

Appendix Three

Palliative Care and Heart Failure

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PREFACE TO APPENDIX 3: PALLIATIVE CARE AND HEART FAILURE

“When assessing the need for specialist palliative care services, each health board should consider the needs of patients with malignant and non-malignant disease.”

Report of the National Advisory Committee on Palliative Care (NACPC) 2001 [1] p. 43.

The Extending Access Study is a response to the recommendation of the NACPC report that the palliative care needs of people with diseases other than cancer be given equal consideration in service provision. Palliative Care for All is the report of this study which was jointly carried out by the HSE and Irish Hospice Foundation.

The study sought to examine the palliative care needs of people with diseases other than cancer, and focused on three non-malignant diseases which have high mortality rates namely:

- Chronic Obstructive Pulmonary Disease
- Dementia
- Heart Failure.

The joint study was overseen by a Steering Committee, which was chaired by the Assistant National Director for Palliative Care and Chronic Illness, HSE. Three Working Groups were established to specifically examine how palliative care could extend to people with COPD, dementia and heart failure respectively within an Irish health service framework. The Steering Committee and Working Groups had representatives from medical, clinical and professional specialists within the field of palliative care and respiratory, dementia care and cardiology and views were also gathered from service users. Each of the working groups advised the IHF project team on the content of the disease-specific appendices. Appendices 1, 2 and 3 of the report provide detailed references and rationale for the development of palliative care in the disease-specific context.

The report contains an extensive glossary and definition section. For ease of reference in this Appendix, the following definitions are used in relation to palliative care:

Palliative Care: an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual [2].

Specialist Palliative Care: those services whose core activity is limited to the provision of palliative care. These services are involved in the care of patients with more complex and demanding care needs, and consequently, require a greater degree of training, staff and other resources. Specialist palliative care services, because of the nature of the needs they are designed to meet, are analogous to secondary or tertiary health care services [1].

Non-Specialist Palliative Care: the practice of palliative care principles by all health care professionals with a focus on quality of life, which includes good symptom control; a holistic approach that takes into account the person’s life experience and current situation; care that encompasses both the dying person and those that matter to that person; and an emphasis on open and sensitive communication, which extends to patients, carers and professional colleagues. Adapted from [1] (2.3).

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Heart Failure and Palliative Care

1. INTRODUCTION

Since the NACPC report of 2001 [1] there has been significant progress made in the funding and development of palliative care services, with advances in specialist inpatient units, community specialist palliative care teams and increases in staffing levels in acute general hospitals. Provision of and access to palliative care services for people with diseases other than cancer has to be further progressed in line with national policy developments [3-7].

This appendix seeks to explain what heart failure is and its prevalence in Ireland. It outlines the international and national policy context of palliative care provision for patients with heart failure, sketches the current configuration of services, presents the findings of the Extending Access Working Group on heart failure and palliative care and outlines their recommendations on the integration of palliative care in the treatment of people with heart failure. These recommendations should be considered with regard to the overarching recommendations in the main body of this report.

2. WHAT IS HEART FAILURE?

Heart failure is said to occur when, despite a normal or increased “filling pressure”, the heart is unable to maintain sufficient cardiac output and oxygen delivery to meet the demands of the metabolising tissues. Symptoms of heart failure include breathlessness, orthopnoea (inability to lie flat), paroxysmal nocturnal dyspnoea, ankle swelling and fatigue. Signs of heart failure include peripheral oedema, raised jugular venous pressure, cardiomegaly, third heart sound, and bibasal pulmonary crackles [8].

According to the European Society of Cardiology (ESC) guidelines a diagnosis of heart failure requires that patients should have the following symptoms of heart failure; shortness of breath or fatigue – at rest or on exertion, ankle swelling, and objective evidence of cardiac dysfunction at rest [8].

The most common underlying cause for heart failure is left ventricular systolic dysfunction. The most frequent reasons for left ventricular systolic function in developed countries are coronary artery disease and hypertension. Other common causes are idiopathic dilated cardiomyopathy, alcohol cardiomyopathy and valvular heart disease [9].

Once a diagnosis of heart failure has been established the New York Heart Association (NYHA) classification may be used to classify the severity of heart failure (see table below) and monitor the effects of therapy. The NYHA classifies four stages of heart failure [10]:

Class	Patient Symptoms
Class I (Mild)	No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, or dyspnoea (shortness of breath).
Class II (Mild)	Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in fatigue, palpitation, or dyspnoea.
Class III (Moderate)	Marked limitation of physical activity. Comfortable at rest, but less than ordinary activity causes fatigue, palpitation, or dyspnoea.
Class IV (Severe)	Unable to carry out any physical activity without discomfort. Symptoms of cardiac insufficiency at rest. If any physical activity is undertaken, discomfort is increased.

In patients with heart failure, treatment with β -blockers, ACE inhibitors and aldosterone receptor blockers improve symptoms, reduce hospitalisations and improve prognosis. Device therapy with implantable cardioverter defibrillators (ICD) and cardiac resynchronisation therapy in selected patients also improve survival [9].

2.1 EPIDEMIOLOGY

It is estimated that between 0.4% and 2% of people in Europe have symptomatic heart disease. The ESC estimates that 14 million people in Europe have heart failure and that 3.6 million people in Europe are diagnosed with heart failure each year.

In 2002 the Irish Heart Foundation predicted an evolving heart failure crisis in Ireland, which at the time affected up to 80,000 people, with an equal number estimated to have impaired left ventricular dysfunction or impending heart failure. Irish Heart Foundation research indicates that there are more than 10,000 new cases of heart failure each year and that it is rapidly becoming one of the most common reasons for emergency admission to Irish hospitals, affecting an estimated 12,000 Irish people each year [12].

This is in line with other studies which estimate that chronic heart failure has an overall population prevalence of approximately 1 to 2%, rising to around 10% in the very elderly. Both incidence and prevalence increase dramatically over the age of 75 years [13]. As the elderly population of Ireland grows and with increasing survival after an acute coronary event the prevalence of heart failure has increased and will continue to increase steadily. The Irish Heart Foundation has estimated that by 2010 over 300,000 people in Ireland will be directly affected by heart failure [12]. Current data available indicates that heart failure is currently approximately 30% of a cardiologist's workload, and this will undoubtedly increase with these changing demographics.

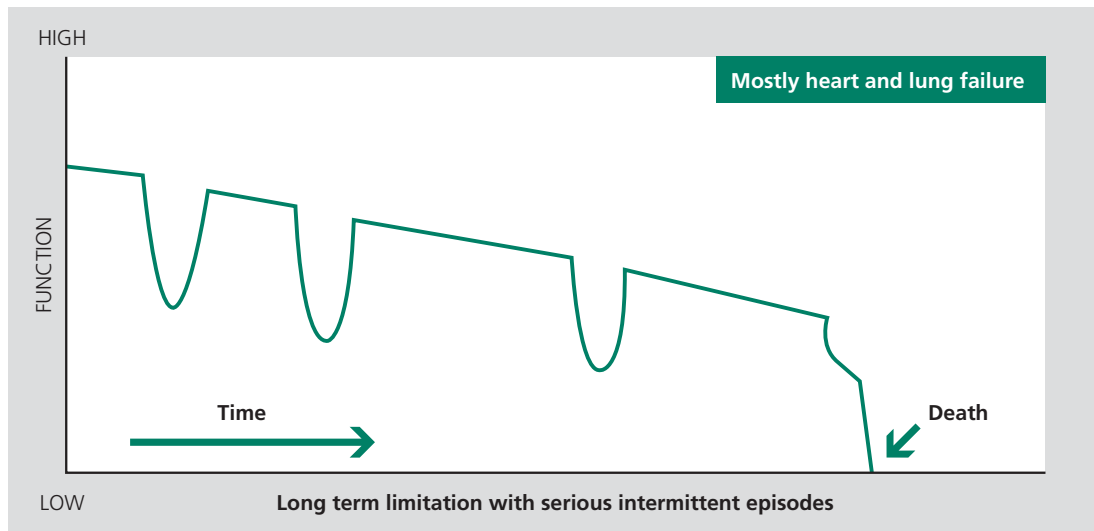
As heart failure is considered a mode, not a cause, of death, it is not notable on death certificates in Ireland, and it is therefore difficult to determine mortality rates.

2.2 PROGNOSIS

Following a first hospital admission for heart failure, 75% of patients have five-year mortality. The life expectancy for patients with chronic heart failure is worse than for any of the common cancers except lung cancer [14]. The ESC reports that the prognosis of heart failure is uniformly poor if the underlying causes cannot be rectified. Half of patients carrying a diagnosis of heart failure will die within four years and in patients with severe heart failure 50% will die within a year [11]. There is a risk of sudden death for up to 50% of heart failure patients [14, 15].

The trajectory illustrated in Diagram 1 is typical of diseases such as heart failure and COPD. It shows a pattern of gradual decline, interspersed with episodes of acute exacerbation, which may be physical and/or psychological in nature. The acute exacerbation phases often require emergency hospital admission and the trajectory shows that health status continues to decline after each such episode. Many people with this disease pattern live with increasing disability for a long period [16]. Murray et al (2007) noted that no typical dying trajectory for people with heart failure could be identified and this work stressed that the patterns of deterioration included social, psychological and spiritual decline as well as the obvious physical deterioration [17].

DIAGRAM 1:
DISEASE TRAJECTORY MOST COMMON IN HEART AND LUNG FAILURE REFLECTING PROGRESSIVE DECLINE AND ACUTE EXACERBATIONS [60]¹⁷



There is emerging evidence that because of advances in treatment, both survival rates and quality of life for some patients has shown an improvement in recent years. This is particularly evident where patients have access to and avail of comprehensive and multidisciplinary heart failure services [19-22]. This prognosis has improved within the last five years as a result of better treatment but many patients will eventually die of progressive heart failure and need palliative care in that phase.

2.3 SYMPTOM BURDEN

Heart failure impairs self-reported quality of life more so than any other common chronic medical disease [14]. The personal burden of heart failure is great with patients experiencing high levels of physical, functional and emotional distress. The uncertain disease trajectory and the possibility of sudden death add to this burden [15, 23, 24], as well as other co-morbidities that frequently occur with this disease. Indeed Simon and Gibb suggest that the uncertainty of the disease trajectory and the possibility of sudden death may impede some physicians in recognising impending death in heart failure patients [25].

In the final phase the physical and psychological symptom burden in the dying heart failure patient has been compared to that of the dying cancer patient. The main reported symptoms are weakness/fatigue (80%), pain (78%), dyspnoea (61%), depression (59%), insomnia (45%), anorexia (43%), anxiety (43%) constipation (37%) and nausea/vomiting (32%) [13, 14, 26].

A study by Nordgren found twenty-one symptoms in patients with heart failure in later stages of the disease and remarked that despite the fact that both nurses and physicians documented several symptoms, was quite remarkable that symptom-controlling measures were only provided sparingly. The study concluded that palliative care would benefit patients suffering from end-stage heart failure [27].

Daley described the final months of a heart failure patient's life as being characterised by distressing and poorly controlled symptoms in addition to other unmet needs such as information about their disease, loss of autonomy and self esteem and social isolation [15].

¹⁷ © Diagram 1 is reproduced with the permission of RAND Health

Heart failure patients are reported as having described their illness as living in the shadow of fear, because of the unpredictability of their next attack, the fact that they may not survive such an attack and that symptom relief is often temporary. Heart failure patients are reported to be stoically struggling to cope with their incapacity. This generally has a devastating consequence on the quality of their daily lives and the nature of their social relationships [24].

2.4 KEY POINTS

- In 2002 over 80,000 people in Ireland were believed to have heart failure and rates of this disease are estimated to be rising by 10,000 new cases each year.
- The population prevalence increases from 1-2% to 10% in the very elderly.
- While mortality rates in Ireland are difficult to ascertain, the life expectancy for patients with heart failure is worse than any common cancer (except lung cancer) though there is evidence to suggest that advances in treatment are reducing mortality and improving quality of life for some patients.
- People with heart failure can experience physical and psychological symptoms that compare to those of the dying cancer patient, with the added burden of fear related to the uncertainty of the disease trajectory, lack of information about prognosis, social isolation and poorly controlled symptoms.

3. OVERVIEW OF HEART FAILURE AND PALLIATIVE CARE

- 3.1 The essence of palliative care is improved quality of life and the alleviation of suffering for people with incurable illness. Control of pain, psychological, social and spiritual problems is paramount [1]. Palliative care is defined by the World Health Organisation (WHO) as the active, total care of patients whose progressive disease is no longer responsive to curative treatment [2].

The poor prognosis and heavy symptom burden of heart failure indicate that many patients with advanced disease may have a very diminished quality of life as well as high mortality rates [11, 13-15, 25, 27]. Despite this evidence their palliative care needs remain largely unmet especially when compared to patients with malignant diseases [28]. The care of heart failure patients generally remains the sole responsibility of cardiology staff, the majority of whom have not received any formal palliative care training [23].

Evidence suggests that heart failure patients often have a poor understanding of the nature of their disease, are less involved in decision making about their care, that prognosis is rarely discussed and there is little acknowledgement that heart failure is a terminal illness [29]. Indeed this lack of discussion about end-of-life issues was found to be a source of fear and anxiety for both patients and carers [28]. The uncertainty of the disease trajectory in heart failure patients and the perceived tension between curative and palliative methods of care are also potential barriers to meeting the needs of dying heart failure patients [24, 28].

An Irish study advocates access to home care services as well as specialist inpatient unit care for people in the final stages of heart failure. The ethos and principles of palliative care should be incorporated into any forthcoming multidisciplinary heart failure programmes and that palliative care skills should be part of training for heart failure nurse specialists (HFNS) working within these care programmes. This study concludes that if the principles of palliative care were adopted and applied throughout a heart failure patient's care, patients and their carers would be better informed about their disease from diagnosis and as the illness progresses the dilemma of when to broach the subject of end-of-life care would become less problematic [24].

A further Irish study interviewed heart failure patients with advanced disease receiving coordinated and structured multidisciplinary care within a disease management framework. This study seeks to establish the specialist palliative care (SPC) needs of heart failure patients who are receiving what is currently structured best practice care for their disease. The study indicates that many of the patients' palliative care needs can be met from within such a comprehensive heart failure service where and when cardiology staff recognise and have the necessary skills to respond to those needs. Recognition by cardiologists of the point at which the focus of a patient's care should shift towards palliative care is pivotal to quality end-of-life care. SPC services will be required by a small proportion of the patients. In common with other studies it found that there is a need for greater information sharing, joint education and collaboration between cardiology and palliative care specialists to address the palliative care needs of patients with advanced heart failure [30].

3.2 IMPLANTABLE CARDIOVERTER DEFIBRILLATORS

An increasing number of heart failure patients have Implantable Cardioverter Defibrillators (ICD) inserted. The purpose of an ICD is to monitor the heart for ventricular arrhythmias and administer a defibrillation shock where appropriate. However these shocks are considered inappropriate when a patient is imminently dying as they can be both distressing and fear inducing [31-35]. There is a growing awareness of the ethical and other dilemmas that such devices introduce for patients with end-stage heart failure. While there are as yet no published guidelines on deactivation of such devices, much of the literature recommends open and sensitive communication about ICD deactivation, as well as collaboration between health professionals to ensure that the function of the ICD is optimised in the patient's best interest [31]. It has been suggested that ideally discussions about deactivation should be part of the consent process of ICD insertion [33].

3.3 KEY POINTS

- National and international evidence suggests that the palliative care needs of people with heart failure are largely unmet.
- There is evidence that the non-specialist palliative care needs of people with heart failure can be addressed from within a comprehensive multi-disciplinary heart failure service.

4. HEART FAILURE AND PALLIATIVE CARE – INTERNATIONAL POLICY AND DEVELOPMENTS

In recent years the imperative to address the unmet palliative care needs of patients with heart failure has been recognised internationally as well as in guidelines from professional groupings of cardiology and heart failure. An overview of such policies and practices helps to inform and assist the emerging debate on this issue in Ireland.

4.1 EUROPEAN SOCIETY OF CARDIOLOGY

The 2005 ESC guidelines on the treatment of heart failure, recommend that palliative treatment in patients who are dying should always be considered and may include the use of opioids for relief of symptoms [11].

These guidelines were updated in August 2008 and recommend a collaborative approach from GPs, Specialist Heart Failure Services and SPC services when the patient reaches the criteria determined to identify end-stage of heart failure. They suggest that such patients should be considered for a structured palliative care approach and note that the essential components of a successful palliative care programme are similar to those of comprehensive heart failure management programmes [36].

The website of the Heart Failure Association of the ESC contains information for patients living with heart failure, including a comprehensive section on planning for end-of-life [37].

4.2 POLICY DEVELOPMENTS IN THE UK

Providing palliative care to people with heart failure has been a feature of UK health policy since 2000. The Department of Health National Service Frameworks document on coronary heart disease, acknowledges the difficulties in predicting end-stage heart failure. This report recommends that a palliative care approach should be taken with heart failure patients and outlines that good symptom control, psychological support and open communication about disease outcomes should be offered to all patients who have heart failure. When the underlying aim of treatment is to control symptoms, a palliative approach with help from palliative care specialists can improve a patient's quality of life [38].

Arising from this work, in 2003 NICE developed and published clinical guidelines for the management of heart failure in adults in primary and secondary care, which also included a full section on end-of-life issues. These guidelines recognise the unmet palliative care needs of heart failure patients in regard to symptom control, psychological and social needs, planning for the future and end-of-life care. They recommend that the opportunity to discuss uncertainty and the possibility of sudden death should be available at all stages of care. They also recommend (inter alia) that the patient's palliative care needs should be identified, assessed and answered at the earliest opportunity and that patients with heart failure should have access to professionals with palliative care skills within the heart failure team [39]. In tandem with this NICE published a paper on the management of heart failure aimed at patients, their carers and the general public including a statement that palliative care should be part of the holistic management of heart failure [40].

As a response to the 2000 policy and arising from the NICE guidelines, the NHS strategy for developing services for heart failure was published as part of the National Services Framework [41]. Part of this strategy is to help people with unresponsive heart failure and other malignant presentations of coronary heart disease to receive appropriate palliative care support. In 2004 the NHS published a document "Supportive and Palliative Care in Advanced Heart Failure" which aims to assist clinical teams to redesign services to reflect the palliative care recommendations of the NICE guidelines [42].

4.2.1 POLICY DEVELOPMENTS IN USA

The Heart Failure Society of America has an end-of-life section in its 2006 Practice Guidelines for the Management of Heart Failure. They recommend triggers for the referral to SPC services and assert that palliative care can and should be delivered concurrently with "active" or "disease-modifying" or "curative" therapies in patients with life-limiting illness. This factor is critically important for those patients with heart failure where boundaries between palliative and disease-modifying care are not clear-cut when compared to diseases such as cancer [43].

The American College of Cardiology and the American Heart Association recommend the use of palliative care for end-stage heart failure patients with improved communication; more attention should be devoted to the provision of comfort measures in the final days of life; professionals caring for patients with advanced heart failure should have realistic expectations for survival and communicate those accurately to patients and families; professionals should provide realistic recommendations for procedures being done within the final days of life that do not add to the hope of recovery or improvement in life quality and finally, that greater attention and research needs to be devoted to the provision of comfort measures in the final days of life, including relief of pain and dyspnoea [44].

4.2.2 POLICY DEVELOPMENTS IN AUSTRALIA AND NEW ZEALAND

The Clinical Guidelines (2006) from the National Heart Foundation of Australia and the Cardiac Society of Australia and New Zealand support an individualised programme of palliative care for patients facing the strong possibility of death within 12 months and who have advanced symptoms (i.e. NYHA Class IV) and poor quality of life, resistant to optimal pharmacological and non-pharmacological therapies. Treating doctors should discuss with their patients the level of intervention appropriate and/or desirable during this phase of their illness, so that unwanted, traumatic interventions are prevented in the last few days of life. The guidelines note that both the patient and their family and carers may need significant emotional support during this process [45].

4.3 SERVICE DEVELOPMENTS – UK

Pooler describes how a shared common desire to improve care for end-stage heart failure patients allowed CNS from different disciplines to work together to provide a new service. The HFNS remained the key worker using the Macmillan CNS as a resource in the community and the patient's GP and local District Nurse were kept informed. The collaborative approach has resulted in greater availability of all levels of palliative care services for patients with end-stage heart failure, has up-skilled both sets of specialist nurses, highlighted learning needs and supported professional development. This service model was not without its difficulties as determining when a patient is at end-stage of cardiac failure and gaining a consensus from the cardiologist and GP can be difficult [46]. This service is committed to developing criteria for referrals to SPC for heart failure patients based on need rather than diagnosis working with both the hospice and cardiologists [47].

This is reiterated by Daly et al who stated that service collaboration with the HFNS between the local hospice and the community palliative care team (CNS, medical consultant, psychologist, social worker) can improve access to palliative care for heart failure patients, with learning achieved through shared information and care [15].

The West Yorkshire Cardiac Network drafted guidelines in 2007 for minimum standards of care that include a six-monthly review of all heart failure patients, including consideration of whether an assessment of supportive and palliative care needs has become appropriate [48].

A service described by Johnson and Haughton documents a joint approach by a cardiologist and SPC physician which sought to address reservations about extending access to palliative care for patients with heart failure. They conclude that different models are needed in different care settings, and shared care approach is recommended. Developing mutual understanding and respect of the different skills of each team is the first step, which can be taken without additional resources [49].

4.4 KEY POINTS

- Health policies in UK, USA, Australia and New Zealand recommend that palliative care should be included in heart failure service frameworks.
- Several countries have comprehensive heart failure guidelines which highlight the role of palliative care for these patients.
- There are some UK community based heart failure initiatives which include palliative care.
- Even with limited resources, positive changes can be achieved where efforts are made to develop collaborative relationships.

5 IRISH POLICY CONTEXT FOR HEART FAILURE AND PALLIATIVE CARE

5.1 CONTEXT

Health policy is set by the Department of Health and Children (DOHC) and implementation is the remit of the HSE. The 2001 Health Strategy Quality and Fairness, A Health System for You provides the overall context for developing services for heart failure and palliative care [50]. In recent years there has been an increasing focus in policy and strategy on the coordinated management of chronic diseases, as well as the prevention of avoidable death and illness. The prevention and management of chronic illness is now one of the priorities of the HSE Transformation Programme [51, 52]. Heart health and the management of heart failure have been part of that focus.

There are a number of key policy and strategy documents and groups which inform the development of heart failure services in Ireland, these are listed below and their individual relevance to developments in heart failure services and palliative care is subsequently examined.

Policy/Strategy Documents

- 1999 The National Cardiovascular Health Strategy, Building Healthier Hearts [53]
- 2002 Irish Heart Foundation strategy document on heart failure services From Crisis to Control: A cohesive strategy for hospital management of Heart Failure in Ireland [12]
- 2006 National Chronic Disease Management Patient Support Programme [51]
- 2007 Audit of Progress on Implementation of Building Healthier Hearts, 1999-2005, Ireland: Take Heart [54].

Policy/Strategy Groups

- 2007 Cardiovascular Health Policy Group (DOHC)
- 2007 Steering Group – National Action Plan for Heart Failure

In 2008 the DOHC published a Policy Framework for the Management of Chronic Illness. Future plans include a HSE framework for the prevention and management of chronic illness and an EAG on cardiovascular health.

5.2.1 CARDIOVASCULAR HEALTH STRATEGY BUILDING HEALTHIER HEARTS

The report of the Cardiovascular Health Strategy Group, Building Healthier Hearts, has served as the national strategic framework since 1999. Because of an increasing prevalence of heart disease it recommended a standardised approach to care of cardiac patients nationwide including:

- Clinical protocols
- Clinical audit and evaluation
- Shared care between hospital and general practice
- Structures for the identification of those at high risk in general practice
- Structures for the care of patients with chronic disease in general practice.

It also recommended that special attention be paid to the integration of patient services from primary care, through pre-hospital emergency care, to services provided in acute hospitals [53].

5.2.2 IRISH HEART FOUNDATION STRATEGY DOCUMENT “FROM CRISIS TO CONTROL – POSITION PAPER ON HOSPITAL MANAGEMENT OR HEART FAILURE IN IRELAND”

The development of hospital services for heart failure has been guided by the 2002 position paper of the Irish Heart Foundation on the management of heart failure within the hospital setting. It recognises that frequent hospital admissions for people with heart failure are a sign of increasing morbidity and recommends that a multi-disciplinary team be put in place to manage heart failure within the hospital. The team would include a physician with an interest in heart failure, a heart failure nurse, a physiotherapist, dietician and psychologist. The report also recommends that care of stable heart failure patients should be devolved to their GPs with constant liaison to ensure rapid responses for patients whose disease deteriorates [12].

5.2.3 AUDIT OF PROGRESS ON THE CARDIOVASCULAR STRATEGY “IRELAND: TAKE HEART”

The HSE undertook an audit of progress on implementation of the cardiovascular strategy in 2006 and identified priority areas for further action. It found that, in relation to heart failure, some progress has been made. It notes that 22 of the 37 AGH have heart failure services delivered on an outpatient basis, and further information on the interactions between hospital and community requires further scrutiny. Among the outstanding gaps are heart failure programmes which include acute and chronic care, across primary and hospital services. The report highlights the growing need for heart failures services because of the increasing prevalence of the disease and the threat it poses to the health of the growing elderly population [54].

5.2.4 NATIONAL CHRONIC DISEASE MANAGEMENT PATIENT SUPPORT PROJECT 2006

The aim of this project was to research and develop a national chronic disease management patient support programme for the HSE. In 2006, the Project Steering Committee published its report recommending that the HSE funds and implements patient support pilot programmes in two locations in 2007 and that these pilots should include patients with heart failure. This will provide an individually tailored programme of telephonic nurse support to patients complementary to the spectrum of clinical care which the patient is receiving. This approach is highly scalable and subject to satisfactory evaluation at the end of the three year pilot, this approach could be established more widely across the country [51].

5.2.5 CARDIOVASCULAR HEALTH POLICY GROUP

In August of 2007 the DOHC established a Cardiovascular Health Policy group to develop a policy framework for cardiovascular disease. It aims to develop a policy framework for the prevention, detection and treatment of cardiovascular disease, which will ensure an integrated and quality assured approach in their management. As well as the DOHC and HSE, the group has representation from the voluntary, statutory and non-governmental organisation services and expects to produce a report in 2008 [55].

5.2.6 DEVELOPMENT OF A NATIONAL ACTION PLAN FOR HEART FAILURE

In 2007 it was agreed that a Heart Failure Action Plan would be developed and implemented, to address the main gaps identified in the audit report Ireland: Take Heart [54]. The objective is to develop a national action plan for heart failure 2008-2011 to improve quality of life and health outcomes, from early detection to care at end-stage, for people affected by or at risk of developing heart failure. It is overseen by a Steering Group comprising experts and representatives selected from the HSE and key stakeholder organisations. A submission on palliative care needs of people with heart failure has been made by the Heart Failure Working Group of the Extending Access Study. The Action Plan is due for completion in 2008.

Each of the reports mentioned above advocates coordinated and holistic care for heart failure patients, but to date none of them specifically addresses the palliative care or end-of-life needs of such patients. Given the timescale of the work of each of the groups mentioned above, this report will provide essential consideration by their membership so the palliative care needs of cardiology patients can be addressed strategically.

5.2.7 KEY POINTS

- Current Irish policy on heart failure does not mention a requirement for palliative care.
- There are opportunities to develop this aspect of the care of people with heart failure in future strategies and services.
- Comprehensive disease management programmes for people with heart failure afford the best opportunity for the integration of palliative care.

6. MAPPING OF IRISH HEART FAILURE SERVICES

6.1 HOSPITAL BASED SERVICES

The picture of services currently in place for heart failure patients in Ireland is provided through a number of surveys and reports, listed below:

- Irish Cardiac Society: National Heart Failure Survey and the Implementation of National Guidelines for the Management of Heart Failure, 2004 [56].
- The report of the National Chronic Disease Management Patient Support Programme, 2006 [51].
- Ireland: Take Heart, Audit of the progress on the implementation of Building Healthier Hearts, 1999 – 2005 [54].

Ireland: Take Heart, describes a range of heart failure programmes, many of which include links between hospital and community care:

- Heart failure clinics, some hospital based, some more integrated including liaison with community practitioners
- Shared care with GPs and structured follow up services.
- Evaluation of BNP¹⁸ testing for diagnosis in primary care setting
- Direct access echocardiography
- Use of telephone follow-up post discharge and telephonic support [54].

While more than half of Irish hospitals now have dedicated inpatient and outpatient heart failure services, services are patchy and distributed unevenly throughout the country. In Cork and Kerry, for example, dedicated heart failure services have not yet been developed and heart failure patients are seen within general cardiology or medical services. A proportion of heart failure patients in Ireland are not seen by cardiologists.

The heart failure unit in St. Vincent's University Hospital (SVUH) in Dublin is the leading specialist service in Ireland and delivers care through a comprehensive disease management programme. Many hospitals are seeking to follow this model with a consultant-led structured care service continuing on an outpatient basis with clinics and community contact via telephone and letter. Other services are adopting more of a shared care approach with hospital based services available to local GPs on an open access basis for diagnosis, advice and monitoring; and incorporating structured care follow up after hospital discharge.

6.2 COMMUNITY BASED SERVICES

Initiatives in community heart failure services are increasing, such as a primary care-led, integrated programme in Galway and the community heart failure programme in the North East. In the latter programme heart failure care is devolved to the community after three months of hospital care.

As yet staffing structures for community heart failure services have not been developed and all heart failure nurses in the country are hospital-based. Patients requiring heart failure intervention must be fit and willing to attend outpatients' clinics. Generally there is no home component to hospital specialist services, although this is being developed through the Heart Failure Advanced Nurse Practitioner (ANP) service in SVUH detailed in 7.2 [57].

¹⁸ B-type Natriuretic Peptide

The post of Cardiovascular Nurse Facilitator supporting General Practice in the diagnosis and management of Heart Failure is planned for 2008 in Galway. This will enable the development of the primary care-led integrated service in Galway by providing support to GPs and Practice Nurses to help in their clinical management of heart failure patients in the community and develop collaborative links between primary and secondary care [58]. The service envisaged is similar to that proposed by the Irish Heart Foundation in 2002 [12, 56].

6.3 KEY POINTS

- Heart failure services in Ireland are still under development. There are large areas of the country where there is no heart failure specific service.
- There is currently no community-based Heart Failure CNS or outreach service.

7 CURRENT PALLIATIVE CARE SERVICES FOR HEART FAILURE PATIENTS IN IRELAND

There is little evidence available on the integration of non-specialist palliative care with established heart failure services in Ireland. Non-specialist palliative care is not established as part of hospital cardiology services and referrals to SPC occur infrequently and on an ad hoc basis. Similarly there has been very limited utilisation of either specialist or non-specialist palliative care for heart failure patients in the community. The lack of appropriate community CNS and other community supports have been identified as a barrier to the inclusion of both specialist and non-specialist palliative care in services for people with heart failure. Heart failure patients are mainly referred to SPC in the acute hospital setting, and these referrals are made in the absence of any formal structures.

- There is little evidence available on the integration of palliative care with established heart failure services in Ireland. Non-specialist palliative care is not established as part of hospital cardiology services and referrals to SPC occur infrequently and on an ad hoc basis.
- Similarly there has been limited evidence of delivery of either specialist or non-specialist palliative care for heart failure patients in the community.

7.1 HEART FAILURE AND PALLIATIVE CARE – A DEVELOPING IRISH SERVICE MODEL

As referred to above, the only example of a service model which could be identified as a fully comprehensive heart failure service is the SVUH Disease Management Programme for heart failure. The programme seeks to improve quality of life for patients with heart failure in the three LHO regions in the vicinity of SVUH through provision of expert multidisciplinary advice, education and support, from diagnosis of disease to death.

This programme seeks to ensure patients are on maximum tolerated evidence-based medical therapy and device therapy according to individual patient needs. It also seeks to empower patients to embrace self-care principles of heart failure management with strong support services for patients and family to respond to deterioration of physical and emotional well being. An important role of the team is to communicate with other health care providers, incorporating primary and secondary care, relating to the changing needs of the patients as disease progresses or improves.

The SVUH heart failure unit plans to develop the palliative care aspect of its service and to utilise the Heart Failure ANP position to liaise with SPC for heart failure patients who are transferred to specialist inpatient unit care, home or AGH. The aim is to combine expertise from both SPC and heart failure care to improve the patients' quality of life in end-stage illness. This service currently has two cardiologists, one ANP, one CNS, psychotherapist, physiotherapist, dietician and administrative staff. Currently one member of the team has palliative care training [57].

7.2

KEY POINTS

- The palliative care component of the SVUH would benefit from evaluation
- Research is needed on shared care models in this area

8

KEY FINDINGS AND CONSIDERATIONS FOR THE PROVISION OF PALLIATIVE CARE FOR PEOPLE WITH HEART FAILURE IN IRELAND

It is acknowledged that although the mortality rate for people with heart failure has decreased, prevalence will increase by 10,000 cases each year. As people will be living longer with the disease, the need for a comprehensive heart failure service including palliative care will be greater than ever before. As the subtlety and rapidity of decline in heart failure patients requires palliative care to be an intrinsic part of service provision, the needs of the patients must be the focus of the treatment.

8.1

SERVICE MODEL AND STRUCTURE

Heart failure services are not uniformly available in all regions and not all patients with heart failure have access to a comprehensive community or hospital-based cardiology service. As appropriate palliative care provision needs to be included in the framework of services for people with heart failure, the potential tensions between the curative and palliative approach to treatment needs to be considered in the overall structure of the service.

Access to SPC for people with end-stage heart failure is not evenly spread throughout the country and there is variation in the role and approach of SPC in specialist inpatient units, AGH and community SPC teams on whether they accept referrals for heart failure patients [30, 59]. Clinicians have reported that access to SPC services are more widely available to patients in an AGH, to a large degree confined to care in the very last days of life.

Currently there is no formal structure for a “shared care” or collaborative approach between SPC and cardiology services where care in a specialist inpatient units is required. Patients who have a long-established relationship with a hospital heart failure team may be uncomfortable or fearful of a change in accessing SPC in an inpatient unit when they are at the final phase of their disease.

EXAMPLE OF A COLLABORATIVE PRACTICE FOR PALLIATIVE CARE IN HEART FAILURE.



St. Vincent's University Hospital heart failure unit has worked in collaboration with community based SPC. A patient was commuting from the south east to Dublin on a daily or alternate daily basis to receive intravenous diuretics for symptomatic relief from pulmonary oedema secondary to end-stage heart failure. The commute was exhausting for both the patient and family members. The patient's GP was asked to assist with his heart failure management and it was agreed with the GP, the patient, the patient's family and the heart failure team that the patient would be have a better quality of life if his treatment was managed locally and he could remain at home. The heart failure team provided a supportive consultation service for the GP about the use of intravenous diuretics. The patient benefited from experienced palliative care services through the local SPC home care team, as well as familiarity and trust with the GP. The heart failure team remained in contact with the family and GP until the patient's death at home which was reported as peaceful and pain-free.

The patient's family and the healthcare professionals all reported a positive experience from this collaborative approach [57].

The case of a patient with heart failure transferred from the care of a cardiology service within an AGH to a specialist inpatient unit without an integrated care approach demonstrated the need for collaborative care guidelines to be evolved. The patient was anxious that cardiology staff would continue to be involved in her care while she was in the SPC inpatient unit, but there was no established protocol for them to have this input in this care setting.

Some progress could be made on piloting and evaluating actions relating to “shared care” as a working model to facilitate palliative care for people with heart failure who are in the acute hospital system as inpatients or outpatients.

The development of comprehensive multi-disciplinary heart failure services throughout the country, including community responses, could create a framework in which the palliative care needs of people with heart failure can begin to be addressed. This will require concerted action between cardiology and SPC teams. Disease management programmes as advocated by HSE would appear to afford the best opportunity for the inclusion of palliative care in heart failure care.

There are no guidelines available for GPs, physicians and CNS in Ireland to facilitate referral and access to SPC for patients with heart failure. Development of referral triggers and eligibility guidelines for SPC would provide clarity in this area.

In addition there is a particular need to prepare for the potential challenges which could arise at end-of-life for heart failure patients with ICDs, specifically how to broach the subject with the patient as to when would be an appropriate stage for deactivation of the device.

8.2 EDUCATION

The successful inclusion of palliative care in heart failure services requires education at both informal and formal/academic route for both cardiology and SPC professionals. Educational needs identified include symptom management, end-of-life interventions, communication skills and developing good working relationships locally between the relevant specialities. Such initiatives need to impact on all relevant staff in hospital and community services.

Informal educational responses could include joint training initiatives between Irish Heart Foundation and SPC representative bodies, with input from the Irish College of General Practitioners, the HSE and Irish Hospice Foundation. As a first step a study day to debate the issues in raised this report could be arranged to approach consensus about how future service developments in heart failure and palliative care can address unmet needs. To encourage and cultivate greater understanding and awareness of professional roles, both cardiology and SPC professionals should foster and develop relationships using a variety of methods such as meetings, annual study days and journals clubs.

8.3 POLICY

Current Irish policy on cardiovascular health in general and heart failure in particular does not mention or address palliative care. However, recent policy focus on heart failure affords the possibility of development of comprehensive heart failure services.

To ensure that palliative care is included in the overall policy and services framework for people with heart failure in Ireland, the Cardiology Policy Group in the DOHC, the Heart Failure Action Plan, programmes from the HSE Transformation for Change, voluntary organisations and all other relevant stakeholders developing heart failure services should be informed of the findings of this study.

8.4 RESEARCH

There has been some research in Ireland on determining the palliative care needs of people with heart failure who are receiving a comprehensive heart failure service [30]. Comprehensive heart failure services are not available to or availed of by all heart failure patients. Further research could be useful to determine the number of heart failure patients who require SPC and how these patients can be identified within a disease management framework.

The service models which include a non-specialist palliative care element within a heart failure service in Ireland require appraisal. An audit and evaluation of those SPC service within AGH which provide services to people with heart failure could also provide information and direction as to how needs are met and where further development is required.

9 CLARIFYING THE ROLE OF PALLIATIVE CARE FOR PEOPLE WITH HEART FAILURE

There were a number of challenges which presented in the course of this study. They include:

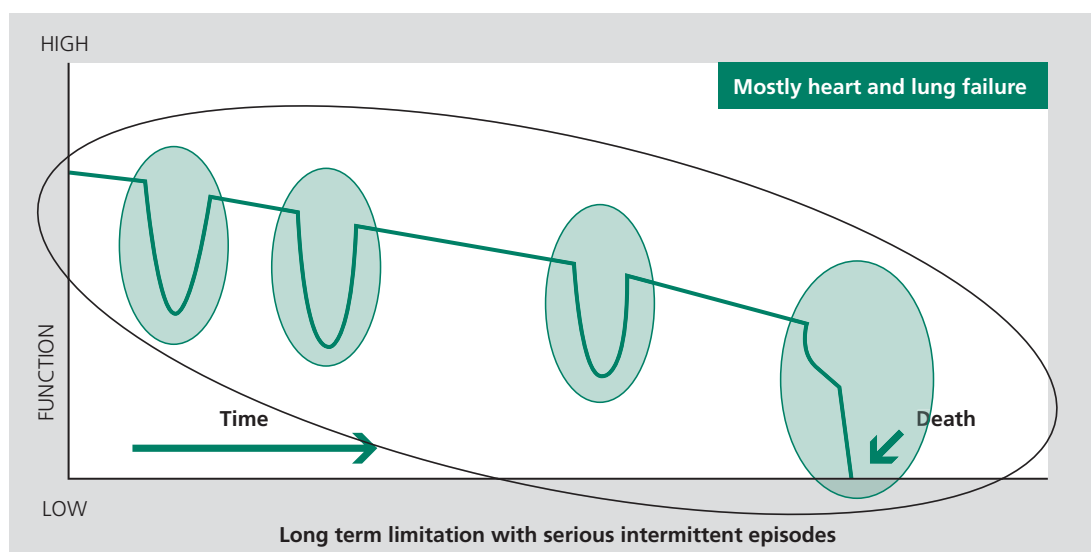
- The unpredictable disease trajectory and prognostication which makes the identification of end-stage heart failure difficult.
- Uncertainty about when discussions on sensitive end-of-life issues could be introduced is compounded by time pressures intrinsic in the high patient population in cardiology, reticence about introducing such issues because of concerns about communications skills and the balance to be struck between active interventionist and palliative therapies.
- Uncertainty about the role of SPC for people with heart failure.

9.1 TIMING OF PALLIATIVE CARE FOR PEOPLE WITH HEART FAILURE

The adaptation of the diagram used on page 125 demonstrates how an understanding of the disease trajectory for people with heart failure can be helpful to illustrate the timing and necessary relationship between heart failure services in delivering non-specialist and specialist palliative care where required.

DIAGRAM 5:

TIMING OF PALLIATIVE CARE IN DISEASE TRAJECTORY MOST COMMON IN HEART AND LUNG FAILURE [ADAPTED FROM 60]¹⁹



Large oval indicates timing for non-specialist palliative care



Green ovals indicate potential timing for SPC

¹⁹ © Diagram 5 is an adaptation of a diagram reproduced with the permission of RAND Health

In Diagram 5 above the large oval suggests that non-specialist palliative care should be included early in the disease trajectory. The role of non-specialist palliative care for people with heart failure includes symptom control, psychological and social needs, planning for the future and opportunity to discuss uncertainty and prognosis. These issues should be addressed by cardiology team who may require training, awareness and support in this area.

Staff addressing needs with patients may from time to time need to seek advice or a consultation from the SPC team if they are not in a position to respond to the palliative care needs that have been identified. The smaller ovals indicate where particular consideration of the need to refer to and discharge from SPC may occur. It must be stressed that the dips represented in the disease trajectory in Diagram 5 reflect extraordinary needs that may include emotional, psychological, spiritual and/or physical needs (such as, but not exclusively, acute exacerbation of heart failure and/or complex co-morbidity). Wherever extraordinary need arises in the disease trajectory which cannot be addressed by the cardiology team, referral to SPC should be considered.

9.2 TRIGGERS FOR REFERRAL TO SPECIALIST PALLIATIVE CARE

When patients who have had their diagnosis of heart failure confirmed by a cardiologist or a physician with a special interest in cardiology, reach a particular point in their journey, the following clinical indicators or triggers may flag the need for a possible referral to SPC:

- Persistence at NYHA Stage III or IV despite optimal treatment
- Where all other options have been explored
- Where the patient is not suitable for surgery.

Cardiology teams need to remain involved in the ongoing cardiac care of patients referred to SPC.

9.3 ELIGIBILITY CRITERIA FOR SPECIALIST PALLIATIVE CARE

The use of standardised eligibility criteria for access to SPC services can assist in providing clarity and equity of access for those patients with SPC needs and strengthens identity of SPC services. Further work is required to determine the most suitable criteria to be used in Ireland.

10. RECOMMENDATIONS

These recommendations should be considered with regard to the overarching recommendations and the plan for their implementation which are detailed in the main body of this report.

H.1 Service Model

A project group is to be established to devise, plan and oversee a proposed Model of Care for patients with NYHA classification of Stage III or IV Heart Failure within a designated health location encompassing an AGH and Primary Health and Social Care Networks and SPC inpatient unit. The model will provide a clear pathway of access to all levels of palliative care for a patient with advanced Heart Failure whose disease is deteriorating. A part time clinical facilitator is required to implement this Model of Care. The model should demonstrate the role, degree of specialism and interface between the different professionals involved; will be supported by informal and formal education initiatives and will have an evaluation component. This model will be linked with the integrated care pathways developing in the HSE Transformation for Change programme and existing and developing cardiology initiatives within AGH, Primary care and SPC. Health Service Executive with support from Irish Hospice Foundation, Irish Cardiac Society and Irish Heart Foundation

H.2 Education

A specific submission on education requirements arising from needs identified in this study has been sent to the Palliative Care Education Taskforce. This is detailed in Appendix 4 of this report and should be taken into account when considering these recommendations.

- a) Joint training initiatives are required for clinical staff working within heart failure services and SPC services to encourage greater understanding of each others roles and enhance opportunities for collaborative models of care. Irish Cardiac Society / Irish Heart Foundation / Palliative Care Education Taskforce / Health Service Executive / Specialist Palliative Care and relevant education departments
- b) Post graduate education for staff working in cardiology should have a defined palliative care component. Health Service Executive / Palliative Care Education Taskforce / Medical Education Training and Research Unit and relevant educational institutions

H.3 Research

Audit and evaluate a SPC service within an AGH which provides services to people with heart failure. This will provide a picture of how SPC in AGH are currently responding to heart failure referrals, and will provide direction as to where further guidelines and service frameworks should be developed (see also H.1). Health Service Executive / Irish Heart Foundation with support from Irish Hospice Foundation

H.4 Policy

- a) Palliative care for people with heart failure must be referenced in all current and future policy related to cardiology.
Department of Health and Children / Health Service Executive
- b) Comprehensive heart failure services should be available throughout the country and must have a community component and include access to appropriate levels of palliative care.
Health Service Executive / Specialist Palliative Care

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