care provision
- the increase of episodes of hospitalisation: these were often unnecessary, and unwanted by patients.

The cost of hospitalisation accounted for two thirds of NHS expenditure on heart failure, however at least half of those episodes could easily have been avoided.

In the final week of life two thirds of patients had poorly controlled pain whilst half had distressing breathlessness, (McCarthy M et al. JRCF 1996 30 325-8) whilst in the final three days of life 40% were treated by either tube/intravenous feeding, artificial ventilation or had attempted resuscitation performed.

Clinicians were still not good at recognising (or accepting) when patients were dying. For many heart failure patients on the day that they died, they would probably appear no more or less ill than any other day of their illness, the result of which was that terminally ill patients often did not have the best management. By applying the palliative care approach to patient management those current inadequacies in treatment could be resolved

Dr Martin Leiper, Consultant in Palliative Medicine, Roxburghe House, Dundee and Chairman of the Heart Failure Working Group explained that in May 2008 the BMJ's Making a Difference poll to decide which of six projects championed by leading doctors and scientists would make the most improvement to patient care, saw palliative care for all at the end of life come top receiving 38% of the 4,000 online votes. In the winning articles, Professor Murray, Aziz Sheikh and Joanne Lynn looked at how the lessons learnt from excellent and accessible palliative care provided to people with cancer could be adapted for the growing group of people with fatal non-malignant conditions such as heart failure and dementia.

Dr Leiper then went on to highlight key issues (in bold) from the recommendations made in the heart failure report:

RECOMMENDATION 1

All patients with advanced heart failure should be provided with both **optimum cardiological management and palliative care**.

- 1.1 All patients with advanced heart failure should be proactively identified and placed **on the primary care supportive and palliative care register**.
- 1.2 All patients with advanced heart failure should be **actively monitored by the primary care team** and assessed to see **if additional advice, assessment or care from the specialist heart failure nursing service** and /or local palliative care service is appropriate.
- 1.3 Primary and secondary care teams should have access to cardiological and specialist palliative care expertise and advice when required.

RECOMMENDATION 2

Health care teams should adopt a holistic approach to the care of patients with heart failure, ensuring not only optimum management of physical symptoms, including those relating to co-morbidities, but also identifying and addressing **practical, social, psychological, emotional and spiritual needs**.

- 2.1 Members of health care teams should be aware of the range of physical symptoms such as **breathlessness, nausea and pain**, and of the effects of complex multiple drug regimes, likely to be experienced by patients with advanced heart failure. They should address these proactively and with palliative care support where necessary.
- 2.2 The needs of people with heart failure and their carers for clinical, practical and **financial information** should be recognised and appropriate written information provided at local level. Health care professionals should be aware of actual or potential financial hardship as a source of stress and practical difficulty for patients and families and should be able to signpost patients to local welfare benefits advice organisations. All patients with advanced heart failure should be considered by their doctors for a 'special rules' **(DS1500)** benefits application.
- 2.3 Members of the health care team should be aware of the multi-agency services available

locally, including **social work services and the voluntary sector**, and where necessary signpost /arrange access to the support required.

- 2.4 Health care professionals should explore the wishes of patients to engage in dialogue about emotional and **spiritual concerns**. Appropriate specialist support should be identified and offered where required.

RECOMMENDATION 3

Members of health care teams should ensure that patients with advanced heart failure and their carers have sufficient **opportunities to discuss, at their own pace** and at times of their choosing, any issues that are important to them, including the management of the condition and its prognosis.

- 3.1 A continuing dialogue of **open, sensitive and honest communication** appropriate to the patient's wishes and needs should be initiated at the time of diagnosis and maintained throughout all stages of the disease trajectory.
- 3.2 All patients with advanced heart failure and their carers should have the opportunity to discuss and make documented decisions regarding their priorities and **preferences for end of life care**. Goals of care should be discussed openly with the patient and family.
- 3.3 **Prognostic uncertainty** should be accepted by clinicians, sensitively communicated to patients and families, and incorporated into a process of joint decision-making and forward planning.
- 3.4 **The possibility of sudden death** should be acknowledged by clinicians as an unpredictable but recognised feature of the heart failure trajectory and the possibility of its occurrence (and where appropriate of preventative strategies) communicated sensitively to patients and carers.

RECOMMENDATION 4

A **model of shared care** involving close collaboration between different healthcare teams should be implemented in the care of patients with advanced heart failure.

- 4.1 Patients should remain in the care of their **primary care team** and of a single hospital care team throughout the course of the patient journey, with specialist advice and support from a cardiologist, palliative care specialist and others as required.
- 4.2 A **key individual** should be identified to co-ordinate care management and to liaise between the patient, family and other healthcare professionals.
- 4.3 There should be a management plan that involves key members of all relevant care teams in decision making processes.
- 4.4 Referral protocols for accessing specialist cardiological and palliative care advice and consultation should be in place for patients with complex needs.
- 4.5 Steps should be taken to improve the sharing of information within and between healthcare teams.
- 4.6 Patients and carers should be provided with the **appropriate telephone contact** numbers and know whom to contact for out of hours care.
- 4.7 **NHS 24** and out of hours providers should be aware of the identity of patients with advanced heart failure and **know how to respond** to any calls.

RECOMMENDATION 5

Arrangements for appropriate end of life care should be in place for all patients with advanced heart failure.

- 5.1 Established tools for end of life care, such as the **Gold Standards Framework** for co-ordinating the care of patients with advanced heart failure and the **Liverpool Integrated Care**

Pathway for managing the last few days or hours of life, should be implemented.

- 5.2 Mechanisms should be in place for the **safe cessation of unnecessary medication and implantable devices**.
- 5.3 Arrangements for **anticipatory prescribing** should be in place, particularly before weekends, as a proactive response to any anticipated worsening of symptoms.

RECOMMENDATION 6

Educational and training opportunities should be provided for all health and social care professionals caring for people with heart failure to enable them to understand the patient's cardiological problems and to address their general palliative care needs.

- 6.1 Reciprocal opportunities to share knowledge and experience and to gain an understanding of the management of patients with advanced heart failure should be available among all health and social care teams involved.
- 6.2 Members of primary care, social care and hospital ward teams who care for heart failure patients should be assisted by their cardiac and palliative care MCNs to access multi-professional training opportunities to develop basic palliative care skills.
- 6.3 Members of specialist palliative care and primary care teams who care for heart failure patients should be assisted by their cardiac and palliative care MCNs to access multi-professional training opportunities to enhance their knowledge and awareness of the clinical needs and cardiological management of such patients.
- 6.4 Advanced clinical communication education programmes using proven experiential teaching and learning methods should be available in all NHS Board areas. Health professionals caring for people with heart failure and their families should attend such training if they have not already done so.
- 6.5 Training opportunities in spiritual care should be available in all NHS Board areas for all interested health professionals to enable them to identify and respond appropriately to the existential suffering and spiritual needs of their patients with advanced heart failure.

RECOMMENDATION 7

Further palliative care **research** should be undertaken in order to:

- examine the need for a flexible, multi-dimensional framework of service for people with advanced heart failure
- identify the most **effective models of care**
- determine which interventions best improve **symptom control and quality of life**.

RECOMMENDATION 8

The **resource implications** of this report and recommendations should be addressed:

- consideration should be given to **reorganisation** of existing services **to meet increasing need** and to support implementation of the above recommendations
- additional **resources** should be made available to both primary and secondary care **to enable full implementation** of the above recommendations.

Discussion:

A discussion ensued, the main points of which were:

- members of primary care, social care and hospital ward teams who care for heart failure patients should be assisted by their cardiac and palliative care managed clinical networks (MCNs) to access multi-professional training opportunities to develop and enhance their knowledge and awareness of the clinical needs and cardiological management of such patients - this should also be brought to the attention of palliative care networks and organisations which should encourage MCNs to consider requests for joint training and services especially in primary care
- 70% of heart failure diagnoses were made during acute admission
- there was a need to turn attention to the identification of primary care heart failure diagnoses
- when a heart failure patient was diagnosed a champion should be allocated to him
- the support of heart failure nurses in primary care was crucial in establishing liaison
- quite a lot could be done now to improve care management
- there was a lack of financial resources to support these services and cardiologists did not have dedicated time for heart failure patients
- in south Manchester the Liverpool Care Pathway was being introduced into cardiology wards
- the Postgraduate Medical Educational and Training Board (PMETB) had now accepted heart failure as a specialism and was offering suitable training
- less than 5% of heart failure patients currently identified were on a register
- GSFS worked well in identifying patients with cancer
- regarding heart failure patients, there was a need to encourage primary care teams to identify such things as recurrent hospital admissions, letters from cardiologists, no 'surprise' of death in 12 months, breathlessness at rest etc.
- there was a resource implication for echocardiograms but the 'surprise' question was reliable
- cardiologists working together with primary care staff could use other less expensive tests
- introducing palliative care at diagnosis was crucial to the quality of life for a heart failure patient
- good care at home at end of life was not readily available for heart failure patients
- some Marie Curie nurses worked in close collaboration with heart failure nurses
- lots of pockets of very positive work was currently being carried out but these needed to be joined up and pulled together
- NHS 24 and OOH working was problematic – there was no algorithm for heart failure
- heart failure patients often had co-morbidities and nursing in the community used a case management approach for patients with multiple admissions
- a key GSFS approach ie identification, assessment and planning, needed to be applied to heart failure patients
- heart failure practice nurses were currently establishing a comprehensive training programme
- telehealth needed to be addressed in the Highlands and Islands

It was noted that the Convener had lodged the following motion earlier that day in Parliament:

**S3M-02137# Michael McMahon (Hamilton North and Bellshill) (Scottish Labour):
Living and Dying with Advanced Heart Failure**

That the Parliament welcomes the publication of *Living and dying with advanced heart failure: a palliative care approach*, by the Scottish Partnership for Palliative Care with the support of British Heart Foundation Scotland and the Scottish Government; notes that people with heart failure have a worse prognosis and poorer quality of life than many cancer patients and that 50% of advanced heart failure patients die within a year of diagnosis, many of them suddenly and unexpectedly, particularly in the west of Scotland; believes that uncertainty around prognosis should not be a barrier to people with advanced heart failure, or those with any other condition, receiving appropriate palliative care; is concerned that, despite the recommendations of the CHD and Stroke Task Force in 2001 that provision needed to be made for palliative care for advanced heart failure, too many of these vulnerable patients are still not getting the care they need at the time that they need it most, and believes that account should be taken of the report's recommendations and that the needs of patients with conditions other than cancer, like advanced heart failure, should be explicitly addressed in the forthcoming palliative care strategy and the refreshed CHD and Stroke Strategy.

The Convener had agreed to push for a heart failure debate in Parliament in the next few months.