

PALLIATIVE CARE FOR ALL

Integrating Palliative Care into
Disease Management Frameworks



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive



THE IRISH
HOSPICE
FOUNDATION

Palliative Care for All

Integrating Palliative Care into Disease Management Frameworks

Joint HSE and IHF Report of the Extending Access Study

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Foreword

Statement from Health Service Executive

The HSE provides thousands of different services in hospitals and communities across the country. At some stage every year, everybody in Ireland will use one or more of the services provided. They are of vital importance to the entire population.

The HSE has a statutory responsibility for planning and commissioning specialist and non-specialist palliative care services on a national basis in conjunction with the voluntary sector in Ireland. The provision of services encompasses a broad range of interventions in multiple locations ranging from acute general hospitals (AGH) and specialist palliative care (SPC) inpatient units to home and community based supports and bereavement supports. Services are accessed in a number of ways across the delivery system.

Current SPC services include:

- SPC Inpatient Units
- Home Care
- Day Services
- SPC in AGH
- Community and other intermediate levels of palliative care in Community Hospitals
- Bereavement Support
- Education and Research.

The ambition of the HSE is that everyone will have easy access to high quality health and social services. This ambition is comparable to the goal of palliative care which is to achieve best quality of life for patients and families. This similarity, along with the acceptance of the need for increased palliative care services and interventions into the future as the demographics suggest an ageing population with increased chronic illnesses, led to this study being undertaken in 2007.

The HSE recognises the potential of palliative care to alleviate pain and distress and the need to work with all to make care available for all who need it. This report underpins that vision, with the key central messages that palliative care should be available as a component part of chronic disease management frameworks and that all SPC services accept referrals based on needs rather than diagnosis.

The report has provided the rationale and signposts for palliative care to be delivered in all settings and at all levels. In seeking to deliver on the recommendations, we must reach out to a wide number of stakeholders both within the specialist palliative care profession and those who work in disease-specific frameworks and older persons' services, those working in policy formation, research and education. This report, in keeping with the 2001 report from the National Advisory Committee on Palliative Care, points the way forward.

James Conway

Assistant National Director for Palliative Care and Chronic Illness, HSE

November 2008

Statement from Irish Hospice Foundation

The Irish Hospice Foundation (IHF) is a not-for-profit organisation that promotes the hospice philosophy and supports the development of hospice and palliative care. IHF's vision is that no one should have to face death or bereavement without appropriate care and support. The IHF seeks to advocate and influence the necessary improvements in the palliative care services in Ireland based on the recommendations of the report of the National Advisory Committee on Palliative Care (NACPC), published and endorsed by the Department of Health and Children.

For some time the IHF has been aware of and concerned about inequity in provision of palliative care for people with diseases other than cancer, and in May 2006 commenced funding a night nursing service specifically for such patients. In 2007 the IHF committed to undertake a development project in this area.

The policy as outlined in the NACPC report is generally supported by all those involved in hospice/palliative care. This policy requires that SPC services be provided on the basis of need and not diagnosis. Some service providers are clearly in breach of this policy. As the taxpayer increasingly funds core services, future service level agreements should require a consistent approach to admission criteria to palliative care services.

As the majority of people who die from diseases other than cancer do not require SPC, the disease-specific services must also incorporate palliative care within the pathway for their patients who have a life-limiting illness. The optimal method for this to be achieved is through shared care.

This report has highlighted the opportunity for collaboration between palliative care professionals and other specialities in the provision of education and guidance relating to the need of patients with advanced incurable illnesses.

The implementation of the recommendations of this report will support the necessary developments in these areas.

Eugene Murray

Chief Executive Officer

Irish Hospice Foundation

November 2008

Methodology

The 2001 report of the NACPC recommends that “when assessing the need for specialist palliative care services, each health board should consider the needs of patients with malignant and non-malignant disease” [1] p.43.

Since the NACPC report there has been significant progress made in the funding and development of palliative care services, with advances in specialist inpatient units, community SPC teams and increases in staffing levels in AGH. 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 [2-7].

Disease Selection

Following discussions the HSE and IHF committed to undertake the Extending Access Study to examine the palliative care needs of adults¹ with diseases other than cancer. The three diseases selected for initial focus of the study were chronic obstructive pulmonary disease (COPD), dementia and heart failure.

The rationale for this selection was based on the following factors:

- Mortality rates for these diseases rank among the highest in Ireland.
- The palliative care needs of people who have these pathologies and do not have a malignant diagnosis are not being responded to in a consistent manner in Ireland.
- Research has indicated that people who have these diseases can experience equal and sometimes greater palliative care needs than people with malignant conditions.
- The HSE Transformation Programme has established disease-specific advisory groups to examine the pathways and clinical interventions for people with these diseases and the findings from this study will inform these advisory groups.
- The National Council for Palliative Care in the UK have established specific policy groups that encompass these diseases which have successfully influenced the development of palliative care in these specific disease frameworks.

The Project Team and the Steering Committee of the Extending Access Study are acutely aware of the need to examine the role of palliative care for those with other non-malignant diseases, including people with chronic kidney disease, cystic fibrosis, pulmonary fibrosis, scleroderma, multiple sclerosis, motor neurone disease (MND) and those with cardio vascular accident. It is hoped that the findings and implementation plan associated with this report will provide the necessary momentum to address the palliative care needs of these patient groups following the publication of this report. It is recognised that people with these diseases will also experience a range of other co-morbidities that may at times become the primary determinant of their health needs, and this should always be taken into account when considering their palliative care needs.

¹ The palliative care model for children with life-limiting illness will be guided by the DoHC Committee on Paediatric Palliative Care and is not addressed in this report.

Process of Study

The Extending Access Study and subsequent compilation of the Palliative Care for All report, was overseen by a Steering Committee chaired by James Conway, Assistant National Director of Palliative Care and Chronic Illness, HSE. Three Working Groups were established to examine the particular palliative care needs of people with COPD, dementia and heart failure, respectively. The Steering Committee and Working Groups had representation from specialists within the field of palliative care and strong clinical and professional representation crossing the specialist areas selected. Each of the Working Groups met five times and informed and advised the Project Team on the content of the disease-specific appendices. The Project Team undertook a wide-ranging review of literature. Views were also sought from service users and/or family members of people with COPD, dementia and heart failure. The representatives from SPC on the Steering Committee and Working Groups met twice during the course of the study to consider and seek consensus on issues arising that were specifically pertinent to SPC.

Consultation Process

The draft report of the Extending Access Study was made available for open consultation from mid-June to early August 2008. Submissions were specifically invited from groups and individuals who have a role in addressing the challenges identified in this report. Sixty submissions were received from groups and individuals. These are listed in Appendix 5.

The main themes arising from the consultation phase related to the role of non-specialist palliative care; use of the eligibility and discharge criteria for access to SPC; the need for accurate data regarding access levels of SPC for people with non-malignant conditions; the need for the report to reference the role of bereavement, family and carers; that implementation of the recommendations requires strong leadership and aspects of the recommendations are resource dependent. The need for specific examination of the role of palliative care for people with other non-malignant conditions was also highlighted. The final report has been amended to take account of these issues.

Terms of Reference for Steering Committee

The study was guided by a Steering Committee, the composition of which sought to ensure comprehensive representation from SPC and from clinicians and representative groups associated with the relevant life-limiting diseases within the scope of the study.

This group worked within the following terms of reference:

- Review and consider current palliative care provision of patients with life-limiting diseases other than cancer in Ireland, with an initial focus on heart failure, dementia and COPD, as generated by the project team and Working Groups.
- Examine and evaluate the work of the disease-specific Working Groups with a view to outlining potential strategies that will determine how the palliative care model can be extended to people with heart failure, dementia and COPD.
- Identify and prioritise project ideas/collaborations for future service innovation in the field of practice.
- Oversee communication strategy of study.
- Oversee and inform the compilation of final report in 2008.

Steering Committee Members

James Conway, Chairperson
Assistant National Director Palliative Care & Chronic Illness, HSE

Mary Corcoran²
Clinical Nurse Specialist Palliative Care

Dr. Sinead Donnelly³
Irish Palliative Medicine Consultants Association

T J Dunford
Regional Development Manager in Palliative Care, HSE

Dr. Emer Loughrey
Irish College of General Practitioners

Anna Marie Lynch, Clinical Nurse Specialist Palliative Care
Chair COPD Working Group

Professor Ken McDonald
Irish Heart Foundation

Maura McDonnell
Specialist Palliative Care Directors of Nursing National Group

Dr. Regina McQuillan
Irish Palliative Medicine Consultants Association

Dr. Eithne Mulloy, Consultant in Respiratory Medicine

Maurice O'Connell, Alzheimer Society of Ireland
Chair Dementia Working Group

Kevin O'Dwyer
Hospice CEO Group

Professor Des O'Neill, Consultant Geriatrician

Dr. Norma O'Leary⁴, SPC Research Fellow
Chair Heart Failure Working Group

Pat Quinlan
Irish Association of Palliative Care

Jim Rhatigan⁵
Hospice and Palliative Care Social Work Group

Awaiting Re-nomination⁶
National Council for Specialist Palliative Care

Project Team

Angela Edghill, Research/Project Assistant,
Irish Hospice Foundation

Marie Lynch, Programme Development Manager,
Irish Hospice Foundation

² Mary Corcoran resigned from the Steering Committee in May 2008

³ Dr. Sinead Donnelly resigned from the Steering Committee in September 2008

⁴ Dr. Norma O'Leary left the group in November 2007 on her appointment as Consultant in the UK

⁵ Aine Canney replaced Jim Rhatigan March 2008

⁶ Dr. Maeve O'Reilly resigned from the Steering Committee in May 2008

Acknowledgments

The Steering Committee and Project Team would like to acknowledge the help and assistance received from all those who have contributed in the compilation of this report, in particular:

- Chairperson and Members of COPD Working Group (listed in Appendix 1)
- Chairperson and Members of Dementia Working Group (listed in Appendix 2)
- Chairpersons and Members of Heart Failure Working Group (listed in Appendix 3)
- Dr. Mary Scully, Specialist in Public Health Medicine, Population Health, HSE
- Dr. Ciaran Smyth, Researcher
- Irish Thoracic Society
- Irish Heart Foundation
- ANAIL – Respiratory Nurses Association of Ireland
- Irish Practice Nurses Association
- Irish Association of Pulmonary Rehabilitation
- Irish Psychiatry of Old Age Nursing Network
- Alzheimer Society of Ireland
- Irish Heart Failure Nurses Association
- Service users and Family members.



Glossary

AGH	Acute General Hospital(s)
AHP	Allied Health Professionals
ANP	Advanced Nurse Practitioner
ASI	Alzheimer Society of Ireland
ATS	American Thoracic Society
CNS	Clinical Nurse Specialist
COPD	Chronic Obstructive Pulmonary Disease
CPE	Continuing Professional Education
DOHC	Department of Health and Children
DSIDC	Dementia Services Information and Development Centre
EAG	Expert Advisory Group(s)
ERS	European Respiratory Society
ESC	European Society of Cardiology
FEV1	Forced Expiratory Volume in 1 second measured in spirometry
HCA	Healthcare Assistant
HFH	Hospice Friendly Hospitals Programme
HFNS	Heart Failure Nurse Specialist
HFSA	Heart Failure Society of America
HIQA	Health Information and Quality Authority
HRB	Health Research Board
HSE	Health Service Executive
IAPR	Irish Association of Pulmonary Rehabilitation
ICD	Internal Cardioverter Defibrillator
IHF	Irish Hospice Foundation
ITS	Irish Thoracic Society
LCP	Liverpool Care Pathway
MDT	Multidisciplinary Team(s)
METR	Medical Education, Training and Research
MND	Motor Neurone Disease
NACPC	National Advisory Committee on Palliative Care
NICE	National Institute for Clinical Excellence (UK)
NYHA	New York Heart Association
PCET	Palliative Care Education Taskforce
SLA	Service Level Agreements
SPC	Specialist Palliative Care
WHO	World Health Organisation

Definitions

The language and terminology used to refer to the care of people who have progressive, life-limiting disease is varied and can often be open to confusion and misinterpretation. For the purposes of consistency definitions and explanations are provided below for the terminology principally used throughout the report.

Palliative care

Palliative care is described by the World Health Organisation (WHO) as an approach that improves the quality of life of patients and their families facing the problem 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.

Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications [8].

Level one – palliative care approach

Palliative care principles should be practiced by all health care professionals. The palliative care approach should be a core skill of every clinician at hospital and community level. Many patients with progressive and advanced disease will have their care needs met comprehensively and satisfactorily without referral to specialist palliative care units or personnel. The palliative care approach aims to promote both physical and psychosocial well-being. It is a vital and integral part of all clinical practice, whatever the illness or its stage, informed by a knowledge and practice of palliative care principles [1].

Level two – general palliative care

At an intermediate level, a proportion of patients and families will benefit from the expertise of health care professionals who, although not engaged full time in palliative care, have had some additional training and experience in palliative care, perhaps to diploma level. Such intermediate level expertise may be available in hospital or community settings [1].

Level three – specialist palliative care

Specialist palliative care (SPC) services are 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. SPC services, because of the nature of the needs they are designed to meet, are analogous to secondary or tertiary health care services. SPC services are those services with palliative care as their core speciality and which are provided by an inter-disciplinary team, under the direction of a consultant physician in palliative medicine. SPC services are available within primary care settings, acute general hospital settings and specialist inpatient units [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). The term "non-specialist palliative care" refers to both Level 1 palliative care approach and Level 2 general palliative care as defined in the NACPC report of 2001.

Community specialist palliative care/Home care teams

Provide specialist support and advice to patients, families and community-based health care professionals when appropriate [1].

Specialist inpatient units

The specialist inpatient unit is the core essential element of the specialist palliative care service. It provides a wide range of specialist services to patients and families, addressing their medical, nursing, psychosocial and spiritual needs [1]. It is also referred to as a hospice.

End-of-life care

There is no exact definition of "end-of-life". However, the evidence indicates that end-of-life care is relevant where there is:

- the presence of a chronic disease(s) or symptoms or functional impairments that persist but may also fluctuate
- the symptoms or impairments resulting from the underlying irreversible disease require formal (paid, professional) or informal (unpaid) care and can lead to death.

Older age and frailty may be surrogates for life-threatening illness and co-morbidity; however, there is insufficient evidence for understanding these variables as components of end-of-life [9].

Life-limiting disease

Any illness where there is no reasonable hope of cure and from which the person will die. (Adapted from [10]).

Chronic disease

Chronic diseases are long-term diseases, lasting more than six months, are non-communicable, involve some functional impairment or disability and are usually incurable [11].

Chronic disease management

Chronic disease management is a system of co-ordinated health care interventions and communications for populations with long-term conditions. Such programmes are patient-centred and holistic, dealing with health and social needs, not just the physical consequences of illness and are predicated on enabling patients self-management and involvement in decision-making and planning, where appropriate [12].

Chronic obstructive pulmonary disease

Chronic obstructive pulmonary disease (COPD) is a progressive disease which causes damage to airways in the lungs making it continually difficult to breathe. It is associated with acute exacerbations [13-15].

Dementia

Dementia is a disease characterised by gradual and progressive impairment in memory, intellect, judgement, language, insight and deterioration in social skills. The individual diagnosed with dementia may also demonstrate an acute sensitivity to his or her social environment and a high level of stress. Alzheimer's Disease is the most common cause of dementia [16].

Heart failure

The term heart failure is used to describe a heart which is not working adequately, the main consequences being accumulation of fluid in the lungs (lung congestion) causing breathlessness, fatigue and leg swelling. Heart failure occurs when the heart is unable to maintain sufficient cardiac output and oxygen delivery to meet the body's needs [17].

Primary care

An approach to care that includes a range of services designed to keep people well, from promotion of health and screening for disease to assessment, diagnosis, treatment and rehabilitation as well as personal social services. The services provide first-level contact that is fully accessible by self-referral and have a strong emphasis on working with communities and individuals to improve their health and social well-being, which would include specialist community services [18].

Secondary care

Specialist care that is typically provided in a hospital setting [18].

Tertiary care

National and regional specialist services for complex specialist care, normally confined to a small number of locations [18].

Allied health professionals

Allied health professionals work with all age groups and within all specialties. Their particular skills and expertise can be the most significant factor in helping people to: recover movement or mobility, overcome visual problems, improve nutritional status, develop communication skills, and restore confidence in everyday living skills [19].

Executive Summary

Introduction

Irish health care policy has recognised that many people with life-limiting diseases should have their palliative care needs met without a referral to SPC. These services have traditionally been directed towards people with malignant diseases, and a small number still restrict their services almost exclusively to people with cancer.

Services for people with life-limiting diseases, including COPD, dementia and heart failure are under-developed and fragmented in Ireland. There is no mention of the need for palliative care for people with life-limiting chronic diseases in the few disease-specific reports and documents available. The decision to select these three diseases for the purposes of the Extending Access Study was informed by the following: they are among the highest mortality rates in Ireland; research has indicated that people with these diseases have palliative care needs that are at least equal to those who have a cancer diagnosis and disease advisory and strategy groups in these areas established by the HSE Transformation Programme will be informed by the findings of this study. It is recognised that people who have a diagnosis of these diseases will typically have a range of other co-morbidities that need to be considered in their care pathway.

Context

The introduction of a chronic disease management programme by the HSE as a response to the changing patterns of diseases and an increasing ageing population is an opportunity to address the palliative care needs of all people with life-limiting illness throughout the patient journey. This approach is endorsed by WHO.

Disease trajectories are often uncertain for those with life-limiting diseases. In addition it is difficult to establish whether an exacerbation of the patient's disease may prove fatal. Professionals who care for such patients may be reluctant to broach the issues related to palliative care. This is despite the fact that the accumulated suffering experienced by people with diseases other than cancer is equal to and sometimes greater than that of people with cancer. Creating an understanding of the disease trajectories of life-limiting chronic illness can provide direction for the delivery of non-specialist and specialist palliative care within the disease-specific management framework.

Integrating Palliative Care in Disease-Specific Service Delivery

End-of-life strategies have featured as part of health policy in the UK, USA and Canada. Such strategies have underpinned and motivated palliative care programmes, end-of-life care services and education initiatives emanating from disease-specific frameworks. Several of these countries have developed a number of disease-specific guidance documents which make explicit reference to and provide direction for the introduction and role of palliative care. They stress the need for palliative care to be part of the overall management of the patient's disease.

International palliative care service-model developments for people with COPD, dementia and heart failure have all focussed on a collaborative approach between primary, secondary and tertiary services, although there is a limited amount of evidence-based data on these programmes. There is a strong focus in the UK on integrated care pathways (i.e. Liverpool Care Pathway), and programmes such as the Gold Standards Framework for the dying patient seek to ensure that such patients receive seamless, well co-ordinated and optimum care in the last few days and months of their life. These care pathways and programmes have been successfully implemented by disease-specific specialists with support from SPC professionals as required.

In comparison, although Irish health policy has outlined its commitment to the development of national palliative care services and developing services on a system of person-centred integrated care crossing organisational boundaries, there is very little evidence of palliative care being delivered within disease-specific services. There are no formal disease-specific guidelines to underpin service delivery at any point in the disease trajectory. However a small number of hospitals in Ireland have introduced care pathways for the dying patient in their last few days of life.

Access to Specialist Palliative Care for People with Non-Malignant Diseases

Since 2001, palliative care reports and policy have predicted that the inclusion of people with non-malignant diseases within the SPC services would increase the demand for the service by 80%. These reports state that the desired level of activity within SPC for these patients would be 25%. Irish data available in 2006 indicates that the level of service delivery in this area is between 5% and 10%. Eleven percent of Irish SPC services reported they restrict their services to people with cancer, MND and HIV/AIDS, and 19% stated that they limit in some way the services they provide for people with conditions other than cancer. Some of the reasons given for limiting access include lack of eligibility criteria, need for more education and resources and the fear that services would be overwhelmed if SPC services were fully opened to patients with non-malignant diseases. It is hoped that as governance, standards development and monitoring of services are increased there will be greater standardisation in terms of equity of access to services in this area. Experience from the UK suggests that it can be beneficial to phase the introduction of a wider availability of SPC services, building up the services once experience is gained. This would assist in addressing the supplementary training and education needs identified by SPC to deal with this population. Additional training is also required by the disease-specific specialties to identify and respond to non-specialist palliative care needs of their patients.

Estimating Non-Malignant Population

Initial projections of the numbers of people with diseases other than cancer who would require access to SPC indicated that the demand for SPC would increase by at least 50%. However recent information gathered from studies in the UK indicates that the demand for SPC service for people with life-limiting, non-malignant diseases varies between 13.6% for support in hospitals and 7.2% for specialist inpatient units. In Ireland a survey in 2004 found that the figures for access to SPC in AGH for non-malignant diseases were 9.2%, 6% for community SPC services and 2.7% for specialist inpatient units. Two Irish SPC services that use a referral system based on need rather than on diagnosis show no evidence of being overwhelmed. Strategies for managing SPC services seeking to provide full access to patients with conditions other than cancer have been beneficial and have included eligibility and discharge criteria, education and training and phasing in changes.

Introduction of Eligibility and Discharge Criteria

Using standardised eligibility and discharge criteria for both malignant and non-malignant disease will assist in more equitable access to SPC in Ireland. This along with the establishment of referral criteria will also help to provide clarity and awareness of the role of SPC for people with diseases other than cancer. Further work is required to determine and introduce mechanisms for standardising access to SPC services in this country.

Although the progressive nature of a life-limiting disease may necessitate increasing SPC input, there are also times when patient's needs may decrease or stabilise to such an extent that they no longer require SPC. The introduction of a discharge policy can assist in the management of referrals to SPC services. Such policies can also create greater clarity for the patient, referring team and SPC staff as to when SPC is no longer required.

It is recommended that a discharge policy could include the following criteria:

- The patient no longer has SPC needs due to symptomatic improvement
- The patient requests discharge from SPC
- The patient prevents effective SPC input.

Discharging patients from SPC services can raise ethical dilemmas for professionals, particularly where the primary, secondary or tertiary care supports are not in place to support the total needs of the patient.

Implementing Change

All patients who have a diagnosis of life-limiting disease should have equal access to all levels of palliative care, with appropriate management of their physical, psychological, social or spiritual symptoms. Cancer deaths account for one-third of the overall deaths in Ireland each year and the majority of palliative care services have developed for people who have this disease. There is little evidence of non-specialist palliative care existing as part of a disease-specific management programme.

Understandably there is a sense of apprehension and sometimes fear amongst staff, patients and families when considering palliative care for people with diseases other than cancer. This unease should not be used as a reason to inhibit service development. The motivation to provide high quality care for people dying with cancer needs now to extend to all people who are diagnosed with a life-limiting disease, regardless of their diagnosis. Much of this high quality care should be provided within existing and developing disease management programmes, with SPC responding where needs become complex and extraordinary.

The key messages in this report include the need for palliative care to be embedded within the disease management frameworks, and that SPC must seek to ensure that they accept referrals based on need rather than diagnosis.

This report has identified a number of barriers and challenges that are inhibiting the development of palliative care for people with diseases other than cancer, and these are addressed in the recommendations from service model, policy, education and research perspectives.

The report recommendations require action from a large number of stakeholders, including government departments, educational institutions, frontline staff and clinical personnel. The implementation of these recommendations is dependent on building positive relationships between a wide range of organisations, professionals, patients and carers. This will only come about where people can see that through collaboration high quality care can be provided for all people who have life-limiting disease whatever their diagnosis.

Chapter One

Introduction

“As everyone on this earth must die, for many this means suffering, including physical, existential and spiritual pain. With chronic diseases, millions have slow painful deaths. A public health approach offers the best opportunity to use our knowledge and skills in cost-effective interventions that can reach everyone.” [20] p.43. Jan Stjenrward, 2007, Chief Cancer WHO Emeritus

1 INTRODUCTION

For over a decade it has been acknowledged that people with diseases other than cancer should have their palliative care needs met [21], and this principle has been adopted in Irish policy documents since 2001 [1].

There has been considerable progress in SPC since the publication of the NACPC report which provided the framework for the development of palliative care services for people with advanced and life threatening diseases in Ireland. Although SPC services are now well established by international standards [7], traditionally these services have been directed towards people with malignant diseases [2]. A small number of SPC services in Ireland still direct their services almost exclusively to people with cancer, MND and AIDS and a number of others restrict in some way the services they provide for patients with conditions other than cancer [7]. This limitation conflicts with the recommendation in the 2001 NACPC report that palliative care services, both specialist and non-specialist, should be available to those who require such services in all care settings, and based on need not diagnosis.

It should be acknowledged that many people with cancer who are referred to SPC have a range of other pathologies which may also present symptoms that require attention from SPC. It has been suggested that the current method of classification of referrals into malignant or non-malignant is excessively simplistic and inappropriate as it does not capture or have regard to the relative importance of the various diagnoses that may exist in an individual.

The HSE acknowledges that services for people with chronic illness – including COPD, dementia and heart failure – need further development in Ireland [12]. The management of life-limiting, non-malignant illness is currently being channelled through projects arising from the HSE Transformation for Change Programme and the National Chronic Disease Management Patient Support Programme [12, 22].

The dearth of disease-specific policy documents for people with life-limiting diseases reflects the uneven service developments for people with COPD, dementia and heart failure. The few disease-specific reports that are available focus on prevention, management and/or rehabilitation strategies and do not acknowledge the need for inclusion of palliative care as part of a holistic approach for people with these diseases. This is despite the fact that 48% of deaths in Ireland in 2006 arose from circulatory and respiratory disease compared to 29% which were cancer related. These factors influenced the rationale for the selection of COPD, dementia and heart failure for the purpose of this study. This decision was also based on research identifying the unmet palliative care needs of people with these diseases which has been highlighted by the disease-specific policy groups established by the UK National Council for Palliative Care. The awareness raised through the work of the Extending Access Study has also influenced the inclusion of palliative care and end-of-life issues in disease-specific HSE strategy and advisory groups.

1.1 KEY MESSAGES

This report has two key messages. Firstly, the principles of palliative care must be embedded within the disease management frameworks. In this way the non-specialist palliative care needs can be considered and addressed by the staff delivering the on-going care, with initial guidance and support from SPC. This will also enable staff to recognise when the patient’s palliative care needs will be better met by the SPC team. Secondly, SPC teams must seek to ensure that they accept referrals based on need rather than diagnosis, so that all people in Ireland can access a SPC service in a setting that is most appropriate to their needs regardless of their diagnosis.

This report seeks to demonstrate the evidence required to facilitate the changes in education, policy, research and service models so that these key points can be achieved. It also seeks to signpost opportunities for SPC professionals to support the development of non-specialist palliative care within current and emerging disease-specific management frameworks. Finally this report provides a backdrop for debate on the development of an end-of-life strategy within Ireland.

Delivering change in any area requires that people take leadership positions and accept responsibility, as well as developing the ability to evaluate and challenge traditional ways of working. Extending both non-specialist and specialist palliative care to people with diseases other than cancer will require conscious direction from the SPC professionals, the specialist professionals working in the disease-specific areas and primary care. Guidance and support is also required from the Department of Health and Children (DOHC) and HSE personnel with responsibility for governance, management and delivery of services.

1.2 REPORT STRUCTURE

Setting the Scene

This examines the rationale and context for providing access to palliative care for people with COPD, dementia and heart failure within a disease management framework. It includes reference to the symptom burden and considers how the different trajectories of these diseases can impact on the delivery of both non-specialist and specialist palliative care. This section also compares the Irish policy and service developments in this area to advances made internationally.

Study Analysis and Deliberations

This seeks to respond to four of the recurring challenges identified during the Extending Access Study regarding access to SPC for people with non-malignant diseases. These are: to determine what would be the expected ratio of people with non-malignant diseases within SPC services; guidance on the role of non-specialist palliative care; to consider appropriate eligibility and discharge criteria for access to SPC and to outline referral triggers to SPC services for people with COPD, dementia and heart failure.

Implementing Change

This provides a summary of the report and details both the overall and disease-specific recommendations required to bring about the necessary changes in this area. It also outlines the plan for implementation of the recommendations.

Appendices 1, 2 and 3

The findings and deliberations of the three disease-specific Working Groups are detailed in Appendices 1, 2 and 3. They include detailed information on symptom burden, epidemiology and international developments in palliative care provision for each of these groups. They also highlight the current Irish context for service delivery, identify the barriers that present and make recommendations on developing palliative care for people with COPD, dementia and heart failure. These appendices have been designed to act as standalone educational resources for all those who have a particular interest in these subject areas.

The content of the main body of the report draws from the disease-specific appendices, as well as gathering a wider view of developments in palliative care for people with non-malignant diseases. The detailed data in these appendices will help to inform the relevant specialist professionals from respiratory medicine, dementia care and cardiology, as well as SPC teams, of the need for palliative care for people with life-limiting non-malignant diseases, both from within the disease-specific service framework and from SPC where such needs arise.

Setting the Scene

This section provides the context for the study on providing access to both specialist and non-specialist palliative care for people with life-limiting diseases other than cancer. This is achieved through an examination of expert general and disease-specific literature on specialist and non-specialist palliative care for patients with non-malignant diseases. The disease-specific information and commentary in each of the three chapters in this section summarises and cross-references the contents of Appendices 1, 2 and 3 to this report which contain detailed information on specialist and non-specialist palliative care and COPD, dementia and heart failure.

Chapter Two

Context

2 CONTEXT

This chapter looks at the context of health service delivery for people with life-limiting diseases taking account of the changing pattern of disease in Ireland and internationally. It considers how the development of a chronic disease management model of healthcare should accommodate all levels of palliative care. It profiles the prevalence and symptom burden of COPD, dementia and heart failure and discusses evidence of the palliative care needs of people with these diseases. Finally, this chapter examines the different disease trajectories of COPD, dementia and heart failure.

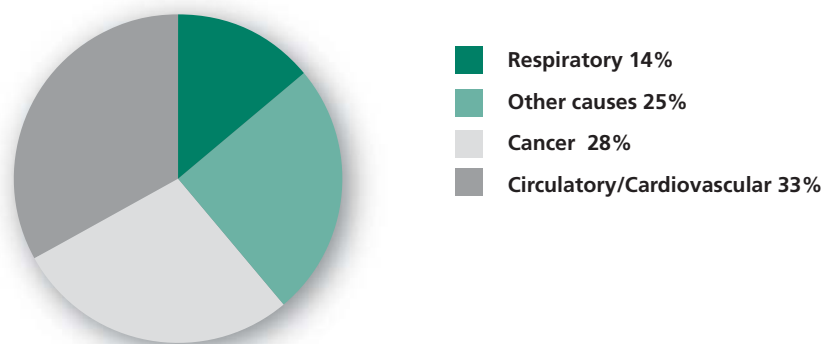
2.1 PALLIATIVE CARE FOR LIFE-LIMITING NON-MALIGNANT DISEASES

Overall life expectancy is increasing in European and other developed countries, with more and more people living beyond 65 years of age. As part of population ageing, the pattern of disease is changing. Increasingly, people die at older ages following illnesses due to serious life-limiting non-malignant diseases which cause a wide range of physical, psychological and social problems [23].

In 2008 a report on palliative care from the European Parliament recognised that further research is urgently required on the aetiology and treatment of non-cancer pain and symptoms, barriers to accessing care, and the care of patients with diseases other than cancer. This report also notes that other areas needing more in-depth study include the care of older people and the social, psychological and spiritual aspects of palliative care [24].

Progressive and life-limiting illness such as cancer, cardiovascular disease and respiratory diseases are among the top five predicted causes of death for 2020 [25]. Mortality data for Ireland shows that of the 27,479 people who died in 2006, 29% died from cancer, 14% from respiratory disease and 35% from diseases of the circulatory system including heart disease. Almost 16,000 of these deaths were in the 75 to 94 age group [26]. It is not possible to collect the number of deaths related to dementia as it is rarely listed as a cause of death.

PRINCIPAL CAUSES OF DEATH 2006 [26]



Diseases such as dementia, COPD and heart failure are major causes of disability and can have a profound effect on the individual's physical and psychological well being, employment, family life and self esteem over a prolonged period. There is growing evidence that patients with such life-limiting diseases have similar palliative care needs to those patients with malignant diseases [27-35].

Recently WHO has encouraged health care systems to adapt to these changes by reducing suffering and supporting people of all ages to live well and maintain their quality of life for as long as possible [23]. In recognition of this fact, the HSE is seeking to introduce a chronic disease management programme, acknowledging this as the essential vehicle for health care systems to respond to the changing pattern of life-limiting diseases and to deliver effective and appropriate health and care services to an ageing

population in Ireland [12]. People who have a life-limiting disease require services from a wide variety of healthcare professionals, along with self-management and the participation of their family or carers. These services should deal holistically with health and social needs, not just the physical consequences of the illness, and should be responsive and adaptable to the whole patient journey from diagnosis to death.

SPC services have an important role in supporting other health care professionals in the delivery of palliative care services at hospital and community level. True patient-focused palliative care can be delivered where there is an effective multi-professional team, with a common knowledge base, goals, and effective lines of communication [36, 37]. Palliative care rehabilitation which is delivered by allied health professionals (AHP) as well as the nursing and medical team helps patients to gain control, independence and dignity, responds quickly to help people adapt to their illness, takes a realistic approach to defined goals and is continually evolving, taking its pace from the individual [38]. Family caregivers often struggle with their own losses and changing roles while dealing with their concerns about their care-giving abilities for their family member with a life-limiting illness. To alleviate stress, overall burden and associated depression, the most important element that interdisciplinary palliative care can provide is good communication. Supporting the family during the process of bereavement is another important part of palliative care for all the team members [24].

If chronic disease management is to be truly patient-centred and holistic, it should address the palliative care needs of patients with life-limiting diseases. Indeed it has been recognised that the process of dying is now more complex, and the convenient separation of end-of-life into a defined period when palliative care services can be mobilised and administered is not possible [39]. This is in line with WHO recommendations that new concepts of palliative care and shared care should mirror more closely the needs arising throughout the whole course of a patient's journey [23, 40].

2.2 PREVALENCE AND SYMPTOM BURDEN

As this report has a specific focus on COPD, dementia and heart failure, it is helpful to outline the symptom burden and general characteristics of each of these diseases to explore the role of palliative care. However it also must be acknowledged that it is common for people with these diseases to present with other co-morbidities which also need to be considered when introducing palliative care.

2.2.1 CHRONIC OBSTRUCTIVE PULMONARY DISEASE

COPD is a progressive disease of the airways. It is estimated that there are between 200,000 and 400,000 people with COPD in Ireland and it is the third leading cause of respiratory death in this country after pneumonia and lung cancer [13, 14]. In Ireland COPD disproportionately affects people from lower socio-economic groups [41] and mortality in severe COPD is between 36% and 50% at two years after admission for an acute exacerbation [42, 43]. Due to current methods of gathering data on cause of death in Ireland, it is difficult to determine exact numbers of people dying from COPD.

The four stages of disease classification for COPD are set out in detail in Appendix 1. Some people experience rapid decline in lung function which may lead to an early death, while others have a gradual, progressive decline punctuated by severe exacerbations. The severity and frequency of such acute episodes accelerates the decline in lung function. As any one of the exacerbations could be fatal, sufferers face the fear of death on a number of occasions [44].

People with advanced COPD experience symptoms which include severe breathlessness on minimum exertion, cough and sputum production, often with the added burden of poor sleep quality, fatigue, loss of appetite, pain, depression, increasing inability to carry out the functions of daily living, social isolation and anxiety [15, 43]. It must also be recognised that people with COPD will often have a number of other co-morbidities which need to be considered in their care pathway. There is evidence that while the symptom burden is equal to that of people with lung cancer, the accumulated suffering for COPD patients is longer and

is compounded by the fact that they face complex decisions over a longer period. The burden of COPD also affects the quality of life of families and carers [45, 46].

The uncertainty of the disease trajectory and identifying whether an exacerbation may prove fatal has been shown to make it difficult for physicians to broach the subject of death. Patients have indicated that this uncertainty about prognosis leads to a sense of isolation from medical staff, creates communication difficulties and increases their unmet needs [46, 47]. Discussions about end-of-life treatment would need to be carefully tailored to individual needs, and the optimal time for this conversation might be at the first review after discharge. This would be aided if patients were given specific information material on this subject in advance to help them consider the issues that present for them [45].

2.2.2 DEMENTIA

Dementia is a gradual and progressive disease which affects over 38,000 people in Ireland. This figure is expected to rise to over 49,000 by 2016 and to 75,000 by 2026. While the prognosis for people newly diagnosed with dementia is highly variable and dependent on co-morbidities and stage of dementia at diagnosis, the life expectancy of someone who has been diagnosed with dementia is generally thought to be between 5 and 20 years [16, 48-50].

People with dementia suffer impairment of memory, intellect, judgement, insight and loss of social skills. The disease trajectory is a gradual, sometimes slow, decline. Further detail on the manifestation of this illness is presented in Appendix 2.

In the final phase of dementia symptoms include increasing memory loss, confusion and disorientation, loss of ability or desire to communicate, move or engage in self care. This may be accompanied by behavioural changes such as aggression or passivity. The ability to swallow and eat independently may be lost, accompanied by loss of appetite. Other complications may include incontinence, delirium, recurrent infections, pneumonia, pain, peripheral shutdown, restlessness and agitation [51].

Symptom prevalence will depend on existing co-morbidities such as cardiac failure or diabetes, and infections such as pneumonia and septicaemia are the most frequent cause of death [52].

There is evidence to suggest that the care needs of people with end-stage dementia are similar to those with advanced cancer, but are of longer duration [27]. The final phase of dementia is particularly challenging given the person's inability to verbally express preferences for their care as their illness progresses and the fact that this phase may be long and difficult to identify. Studies have shown that people with dementia have not had the benefit of palliative care services because staff did not recognise the terminal phase or nature of the disease [53].

2.2.3 HEART FAILURE

Heart failure is said to occur when the heart is unable to maintain sufficient cardiac output and oxygen delivery to meet the body's needs [54].

In Ireland it is estimated that more than 10,000 new cases are diagnosed each year. Estimates suggest that by 2010 over 300,000 people in Ireland will be directly affected by heart failure. Incidence and prevalence are increasing as the elderly population of Ireland grows and with better survival rates after an acute coronary event [55]. People who have a diagnosis of heart failure frequently have other co-morbidities which need to be considered in their care pathway.

The four stages of severity of heart failure as described by New York Heart Association Classification (NYHA) [56] are detailed in Appendix 3. The disease trajectory in heart failure is described as a slow

decline punctuated by periods of rapid deterioration leading to acute hospital admissions. Half of the patients with a diagnosis of heart failure will die in four years and of those with severe heart failure, 50% will die within a year [29, 55, 57].

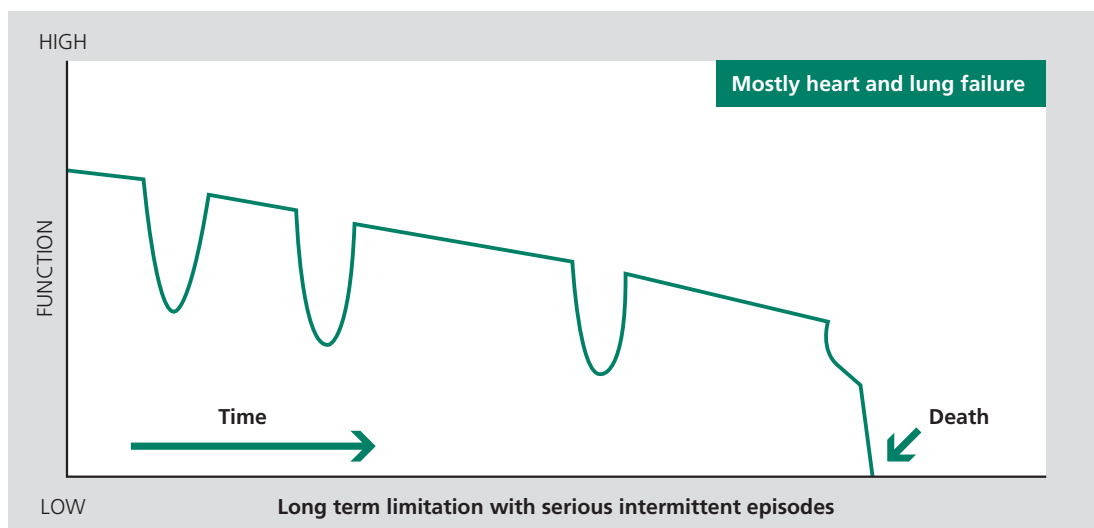
The personal burden of advanced heart failure can be immense with patients experiencing high levels of physical, functional and emotional distress. The uncertain disease trajectory and the possibility of sudden death add to the burden [29, 58, 59]. At the final phase, the physical and psychological symptom burden in the dying heart failure patient has been compared to that of the dying cancer patient. Reported symptoms include weakness, fatigue, pain, dyspnoea, depression, insomnia, anorexia, anxiety, constipation, nausea and vomiting. Patients with advanced disease may have a poor quality of life because of poor prognosis and heavy symptom burden. Lack of discussion about end-of-life issues has been found to be a source of fear and anxiety for both patients and carers [32, 34].

2.3 DISEASE TRAJECTORIES, LIFE-LIMITING DISEASES AND PALLIATIVE CARE

The pattern of disease progression for each disease and for each individual will be different, depending on a variety of factors including age, co-morbidities and level of care. Distinct patterns of disease trajectory have been identified for people with life-limiting illness [25, 60]. Understanding these trajectories, and how they differ from the trajectory for patients with malignant disease, can assist in the management of such patients prior to their death [61]. It can also provide direction for the delivery of palliative care within individual disease management frameworks, so that such care will be delivered on the basis of need not diagnosis [25].

The trajectory illustrated in Diagram 1 is typical of diseases such as COPD or heart failure. 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 [23]. 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 [62].

DIAGRAM 1:
DISEASE TRAJECTORY MOST COMMON IN HEART AND LUNG FAILURE REFLECTING PROGRESSIVE DECLINE AND ACUTE EXACERBATIONS [60]⁷



⁷ © Diagrams 1, 2 and 3 are reproduced with the permission of RAND Health

Diagram 2 shows the disease trajectory most typically experienced by frail elderly people and those with dementia. The trajectory is one of gradual decline from an already low baseline of physical or cognitive functioning [25]. This pattern may also be applicable to people with progressive neurological diseases including those with MND [63].

DIAGRAM 2:
DISEASE TRAJECTORY MOST COMMON IN DEMENTIA AND FRAILITY [60]⁸

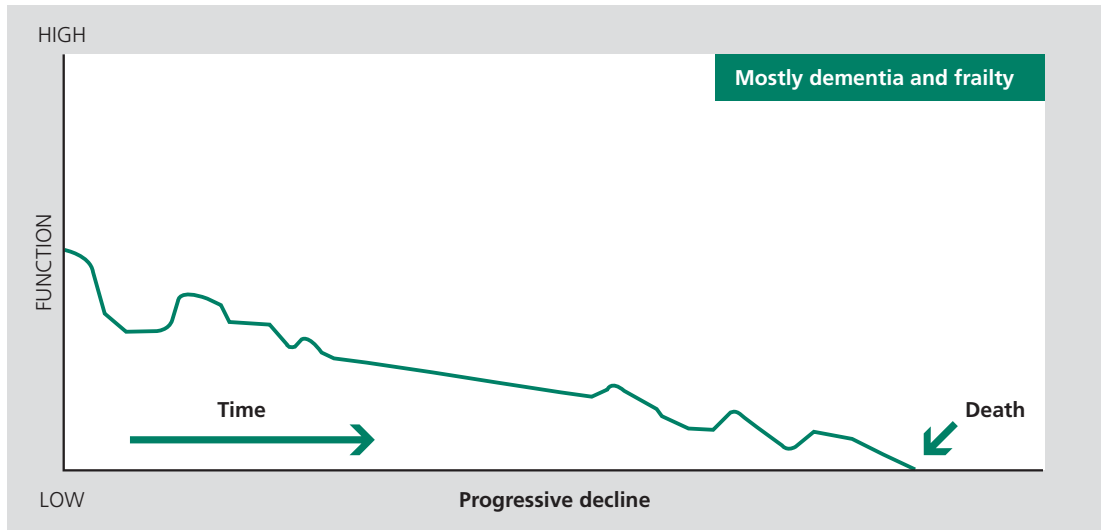
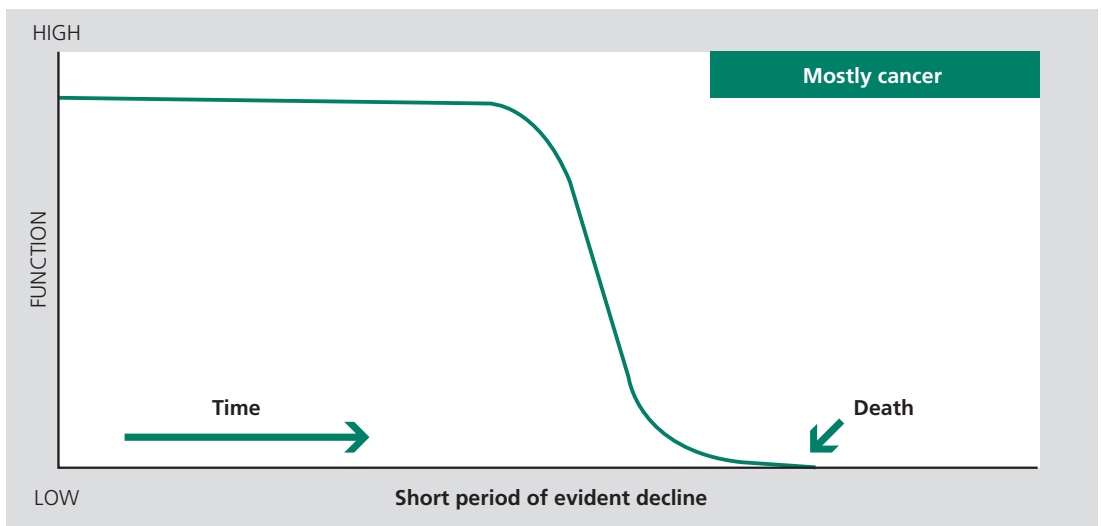


Diagram 3, the trajectory with a steady progression and a clearly identifiable final phase, is one which is applicable to most cancers, though as treatment regimes improve this pattern is changing [64].

DIAGRAM 3:
DISEASE TRAJECTORY MOST COMMON IN CANCER [60]⁸



Understanding and considering these different trajectories may help professionals take on board, at an earlier stage than would otherwise be the case, that progressive deterioration and death are inevitable. It also reinforces the requirement for non-specialist palliative care to be included in disease management frameworks [62].

⁸ © Diagrams 1, 2 and 3 are reproduced with the permission of RAND Health

2.4 DELIVERING PALLIATIVE CARE FOR PEOPLE WITH LIFE-LIMITING NON-MALIGNANT DISEASES

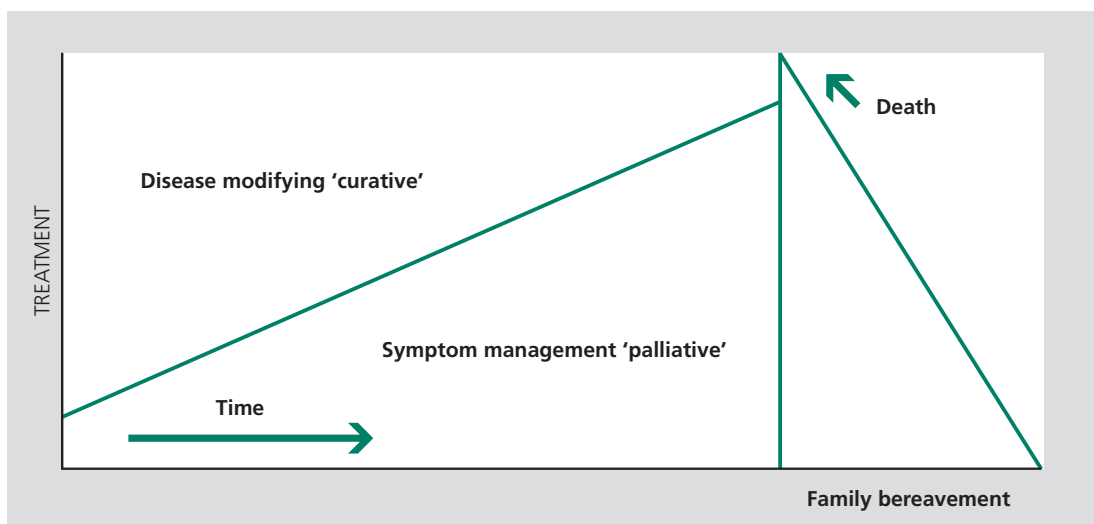
Traditionally SPC services have been developed to respond to the needs of cancer patients where the disease trajectory is steadily progressive with a defined terminal phase. Assessing and addressing both the specialist and non-specialist palliative care needs of those patients with non-malignant diseases, particularly those with a complex and uncertain prognosis, may require a different approach [23] and it is helpful if patients, families and clinicians accept and incorporate such prognostic uncertainty into their decision making [65].

Murray and Sheikh note that palliative care underscores the need for anticipatory personal care for everyone with life-limiting diseases, and that the lessons learned from palliative care for cancer need to be applied to other life-limiting diseases. Health services must respect the importance of clinicians and patients having time together in the context of a relationship which allows for continuity of care and that palliative care needs can be more readily accommodated in such a relationship [66].

For people with life-limiting non-malignant diseases, it is often appropriate that non-specialist or specialist palliative care should be provided alongside disease modifying interventions. Such palliative interventions can be delivered by professionals from within specialties other than SPC where there is suitable skill and awareness [23, 29, 67-71].

The unpredictable disease trajectories illustrated in Diagrams 1 and 2 above are frequently cited as barriers for patients to access SPC [7, 72]. The model set out in Diagram 4 described by Lynn et al, outlines how palliative care is part of the continuing care pathway for the patient, with SPC services providing care directly in response to the complex needs which may arise at the end-of-life period, but with earlier palliative care needs being responded to in tandem with disease modifying therapies by the disease-specific specialists [23, 60]. It shows how the level of palliative care intervention increases as the disease progresses and as curative therapies become less appropriate. Where extraordinary needs arise throughout the trajectory, the services of the SPC team may be required in an advisory role, as collaborative/shared care, or as direct providers.

DIAGRAM 4:
TRAJECTORY MODEL OF PALLIATIVE CARE [60]⁹



There are implications and needs arising from this approach. Non-specialist palliative care, delivered by – for instance – members of a cardiology, dementia care or respiratory team requires the availability of personnel with relevant training. Equally, SPC personnel more accustomed to dealing largely with people

⁹ © Diagram 4 is reproduced with the permission of RAND Health

with cancer may need guidance on the disease-specific symptoms which present in dementia, heart failure, COPD and other life-limiting diseases. In such circumstances, the development of further education including production of information leaflets to provide awareness of the need for non-specialist palliative care from within the relevant specialty would be beneficial.

In recognition of the increasing elderly population, the unpredictable trajectories described earlier and the difficulty in defining a period when palliative care services need to be mobilised, it would be helpful to consider some overarching strategy that would provide guidance and support to prepare people for end-of-life.

These areas will be further examined in subsequent chapters of this report.

2.5 KEY POINTS

- Patients with COPD, dementia and heart failure can have palliative care needs of longer duration and equal to those of people with malignant diseases.
- Understanding the different disease trajectories of non-malignant diseases can provide direction for the delivery of non-specialist care alongside disease modifying therapies, with SPC service input where complex needs arise.
- Disease management strategies can provide the framework for addressing the palliative care and end-of-life needs of people with progressive life-limiting non-malignant diseases.
- Opportunities for education and training in palliative care are required for all levels of staff (including SPC, disease-specific specialties and primary care staff) that interface with people with life-limiting, non-malignant disease.
- Development of education and guidance materials would assist in clarification of the role of both non-specialist and specialist palliative care.
- WHO recommends that palliative and shared care models reflect the whole of the patient journey. This could be supported by an end-of-life strategy which would motivate and drive initiatives to respond comprehensively to the needs people who are facing death.

Chapter Three

Policy

3 IRISH HEALTH SERVICE POLICY AND STUDIES RELEVANT TO LIFE-LIMITING NON-MALIGNANT ILLNESS AND PALLIATIVE CARE

This chapter details Irish health policy relevant to life-limiting, non-malignant illnesses and palliative care. It examines domestic policy relative to international policy, strategies and reports regarding the development of palliative care in disease-specific service interventions.

3.1 INTRODUCTION

Since 2001 Irish health policy has advocated that both non-specialist and specialist palliative care should be available to all people in all settings, and this is one of the principle tenets of the report of the NACPC 2001. This report has provided the framework for the development of comprehensive SPC services and is based on provision of services to people with both malignant and non-malignant diseases. The Irish National Health Strategy: Quality and Fairness and the Primary Care Strategy published in 2001, outlined commitment to the development of national palliative care services, and fully supported the recommendations of the NACPC report. The Primary Care Strategy specifically noted that primary care teams would integrate with the community based SPC teams, and this integration would be supported by the necessary development of SPC referral protocols, discharge plans, integrated pathways and shared care arrangements [1, 18, 73].

The adoption of a population health approach by the HSE in 2007 reinforces the principles of the health strategy with a particular emphasis on reducing health inequalities, ensuring HSE services are person-centred and seeking to integrate services across the entire continuum of care which cross organisational boundaries [74]. This would mirror the holistic approach that is promoted by palliative care.

3.2 POLICIES AND STUDIES RELATING TO LIFE-LIMITING DISEASES

There has been recent evidence of some commitment to the development of Irish health services for people with life-limiting diseases which are chronic in nature, with the publication of the National Chronic Disease Management Patient Support Programme (2006) [12], the establishment of the Expert Advisory Group (EAG) on Older Persons [75, 76] and the priorities and initiatives arising from the HSE Transformation Programme [22].

In 2008 the DOHC published a policy framework for the management of chronic diseases. It proposes:

- policy development in evidence-based disease management programmes which focus on the total course of the disease
- clinical guidelines for the management of major chronic diseases, and
- an emphasis on shared model of care described as clinical care which is shared between primary care and specialist services, the latter playing a central role in care of patients with chronic disease [11].

These reports and initiatives acknowledge that there has been an inadequate response to the increasing burden of chronic disease. Health services must re-orientate to support patients through the development of primary care teams and a range of self management and empowerment programmes, with a focus on integrated care pathways. However there has been minimal direction regarding access to palliative care in these publications.

3.2.1 REPORTS AND POLICIES RELATED TO PALLIATIVE CARE

The recommendations in the NACPC report included the introduction of national standardised performance indicators and outcome measures to assist in evaluation and maintenance of quality standards. In the past few years, some progress has been made in piloting a Minimum Data Set and in 2008 the HSE has indicated commitment to implement the Minimum Data Set for SPC [5].

Following the report of the NACPC [1] which estimated that the impact of providing SPC to people with non-malignant diseases could increase the demand for SPC by 80%, a number of reports and studies have addressed the area of access to SPC for people with non-malignant diseases. These include the Baseline Study, the report of the International Expert Advisory Group and the Health Board Palliative Care Needs Assessments. These are discussed in more detail below.

The Baseline Study in 2006, which sought to identify the gaps and challenges in the development of palliative care services in Ireland, noted that despite the recommendations of the NACPC report there was still a very low level of SPC service delivery to patients with conditions other than cancer [2]. This report noted that there is huge geographical variance in the pace of development of SPC services, which has prolonged care inequities for people with life-limiting illness. It also listed the provision of education and training to support the development of non-specialist palliative care as one of the many challenges remaining in implementing the recommendations of the report of the NACPC.

The report of the International Expert Advisory Group was initiated by Marymount Hospice, Cork. It sought to accelerate the recommendations of the NACPC report, with a focus on best practice. It stated that the desired level of activity for SPC services for diseases other than cancer is 25%. It also stressed the importance of choosing appropriate settings for palliative care for people with diseases other than cancer, due to symptom complexity, and stratified levels of intervention.

This report highlighted a number of areas which would assist in the development of services for people with non-malignant diseases including:

- The development of relationships between SPC staff and doctors in acute hospitals.
- The provision of education modules to all health care staff to raise awareness of palliative care needs of patients who do not have cancer.
- Further research to inform policies and practice, and provision of specific palliative approaches for non-malignant diseases which include holistic care.
- Monitoring by funders of SPC services to ensure that services to patients with non-malignant diseases, are based on need not diagnosis, and that this is reflected in their admission policies.
- Adequate supply of inpatient care beds at intermediate level due to reluctance to admit these patients to SPC inpatient beds [77].

In response to the report of the NACPC, palliative care needs assessments were carried out by all Health Boards (HSE), between 2002 and 2006. Seven of the eight needs assessments examined by the study recognised the need for services for people with non-malignant diseases, with the majority indicating the requirement of education and training provision to assist this development. Two of the needs assessments reported a high level of dissatisfaction amongst GPs about the lack of SPC service provision for people with diseases other than cancer, and there was similar consensus in regard to the need for establishment of SPC referral and discharge protocols. This is supported by a recent survey of access to palliative care services for patients with conditions other than cancer in Ireland, where 19% of SPC services surveyed limited the care they provided for such patients [7].

An Irish research study in 2008 relating to end-of-life care for older people in acute and long stay care settings found that there are significant education and training gaps in relation to non-specialist palliative care provision, and there are very low levels of access to consultant-led palliative care teams in long stay facilities. It also suggested that there should be greater collaboration between SPC and gerontological care [39].

3.3 EDUCATION DEVELOPMENTS

3.3.1 The Palliative Care Education Taskforce (PCET) was established in February 2008 following on from an Education Round Table Meeting in October 2006 [78]. Its aim is to support the strategic development of education in palliative care, and its membership is representative of National Council for Specialist Palliative Care, the Irish Association of Palliative Care, IHF, and palliative care education and service providers.

Five levels of palliative education intervention have been identified as being required to underpin the strategic development as follows:

- Level 1: Pre-qualification professional training, the foundations of a palliative care approach
- Level 2: Generalist continuing professional education
- Level 3: Specialist preparation
- Level 4: Post-specialist support for leadership
- Level 5: General public education and information.

The PCET is initially addressing Level 2 – generalist continuing professional education. This includes examination of the education responses required to support the provision of appropriate levels of palliative care for people with non-malignant diseases and care of older persons, as well as the national co-ordination and support of existing and future training activities [79].

3.3.2 In conjunction with PCET the IHF is preparing a training programme for Nursing Homes Ireland, the representative organisation for the private and voluntary nursing homes sector. This training programme is seeking to establish a common multi-disciplinary approach to Level 1 (introductory) palliative care education in Ireland for nursing home staff. Training will involve single workshop training in nursing homes or local venues and exchange visits to hospices [80]. This development arose following a request from Nursing Homes Ireland for further training to support residential homes and was also linked with the publication of the End-of-Life Care for Older People in Acute and Long-Stay Care Settings in Ireland report [39]. This training programme is envisaged as a single activity to form part of a broader quality initiative in this area.

3.3.3 An All-Ireland Institute for Hospice and Palliative Care is at planning stage. It is anticipated that the establishment of such an Institute will improve the experience and understanding of palliative and end-of-life care on the island of Ireland, by enhancing the capacity to develop knowledge, promote learning, influence policy and shape practice [81].

MEDICAL EDUCATION AND TRAINING



The HSE has developed a strategy for medical education, training and research. A Medical Education, Training and Research (METR) Unit is to be established in 2008. The METR unit will be located centrally within the HSE, initially in the Office of the CEO. A strategic implementation plan for the establishment of the unit and associated governance structures is being finalised. The HSE is also setting up an Education, Training and Research (ERT) sub-committee representative of all healthcare professionals and HSE executive management to co-ordinate and align all education, training and research functions throughout the HSE. The HSE Medical Education, Training and Research Strategy document and the ETR Implementation plan will guide development in these areas and will have a critical role in the development of palliative care education [82, 83].

3.4 MONITORING, GOVERNANCE AND PERFORMANCE INDICATORS

In 2005 the Palliative Care Accreditation Scheme was developed by Irish Health Services Accreditation Board (IHSAB), specifically for the Specialist Standalone Palliative Care Services, incorporating the organisation's inpatient, day care, outpatient and home care services. Within the accreditation criteria was a specific criterion stating that the service must have evidence "of the provision of equal opportunity to access care/service, e.g. admissions policies for patients/clients with non-malignant disease" P. 113 [84]. One specialist palliative care inpatient unit has achieved accreditation under this scheme. IHSAB are now incorporated within Health Information and Quality Authority (HIQA), and HIQA are preparing to introduce a licensing system to replace the accreditation scheme. Patient focus, safety, effectiveness, efficiency, fairness and access are likely to remain important indicators of a quality healthcare service.

In 2008 HIQA published National Quality Standards for Residential Settings for Older People and these include a standard on end-of-life care, as well as supplementary criteria for dementia-specific residential care units for older people [85].

The HSE has Service Level Agreements (SLA) with statutory and voluntary organisations providing services on their behalf. A standardised SLA is being developed by a National Steering Group which will include a schedule relating to services encompassed, payment arrangements and elements supportive of governance and monitoring of services. It is hoped to commence implementation plans shortly to put revised SLA in place [86].

3.5 DISEASE-SPECIFIC

Chronic Obstructive Pulmonary Disease

One of the initiatives arising from the HSE Transformation Programme has been the establishment of a steering group to develop a national strategy for the management of COPD with a view to reducing the burden of disease in terms of adverse impact on quality of life, avoidable illness, disability and death. This group is due to report in 2008 and following interaction with the project team of the Extending Access Study has referenced the need for palliative care for people with COPD. Prior to this development there has been very little recognition of the specific needs of people with COPD in health strategies and policy documents in Ireland.

Dementia

There have been several studies and reports which have indicated that dementia services have been under resourced for the past decade, and the fragmented structure of dementia services inhibits the development of person-centred services which are fundamental for people with dementia [87, 88]. In 2008 the report on End-of-Life Care for Older People in Acute and Long Stay Settings in Ireland indicated a lack of awareness of the life-threatening nature of dementia, and a failure to integrate end-of-life care with gerontological care [39]. It has been recognised that the principles of person-centred dementia care mirror the broad principles of palliative care, and the care of persons with advanced dementia would be significantly enhanced by close collaboration, guidance and support from SPC [89]. The establishment of the EAG on Older Persons in 2006 [76], and the National Working Group on Dementia at the end of 2007 [90] have indicated a commitment to address these deficits.

Heart Failure

The development of heart failure services in Ireland has been informed by the DOHC reports: Building Healthier Hearts (1999) [91] and Ireland; Take Heart (2006) [92]. 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 [55]. Although each of these reports advocates coordinated and holistic care for heart failure patients, they do not specifically address the palliative care or end-of-life needs of such patients.

In 2007 it was agreed by the HSE that a Heart Failure Action Plan would be devised and implemented to improve quality of life and health outcomes for people affected by heart failure and to address the main gaps identified in the audit report Ireland: Take Heart. The palliative care needs of heart failure patients will be considered in the Action Plan, which has been informed by the deliberations of the Extending Access Study and is due for completion in 2008.

3.6 INTERNATIONAL POLICY AND STUDIES

This section refers to relevant international health strategies, reports and studies that refer to both the development of palliative care for life-limiting non-malignant diseases generally and for COPD, dementia and heart failure in particular.

3.6.1 UNITED KINGDOM

Since the early 1990s initiatives by the Scottish Management Executive, National Health Service (NHS) Executive, the Welsh Assembly and the UK government have recommended that SPC providers should not focus exclusively on cancer and should address the inequity of service provision [93-95].

The need for palliative care in disease-specific guidance documents was outlined between 2003 and 2007 by the National Institute for Clinical Excellence (NICE) in their publications on heart failure, COPD, and dementia [96-98]. During this time the National Council for Palliative Care in the UK produced several reports and discussion papers which helped to influence health policy and increase access to palliative care at all levels in the UK [89, 99].

The End-of-Life Care Strategy arose from plans in 2003 by the NHS to improve care for people nearing end-of-life [100, 101]. This strategy and resulting programmes such as the joint palliative care training programmes for primary care teams based on partnership with Macmillan Cancer Relief and Marie Curie Cancer Care [102, 103]; Gold Standards Framework; and Liverpool Care Pathway [103-105] aim to offer all adult patients the choice of and access to high quality end-of-life care, regardless of their diagnosis. Such initiatives enable services to respond to the needs of people nearing end-of-life, including those with renal problems, heart failure, COPD, neurological disease and cancer.

Since 2006 two further reports from the Scottish Council for Palliative Care and Help the Hospices have been published with specific guidance on developing palliative care services for people with non-malignant diseases [106, 107].

The Mental Capacity Act, introduced in 2005, created a new law about the way in which decisions are made on behalf of people aged 16 or over who lack the capacity to make those decisions for themselves. Examples include some people reaching the end-stage of a life-threatening disease, such as people with dementia and those with learning disabilities [108].

3.6.2 USA

In 1997, the Committee on Care at End-of-Life in the USA recommended that there should be improved access to palliative care for all regardless of diagnosis. Nearly half of all Medicare hospice benefit recipients had a non-cancer diagnosis in 2000, although it should be noted that this level of access could have financial motivation [7, 109]. In relation to education, in 2001 the California State Legislature made it compulsory for all doctors to undergo training in pain management and palliative care within four years of qualification and since 2003 medical schools in the US have been mandated to include end-of-life care on the curriculum [110].

3.6.3 CANADA

Policy developments in Canada gained momentum in 2000 when a collaborative approach was proposed to improve access to palliative and end-of-life care by the Quality End-of-Life Coalition of Canada which represents 31 stakeholders. Since then there have been several initiatives in palliative care education for medical students and research beyond cancer with the aim of ensuring that all Canadians receive quality palliative and end-of-life care regardless of their diagnosis [111].

3.6.4 AUSTRALIA

In 2000 the Australian Federal Government's National Palliative Care Strategy recognised that palliative care should be delivered on the basis of need not diagnosis [112]. Progress has been made in the areas of medical education and training as well as wider service provision programmes with regard to palliative care [113]. In 2006 Palliative Care Needs Assessment Guidelines were published to assist those caring for people with a life-limiting illness to ensure that they are offering the most appropriate care to meet their patients' specific needs [114].

3.7 DISEASE-SPECIFIC POLICY AND STUDIES

Chronic Obstructive Pulmonary Disease

The American Thoracic Society (ATS) and the European Respiratory Society (ERS) produced joint COPD guidelines in 2004 which highlight that patients with advanced COPD may benefit from integrating palliative care into routine care [70]. The ATS/ERS statement on Pulmonary Rehabilitation in 2006 states that Pulmonary Rehabilitation programmes provide an opportunity to assist in advance care planning and end-of-life education [115]. More recently the ATS has produced an official clinical policy statement endorsing the concept that non-specialist and specialist palliative care should be available to patients at all stages of illness and recommending that respiratory clinicians should have basic competencies in palliative care and should consult with their SPC colleagues where the situation demands it [71]. In the UK, both the NICE guidelines on COPD and the Welsh Assembly consultative document on palliative care commissioning state that people with COPD should have full access to multidisciplinary palliative care services. To date it has been difficult to determine the impact this has had on access to services [97, 116].

Dementia

Reports from the UK and Australia provide guidance and direction as to the role and potential utility of palliative care interventions for people with advanced dementia [51, 117]. The UK NICE guidelines on supporting people with dementia and their carers state that dementia care should incorporate non-specialist palliative care from the time of diagnosis until death [98]. It has been recognised that palliative care fits well with the philosophy of person-centred dementia care, however more education and joint collaboration is needed for staff in dementia services to meet the palliative care needs of people with dementia [118]. A Scottish study which investigated whether the palliative care needs of people with end-stage dementia were being met identified very significant gaps [119]. An action learning educational project has been developed for both carers and relatives to address the needs identified in this study and to embed palliative care practices in the workplace. Evaluation of the study is due early in 2009 [120]. The guidelines being prepared by Alzheimer Europe on end-of-life care for people with dementia will also support future developments and direction in this area [121].

Heart Failure

Palliative care for people with heart failure has been a feature of UK health policy since 2000 and the 2003 NICE guidelines on the management of heart failure contain a section on end-of-life issues including the recommendation that palliative care should be part of the holistic management of heart failure from within the heart failure team [96, 122]. The European Society of Cardiology (ESC) 2005 guidelines on the treatment of heart failure recommend consideration of palliative treatment in patients who are at the end-stage of their disease [57]. The 2008 ESC guidelines recommend that patients with the clinical

features of advanced heart failure who have a poor short term prognosis and who continue to experience symptoms despite optimal therapy should be considered for a structured palliative care approach, including addressing psychological symptoms. The guidelines encourage a collaborative or shared care approach between cardiologists and SPC to address the palliative care needs of such patients and suggest that the essential elements of a palliative care programme are similar to those of comprehensive heart failure management programmes [123]. The Heart Failure Society of America has an end-of-life section in its 2006 Practice Guidelines which asserts that palliative care can and should be delivered concurrently with active or disease-modifying therapies [124]. Both the American College of Cardiology and the American Heart Association recommend non-specialist palliative care for end-stage heart failure patients with specialist palliative care input where appropriate [125]. Similar recommendations are to be found in clinical guidelines from Australia and New Zealand [126].

3.8 KEY POINTS

- For the past decade international health policy has acknowledged that both specialist and non-specialist palliative care should be available to people with diseases other than cancer.
- Several countries have comprehensive disease-specific guidelines which highlight the role of non-specialist palliative care for patients with non-malignant diseases. End-of-life strategies and coalitions have emerged as a means of implementing specific service responses to support people in the final phase of their illness, regardless of their diagnosis, and these strategies are supported by education and training initiatives. Medical education in palliative and end-of-life care is now compulsory in parts of the USA and Canada.
- Irish health policy has committed to the inclusion of palliative care for all people in all settings since 2001 and encouraged the development of integrated care and referral guidelines to assist in the integration of SPC teams with primary care teams, and support the development of non-specialist palliative care.
- The HSE have acknowledged that services for people with life-limiting, non-malignant diseases have been under-developed to date, however initiatives under the Transformation Programme have given a commitment to consider the role of palliative care for people with heart failure, dementia and COPD.
- Recent initiatives in palliative care education in Ireland signpost commitment to address the current deficits in palliative care education for people with life-limiting diseases.
- In 2001 it was reported that extending access to SPC for people with diseases other than cancer will increase the demand for SPC in Ireland by up to 80%. In 2005 it was reported that non-malignant activity will represent 25% of total SPC caseload. This subject will be further examined in Chapter 5.
- There is a need for further development of monitoring or governance systems to ensure that equal access to SPC is introduced in Ireland ensuring that such services are based on need rather than diagnosis, as a small number of Irish SPC services still direct their services solely to people with cancer, MND, HIV and AIDS [7, 127].

Chapter Four

Service Models

4 SERVICE MODELS

To identify potential opportunities and challenges for implementing palliative care for people with life-limiting non-malignant diseases, it is helpful to consider service initiatives in this area from other countries. This section will examine care pathways for the dying patient as well as looking at some disease-specific interventions from the UK, and will conclude with a picture of the current Irish services in this area.

4.1 CARE PATHWAYS AND PROGRAMMES

Integrated end-of-life care pathways and programmes have been recognised as a means of ensuring patients receive co-ordinated and seamless care, and are particularly valuable to ensure that the services respond to the changing needs of the dying patient [128, 129]. Integrated care pathways are multi-professional documents to enable evidence-based care and to support clinical governance. The care pathways for the dying patient aim to remove any variations which may occur in treatment and care of the dying in all settings. Integrated care pathways and the recognition of the specialty of palliative care are a response to patient expectation of care and dignity at the end-of-life [130].

Programmes such as integrated and managed care pathways, outreach programmes, shared care and telemedicine contribute to greater equity in access to care, enhancing continuity. Generally these initiatives are dependent on a well-functioning primary and secondary healthcare system. Empowering primary care practitioners, particularly community and home-care nurses, by training and education combined with support and supervision has been successful in some cases in the delivery of primary palliative care. Hospital services should work closely with the specialty services and primary care services dealing with the specific problems of the patients at the end of their lives to ensure a proper transition [24].

Specific integrated care pathways and programmes have been developed in the UK for patients who are approaching end-of-life: the Gold Standards Framework (GSF) and the Liverpool Care Pathway for the Dying Patient [103, 104].

These are part of the UK End-of-Life Care Strategy and are discussed in more detail below. This end-of-life strategy is seeking to extend the quality of care that patients currently receive in hospices and SPC services to all people who are approaching end-of-life [100].

4.1.1 LIVERPOOL CARE PATHWAY

The Liverpool Care Pathway (LCP), an integrated care pathway, was developed in 2001 to provide a mechanism for dying patients, and their relatives and carers, to receive a high standard of care in the last hours and days of life. The LCP was originally developed for cancer patients in the acute environment, but has since been adapted for use in all generic care settings irrespective of diagnosis [105]. It encourages a multi-professional approach to the delivery of care that focuses on the physical, psychological and spiritual comfort of patients and their relatives, and it has been implemented by both non-specialist and specialist palliative care providers [131].

Once the pathway is commenced, the goals of care prompt staff to consider the continued need for invasive procedures and whether current medications are conferring benefit. Staff seeking to use the LCP must continue to reflect, challenge and use critical decision making in their approach to their work. It is acknowledged that education led by SPC is fundamental to the implementation of the pathway [131].

There is some evidence to suggest that the introduction of integrated care pathways for the dying have particular benefits for patients with diseases other than cancer. Mirando et al document the implementation of an Integrated Care Pathway for the dying based on the LCP in a general hospital in the UK. Initial results showed that 60% of patients cared for on the pathway were those with diseases other than cancer, and this concurs with results from another study in this area. This has raised awareness of the importance of introducing non-specialist palliative care in disease-specific specialities [130, 131].

4.1.2 GOLD STANDARDS FRAMEWORK AND MACMILLAN GP FACILITATORS

The GSF is a systematic evidence-based approach to optimising the care for patients nearing the end-of-life in the community and care homes, so that people are enabled to live and die where they choose. It can assist in preventing unnecessary hospital admissions [132]. End-of-life care initiatives in primary care in the UK have been based on the GSF and the work of the Macmillan GP facilitators [133]. The recent UK End-of-Life Care Strategy recognises the pivotal role that GPs have in the provision of end-of-life care and care for the bereaved, and anticipate that in the UK a GP would be expected to manage six or seven patients in the dying phase of their illness each year [100]. The Macmillan GP Facilitator is key to the success of the implementation of the GSF, as they support and develop the work of the primary care team via teaching sessions, provision of regular feedback and encouraging local ownership and team approach in response to the palliative care needs of all patients regardless of diagnosis [134].

4.1.3 MARIE CURIE CANCER CARE DELIVERING CHOICE PROGRAMME

This programme aims to improve the way palliative care is delivered so that, regardless of their diagnosis, people with palliative care needs are supported to die in their place of choice. The programme is based on partnerships between NHS, voluntary sector, social services and other health care providers, with a focus on providing patient-centred 24-hour service model [100].

4.2 UK DISEASE-SPECIFIC SERVICE DEVELOPMENTS

Chronic Obstructive Pulmonary Disease

Although there is significant acknowledgement of the role of non-specialist and specialist palliative care for people with COPD from both a policy and research perspective, it has been difficult to identify evidence-based service interventions in this area. The two UK programmes identified are described in detail in Appendix 1 [135, 136], and are based on collaboration between primary and specialist service providers. They identified the need to establish criteria which will indicate end-stage COPD so as to prompt referral to SPC and emphasised the need for collaboration between primary, secondary and tertiary care. Enhanced co-operation between multidisciplinary teams yields significant reduction in admissions and readmissions to hospital in the last years of patients' lives.

Dementia

There are a limited number of examples of evidence-based practice which combine non-specialist and specialist palliative care as part of dementia services. In seeking to examine existing palliative care services in the UK the National Council for Palliative Care has recently carried out a mapping exercise to determine good practice in this area and a summary of emerging practices they identified are listed in Appendix 2 [137].

Heart Failure

A number of UK-based services in heart failure have a palliative component. A collaborative approach between the Heart Failure Nurse Specialist and Macmillan CNS described by Pooler. [138] and also by Daley [29] demonstrated how both sets of nurses enhanced their skills by working along side each other, improving palliative care services to patients and highlighted the need for consensus for such intervention from all key staff involved in the patients' care. The shared care approach is also recommended by Johnson and Haughton [67]. They comment that developing mutual understanding and respect of different skills with the specialties can yield effective results in palliative care for patients with heart failure and that this step does not require additional resources. These service models are explored in more detail in Appendix 3.

4.3 IRISH HEALTH SERVICES AND AVAILABILITY OF PALLIATIVE CARE FOR PEOPLE WITH DISEASES OTHER THAN CANCER

The HSE is responsible for the national provision of Health and Personal Social Services. This is managed and delivered through Primary, Community and Continuing Care and the National Hospitals Office. Services for people with SPC needs have received significant investment in the past five years and Irish services are well developed by international standards [7]. It should be acknowledged however, that palliative care initiatives for people with COPD, dementia and heart failure could be further enhanced.

4.3.1 SERVICES FOR PEOPLE WITH LIFE-LIMITING DISEASES

Community and primary care services are currently at different stages of development in Ireland and progress on the roll out of primary care teams has been slower than anticipated. These factors, in addition to the need for further development of an integrated service provision between hospital and community/primary care services, affect the development of disease specialist services which incorporate palliative care. This is demonstrated below.

Currently most people with life-limiting diseases are cared for largely by their GP. When they experience an exacerbation of their illness, they attend their GP, or if their disease is more serious they seek access to medical services via the Accident and Emergency Department of their local hospital. In such cases they will be seen by the consultant on call, and are generally transferred to their main consultant the next working day. Hospital admissions under such circumstances concentrate on treating the exacerbation and discharging the patient home, usually back to the care of the GP. On admission, depending on the need of the individual and availability, the patient may be attended to by a CNS who is involved in the assessment, planning delivery and evaluation of care. As well as carrying a clinical caseload the consultancy and education aspect of the CNS role facilitates work across traditional primary and secondary boundaries [140, 141]. The patient could also be referred to physiotherapy, occupational therapy, social work and other allied health professions. Where appropriate and where possible, these services will refer onto the community-based services.

There are very few CNS working within the hospital-based multi-disciplinary teams that are available to visit their patients in the community. Some GPs employ practice nurses. Practice nurses often have additional qualifications in respiratory, cardiology and dementia care [140]. However primary and community care has a pivotal role in the care of people nearing end-of-life as up to 90% of care of patients in their last 12 months of life occurs at home, with support of a GP, public health nurse (PHN) as well as practice nurses, occupational therapists, physiotherapists, speech and language therapists and occasionally other members of the multidisciplinary team (MDT) [142]. In many parts of the country, primary and community care will prioritise palliative care patients needing end-of-life comfort measures in the home, are often the primary advocates for seeking good care for their patients and frequently underpin the work by the community specialist home care team, including provision of bereavement support.

Previous Irish work in this area has identified that GPs see themselves as key figures in supporting the patient and family when a life-limiting diagnosis is being made, and in the delivery of palliative care. GPs identified that they would benefit from further education in palliative medicine, with specific emphasis on pain control and symptom relief [143, 144]. To date there are no formal frameworks for GPs or other community staff to seek support and resources in relation to palliative care needs of their patients. Local responses have been developed in many areas and there is strong commitment from GPs and other staff to provide high quality care for people dying in the community. Consideration needs to be given to the GPs' workload as the role of palliative care for people with conditions other than cancer expands.

4.3.2 SPECIALIST PALLIATIVE CARE SERVICES FOR PEOPLE WITH LIFE-LIMITING DISEASES

SPC services are available through specialist inpatient units, community SPC teams and the majority of AGH. The level of development of these teams varies around the country [2]. If patients are deemed to have SPC needs while an inpatient they may be referred to the SPC team for assessment on a consult basis. Following assessment, support and advice from SPC will be provided to the referring team on a continuing basis as needed. Some hospitals may provide SPC outpatient care on a joint basis with medical teams from other specialties though this practice is not widespread. Access to inpatient and community SPC services for people with diseases other than cancer varies throughout the country. The future establishment of the role of the Advanced Nurse Practitioner (ANP) within palliative care will build on the evidence required for practice development in this area [1].

4.4 CARE PATHWAYS AND PROGRAMMES

4.4.1 A number of AGH and extended care units in Ireland have adapted and implemented the LCP, to plan care in the last hours and days of life. (See 4.1.1).

4.4.2 The Hospice Friendly Hospitals (HFH) Programme is a 5-year national programme aimed at improving end-of-life care in Irish hospitals [149]. It is an initiative of the IHF and is the first national programme of its kind in Europe. Currently 42 acute and community hospitals are participating in the Programme nationwide.

The overall aim of the HFH Programme is to put hospice principles into hospital practice so as to ensure that a systematic quality approach exists within the health services to facilitate a good death when it is expected, or can be predicted, and supportive systems when death occurs unexpectedly. In order to achieve this, the HFH programme aims to:

- Develop comprehensive patient focused standards for all hospitals in relation to dying, death and bereavement.
- Develop the capacity of acute and community hospitals to introduce and sustain these standards.
- Improve the overall culture in hospitals and institutions in relation to dying, death and bereavement.
- Audit end-of-life care provision in acute and community hospitals.

Four key themes support the aims of this programme: integrated care; design and dignity; communication and patient autonomy. By working with these themes adequate supports and systems will be in place to ensure quality end-of-life experiences for all patients, families and staff. Participating hospitals in the HFH programme are using the Design and Dignity Guidelines for Physical Environments of Hospitals Supporting End-of-Life Care which were published in 2008 [150].

EXAMPLE OF HSE COMMUNITY INITIATIVE



HSE Community Intervention Teams (CIT) seeks to bridge the primary and community services in a client centred and holistic manner. The principal aim continues to be delivering required care in the most appropriate setting for the clients needs. The North Dublin CIT is one of 4 pilot sites in the country which have been operating for the past 2 years. Their emphasis is to provide a rapid response and after hours nursing service in a community setting, preventing unnecessary hospitalisation and promoting early discharge. The team is nurse led, has a full time medical social worker and has established strong links with the GPs and Services for Older Persons in the locality. Over an 18 month period the services received 1,500 referrals of which 40 required palliative interventions. The intervention from these teams is usually time limited to 3 days after discharge [145].

One of the principal objectives of the HFH programme is the development and adoption of palliative care approach (non-specialist palliative care) throughout hospitals in Ireland with all staff trained in palliative care principles, and this is linked to the patient-focussed standards relating to staff training.

Milford Care Centre, with the support of HFH Programme and IHF are developing a training opportunity to deliver on this objective, in the form of a distance learning eight-week certificate course aimed at doctors and nurses. The course – Delivering Care at the End-of-Life: Palliative Care Principles and Practice [151] – has been adapted for use in Ireland from the UK Princess Alice Certificate Course [152]. In the first year the HFH programme will provide 55 bursaries to staff of hospitals participating in the HFH Programme.

- 4.4.3 St. Francis Hospice is currently undertaking a two year programme in Dublin to seek to enhance non-specialist palliative care more effectively in three public nursing units. It is intended that this model, which will include rigorous evaluation, may help identify how best to improve delivery of the palliative care approach in non-specialist palliative care settings [153].

4.5 DISEASE-SPECIFIC INTERVENTIONS

- A small number of initiatives to address the broader palliative care needs of patients with **COPD** have been identified. A number of AGH have included a palliative care component in pulmonary rehabilitation programmes, and the Irish Association of Pulmonary Rehabilitation (IAPR) is seeking to standardise the format for such programmes. One teaching hospital has begun a small scale outreach project for people with severe COPD with encouraging results. Although there have been some recent respiratory outreach initiatives to address the existing gaps between primary, secondary and tertiary healthcare services, currently none of these has a specific palliative care content. These are detailed in Appendix 1.
- Despite the fragmentation of services for people with **dementia**, some dementia services (particularly those for people with intellectual disabilities) have begun to incorporate a palliative care component, and there are pockets of evidence of developing alliances between palliative care teams and services for people with dementia. These are explored in more detail in Appendix 2.
- There is little evidence available on the integration of palliative care within 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 palliative care for heart failure patients in the community. CNS working in heart failure and SPC report that heart failure patients are occasionally referred to SPC, mainly in acute hospital settings. St. Vincents University Hospital (SVUH), Dublin which has a comprehensive heart failure service has plans to develop a palliative component as part of this service [154]. Appendix 3 provides more detail.

PATIENT AND FAMILY ADVOCACY IN PALLIATIVE CARE



Caution about service user involvement in service developments within palliative care has been commonplace with many people suggesting that people with life-limiting conditions may be “too ill to talk” [146], yet implicit in the principles of palliative care is keeping the patient and family at the centre of their care [147]. The HSE recognises that service users should be centrally involved in their own care and has developed a strategy to assist this process, which includes a focus on advocacy and service user involvement in chronic disease management policy and practice [148] and should include their views on issues relating to palliative care.

Although developments are taking place in education and training in palliative care at undergraduate level in medicine and nursing, there is some inconsistency in the framework adopted by the different educational institutions. At post graduate level a specialist module on palliative care is included in the Higher Diploma in Specialist Nursing in Intellectual Disability and Dementia in the School of Nursing and Midwifery in Trinity College [155]. Further details of the extent of palliative care training at graduate and post-graduate level can be obtained from the PCET which is contactable through the IHF [79]. Appendix 4 details the educational requirements necessary to address this area as identified by the Extending Access Study.

4.6 KEY POINTS

- Integrated care pathways and programmes have been shown to be effective in delivering integrated care for patients who are dying from cancer or other life-limiting diseases. These have been effectively used in AGH and community services in the UK and are recommended in Irish health policy.
- Specialist services for COPD, dementia and heart failure are not available to patients in all areas of the country.
- The delay in the development of HSE primary care teams (both medical and MDT) and the lack of community-based specialist respiratory, dementia and heart failure nurses militate against development of the types of collaborative practice developing in the UK which could deliver non-specialist palliative care for these patients.
- There are very few examples of palliative care being incorporated as part of respiratory, dementia and cardiology services in Ireland. The few emerging models would benefit from further collaboration with SPC teams. An evaluation of these interventions would provide some evidence-based information to guide future service delivery.
- Further investigation is required to ascertain the level and range of access to SPC services in inpatient and community settings and with particular emphasis on AGH settings.
- Initiatives such as the HFH Programme will assist in raising awareness of the palliative care needs of people with diseases other than cancer as part of a wider end-of-life strategy or forum and promote the development of non-specialist palliative care throughout all services in hospitals in Ireland.
- The level of palliative care education available at post-graduate and under-graduate level is inconsistent.

Study Analysis and Deliberations

Throughout the course of the study there were a number of practical suggestions identified as helpful for the development of palliative care services for people with diseases other than cancer, namely: clarification as to predicted levels of referrals to SPC for people with non-malignant diseases, the implementation of standard eligibility criteria for referrals to SPC and the need for disease-specific referral triggers to indicate when SPC could be appropriate.

The study examined these areas in detail and the findings are presented in this section.

Chapter Five

Estimating Levels of Non-Malignant Access to Specialist Palliative Care

5 DATA ON ACCESS TO SPECIALIST PALLIATIVE CARE FOR NON-MALIGNANT DISEASES

Several studies and epidemiologically-based estimates that have been identified in this area are summarised below. Some have given rise to fears that SPC services would be overwhelmed if patients with diseases other than cancer were included for SPC services.

- A study by Addington Hall et al (1998) stated there would be an increase of at least 79% in caseload for SPC specialists if these services were made fully available to patients with a disease other than cancer [21].
- A study by Kite (1999) cites a survey of GPs and concludes that while there are resource implications for the extension of SPC to patients with non-malignant diseases, there is no evidence to support the contention that services will be overwhelmed [156].
- Gott et al (2001) examined activity in AGH in the UK in 1999. Twenty five percent of patients were identified as having palliative care needs, with 10% of these requiring a referral to SPC. Of the 25% identified, almost half of these were patients with a diagnosis other than cancer [157].
- The Rosenwax study (2005) identified that between 0.28% and 0.5% of people in the general population in any one year could potentially benefit from a palliative care approach (patients with cancer and those with other diseases) and that a proportion of these people would benefit from SPC services. The team was unable to be any more specific about the potential SPC cohort and advocate further research to estimate those people within the identified patient population who would require SPC services [158].

5.1 UK REPORTS

Two reports from the UK in 2007 which are detailed below do not support the contention that SPC services will be inundated by the inclusion of patients other than those with cancer. In fact they indicate that the fears that SPC services would be overwhelmed by open access have not been realised [159, 160].

The 2007 evaluation of inclusive SPC services by Addington Hall et al reported that the rates of referral for non-malignant diseases were varied, with some higher and some lower than expected. Aspects of the palliative care service reporting higher rates were complementary therapy, social support and hospice at home, and those reporting lower rates were specialist community, day and inpatient palliative services.

This evaluation also demonstrated that SPC services which have already extended access to patients with non-malignant diseases have introduced the following strategies to ensure both the provision of an appropriate service to patients and to avoid their services being overwhelmed:

- Accurate referral and discharge criteria
- Rigorous review and audit of the service being provided
- Starting small and building on work once experience is gained.

The evaluation concluded that:

- Specialist inpatient units can contribute a wide range of services to care of patients with diseases other than cancer via direct patient care, and indirectly through palliative education for both specialist and generalist staff.
- Specialist inpatient units should not be put off by concerns about being overwhelmed.
- An essential element of extending hospice care to patients with conditions other than cancer is education and training [160].

In December 2007 the National Council for Palliative Care in the UK published comparison figures over the past ten years on access to SPC by patients with diseases other than cancer, based on information gathered from the UK Minimum Data Set. Although these do indicate an increase in access to SPC services by people with non-malignant diseases, they do not show the large increases predicted in some of the studies mentioned earlier. This data is set out below.

UK National Council for Palliative Care Minimum Data Set

	1996/7	2006/7
Hospital Support	5%	13.6%
Day Care	6%	10.1%
Home Care	3%	7.3%
Inpatient Care	5%	7.2%

The percentage shown is that of patients with diseases other than cancer accessing SPC services in all settings as a proportion of the total SPC patient population for those services. Access rates in 2006/2007 are 7.3% for home care and 7.2% for inpatient care [159].

5.2 IRISH DATA

There have been two studies in Ireland which have examined access to SPC for people with diseases other than cancer, and more recent reported data from SPC services. This data will help to inform the level of access to SPC for this patient population in this country in the absence of any standardised data gathering system.

- In 2006 Corcoran carried out a retrospective survey of patients with a non-malignant diagnosis who were referred to a specialist inpatient unit in Ireland over a six year period, (2000-2005). The findings of this longitudinal study indicated:
 - 6.35% of all referrals to community SPC services were non-malignant
 - 2.9% of all the referrals to the SPC inpatient unit were non-malignant [72].
- A study by O’Leary et al examined the provision for SPC for people with non-malignant diseases in Ireland based on 2004 figures. With a 100% response rate, all respondents claimed that their service was available to non-cancer patients; however three of the inpatient units surveyed limited access to SPC to people with cancer, MND and HIV/AIDS only. The breakdown of access for was reported as follows:
 - 6% of all referrals to SPC home care team were non-malignant
 - 2.7% of all referrals to SPC inpatient unit were non-malignant
 - 9.2% of all referrals to SPC AGH team were non-malignant [7].
- O’Leary’s study concluded that the proportion of non-malignant patients of the overall SPC workload has remained steady at less than 10% over the last decade, similar to figures from UK, Australia and New Zealand [7].
- The Extending Access Study sought up-to-date information from community SPC home care services attached to the eight specialist inpatient units in Ireland regarding their level of provision of services to people with diseases other than cancer in 2006 and 2007. Seven services provided this information and the average figure on non-malignant access to community based SPC was 7%. Two of the seven surveyed indicated they restricted non-malignant access largely to MND patients. Two of these services reported that SPC access trends are increasing in 2008 for non-malignant referrals.

- Marymount Hospice in Cork and Milford Hospice in Limerick report that their SPC services have openly accepted patients with SPC needs irrespective of diagnosis for the past number of years. During this period of time the referrals for patients with non-malignant disease have averaged 7% [161].

5.3 SUMMARY

The data demonstrates that in recent years access in Ireland to community SPC services has averaged between 6% and 7% for people with diseases other than cancer, with an average 3% access to the SPC inpatient unit. It is noteworthy that these reported levels of access in community SPC services and inpatient units arise from a needs-based referral system. The IHF is aware that the operation of this referral system based on needs not diagnosis is not widely promoted or publicised by the specialist inpatient units. Greater awareness of the use of this needs-based referral system is likely to increase levels of referral.

The recent studies and data available on access to SPC in Ireland [7] and the UK [159, 160] show an increase in the number of referrals of patients with non-malignant conditions where a needs-based referral system is adopted. However they do not support the initial predictions that SPC services would be overwhelmed by extending their services to people with diseases other than cancer. They do indicate that strategies are required to manage services which are seeking to provide full access to SPC, particularly phasing the level of increase, providing education and training to encourage non-specialist palliative care and the introduction of eligibility and discharge guidelines. Such strategies can help to ensure the provision of appropriate services and prevent inappropriate referrals [160].

It is important to acknowledge that currently there is no uniform national method in place to assess the level of access to SPC for people with conditions other than cancer, and the evidence outlined above provides a snapshot in time of level of access to SPC services for people with non-malignant conditions. Following a recommendation of the NACPC report, the HSE has piloted the Irish Minimum Data Set for palliative care in a number of SPC sites for the past number of years, and has indicated its commitment to implement this in 2008 [5]. When this is fully operational it will form the basis for calculation of national statistics for SPC, including access to SPC for people with diseases other than cancer, and will provide a standardised mechanism for comparisons.

Chapter Six

The Role of Non-Specialist Palliative Care; Eligibility, Referral and Discharge Criteria for Specialist Palliative Care

6 INTRODUCTION

In order for both non-specialist and specialist palliative care to be available in all care settings more clarification is required with regard to the timing and role of all levels of palliative care. The identification of eligibility, referral triggers and discharge criteria for SPC services will also assist this process. This chapter seeks to provide some clarification and guidance in these areas and also seeks to outline where the responsibility lies for bringing about change in this area.

6.1 TIMING AND ROLE OF NON-SPECIALIST PALLIATIVE CARE

The primary endeavour of palliative care is optimising quality of life with a view to achieving a timely, dignified and peaceful death. If clinicians and health professionals are able to recognise unmet physical, social, psychological and/or spiritual needs that are causing significant distress to a patient with a life-limiting illness, and to respond and refer appropriately, a truly holistic approach to the care of their patients can be achieved [62]. Introducing non-specialist palliative care can facilitate this holistic approach in the care pathway of a person with a life-limiting illness. This approach can assist a patient with a life-limiting illness to regain some control, independence and dignity in their life. Non-specialist palliative care should be anticipatory care which meets all dimensions of needs of a patient with a life-limiting illness [162], should be responsive to help people adapt to their illness, take a realistic approach to defined goals and take its pace from the individual [38].

Non-specialist palliative care has been described by NICE UK as the provision of basic levels of symptom control, psychological, social and spiritual support and provision of open and sensitive communication with patients and their families. It is recommended that providers of non-specialist palliative care should assess patients' needs on a regular basis and know when to seek advice from or refer to SPC [163]. Training, education and support measures must be in place to ensure that all staff are aware of and can respond to the total palliative care needs of their patients. In seeking to achieve the integrated care of a patient with a life-limiting illness the development of skills should include focus on the comfort measures that can be undertaken to alleviate and soothe rather than necessarily treat, with specific attention given to mouth care, positioning, pressure care and fluid balance [24, 163].

The majority of non-specialist palliative care is provided by GPs, community nursing staff, AHPs and social work staff. It must be acknowledged that this may form only a small part of the normal workload of these staff [1, 29, 163].

When introducing non-specialist palliative care, it is advisable to have locally agreed guidelines and clarity on the ethics and duties that underpin changes in emphasis from disease-modifying interventions to palliative strategies. This process can provide a number of challenges for both the patient and staff involved [60, 128, 132].

The diagrams in Chapter 2 of this report demonstrate the unpredictable trajectory of life-limiting non-malignant diseases, when compared with pathways traditionally associated with malignant diseases. These diagrams have been adapted below to represent the timing of non-specialist palliative care in the non-malignant disease trajectory – the large oval throughout the disease trajectory – as well as the potential timing to refer to SPC which is denoted by a smaller oval.

Diagram 5 specifically represents the timing of non-specialist palliative care and potential for referral to SPC for people with COPD and heart failure. Diagram 6 outlines potential timing of palliative care (both specialist and non-specialist) for people with dementia or those who are frail.

DIAGRAM 5:
TIMING OF PALLIATIVE CARE IN DISEASE TRAJECTORY MOST COMMON IN HEART AND LUNG FAILURE [ADAPTED FROM 60]¹⁰

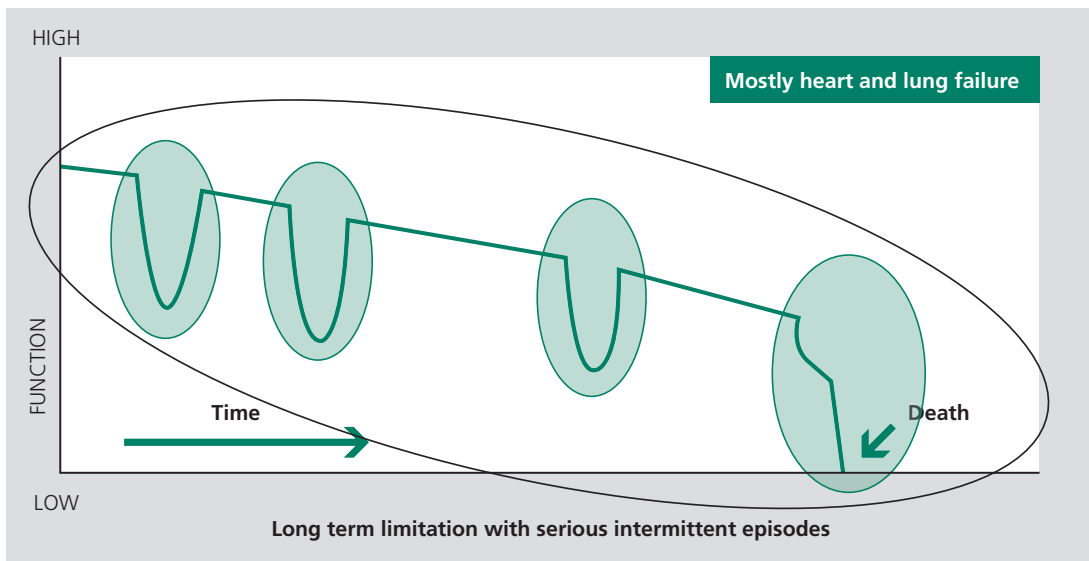
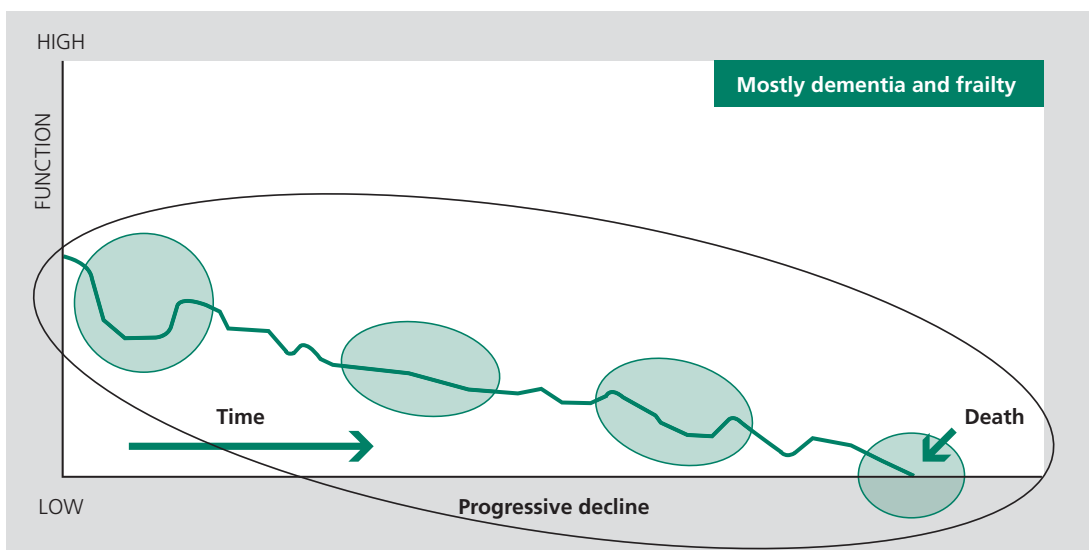




DIAGRAM 6:
TIMING OF PALLIATIVE CARE IN DISEASE TRAJECTORY MOST COMMON IN DEMENTIA AND FRAILITY [ADAPTED FROM 60]¹⁰



-  Large oval indicates timing for non-specialist palliative care
-  Green ovals indicate potential timing for SPC

These adapted diagrams seek to visually represent the timing of non-specialist palliative care within disease trajectory of those with non-malignant life-limiting disease. Using this approach should prompt queries relating to pain management, advance planning, disease trajectory, spiritual and psychosocial matters [25, 62, 148]. Staff addressing such needs with patients may from time to time require advice or a consultation with the SPC team if they are not in a position to respond to the palliative care needs that have been identified. It is important to note that palliative care needs can extend beyond the death of a patient, as often the primary care services remain involved with the family during the bereavement process.

¹⁰ © Diagrams 5 and 6 are adapted from a diagram reproduced with the permission of RAND Health

The smaller shaded oval in each of the diagrams indicates where particular consideration of the need to refer to and discharge from SPC may arise. 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 COPD or heart failure and/or complex co-morbidity). Wherever extraordinary need arises in the disease trajectory which cannot be addressed by the interventions from the attending team, referral to SPC should be considered.

Diagram 6 illustrates the insidious nature of decline that exists for people with dementia and/or who are frail/elderly which makes it more difficult to determine triggers to predict the need for referral to SPC for people with these diseases. Nevertheless the relationship between professionals who care for these people on a daily basis and the SPC team should be similar to those with more distinct exacerbations and remissions. It is accepted that the full application of this model would be dependent on a fully resourced disease-specific service framework. However some health services in Ireland are delivering on aspects of this model both from disease-specific and SPC interventions.

6.2 ELIGIBILITY CRITERIA FOR SPECIALIST PALLIATIVE CARE

In the absence of formal eligibility guidelines as indicators for referral to SPC, the common prompt “would I be surprised if this patient were to die within a year?” and the observation that the patient is deteriorating despite optimum medical treatment are often used. Although many service providers have developed their own individual eligibility and discharge criteria, the use of standardised eligibility and discharge criteria for both malignant and non-malignant diseases is recommended to assist in an equitable and consistent approach being applied for SPC services [7, 160]. The implementation of such criteria is particularly relevant when considering the often uncertain disease trajectory for non-malignant diseases as well as managing discharge of some patients who may refuse or are reluctant to leave a service.

The Extending Access Study sought to identify eligibility criteria that have been used for referral to SPC services for all life-limiting diseases, including cancer and other diagnoses, which could be considered for use within an Irish health context, and these are briefly outlined below.

6.2.1 LYNN 2003

Lynn documented the USA National Hospital’s Office general guidelines which require that:

- The patient and their family are aware of the life-limiting nature of the disease.
- That they have elected to pursue treatment aimed at symptom relief.
- That there is evidence of progressive disease coupled with multiple hospital admissions or emergency department visits, or a documented decline in function or unintentional progressive weight loss [60].

SELF-CARE FOR STAFF



The introduction of a self-care plan for palliative care providers encourages the development of protective practices and provides a systematic approach to identifying warning signs of stress and burnout in four self care domains [168]. This is particularly important for staff who work in isolation or are not part of a palliative care team, and self-care strategies can contribute to the quality of care that staff provide when working with patients with palliative care needs [169].

HSE West Palliative care services have recognised the need for this in their strategic plan, and one of their key recommendations is to ensure that a comprehensive range of fully developed staff support services is available in all SPC centres [148].

6.2.2 GRBICH 2005

The guidelines documented by Lynn were adapted by Grbich to include an unanticipated medical crisis precipitating a discussion on end-of-life care as one of the additions to progressive disease status [170].

6.2.3 BENNETT 2000

In 2000, Bennett et al drew up the Leeds Eligibility Criteria when seeking to change a diagnosis-based service to a needs-based service without any change in resources. These criteria have three key components, which focus on improving the quality of life for patients facing their own death and take into account that SPC is largely inappropriate for patients with disease that is stable/inactive. Implicit in introducing the criteria into clinical practice is the need for regular patient review. The criteria can be used as both entry and exit criteria to SPC services.

The criteria are:

1. **The patient has active progressive disease**
The patient will have a prognosis that is limited and the focus of care is quality of life.
2. **The patient presents with an extraordinary level of need**
This refers to a significant breadth/depth of need within physical, psychological, social or spiritual domains that is over and above the ordinary, or that cannot be met by the referring team. Examples of extraordinary need would include uncontrolled or complicated symptoms, considering complex situations relating to withdrawal or withholding of treatment, or requests for euthanasia.
3. **The patient has been assessed by a specialist palliative care service**
Patients who meet the first two criteria should be referred for SPC for assessment which should be performed by a nurse or doctor based in the SPC service, and the subsequent management will be determined by the assessment and will be by agreement with the patient, carer and referring team [171].

Bennett et al recommend that the care of patients should be based on models of shared care with primary and secondary care teams. The degree of input and expertise required from SPC will be determined by the patients' needs following the assessment by SPC staff. This assessment should be made as accessible and responsive as possible to the patients' needs. Bennett et al acknowledge that the definitions used may have some limitations. However the criteria have been used as arbiters when making uncomfortable decisions about the acceptance or rejection of patients and thus serve to reduce bias of SPC team members during this process. A common referral form based on these criteria has been devised to assist in the implementation [171].

- 6.2.4 The Leeds Eligibility Criteria were deemed to be most applicable eligibility criteria to be used in an Irish context by the SPC representatives of the Extending Access Study. To further determine their suitability, evidence is required as to clinical application of these criteria, with the concepts of the criteria requiring further guidance and explanation.

6.3 THE NEED FOR DISEASE-SPECIFIC REFERRAL TRIGGERS TO SPECIALIST PALLIATIVE CARE

Several studies recommend the use of disease-specific triggers to assist other specialities in recognising the signs and symptoms in particular diseases which may signal the need for a referral to SPC services [72, 127, 128, 132]. Disease-specific triggers can be particularly useful for non-malignant diseases due to the variable disease trajectory. The referral to SPC could be for clinical management from a medical or nursing perspective, or else the management of needs that can be met by the SPC, MDT or AHP. The SPC consultation for people with non-malignant diseases can frequently be once-off assessment, and would generally be based on a collaborative approach recognising the need for ongoing input from the disease-specific specialist.

The three Working Groups of the Extending Access Study determined referral triggers to SPC for COPD, dementia and heart failure. These are outlined below, and are referred to again in Appendices 1, 2 & 3 respectively.

6.3.1 CHRONIC OBSTRUCTIVE PULMONARY DISEASE REFERRAL TRIGGERS

It is recognised that patients with COPD who present with the indicators described below may require SPC services.

- Forced expiratory volume in one second (FEV1) <30% predicted accompanied by severely limited and declining performance status.
- Increased intensity of symptoms despite optimal treatment.
- Plus at least one of the following criteria:
 - advanced age
 - presence of multiple morbidities
 - severe systemic manifestations/complications of COPD [23,172].

Decisions to refer to SPC may be prompted following a respiratory assessment by a consultant respiratory physician.

6.3.2 DEMENTIA REFERRAL TRIGGERS

The following indicators are to be used as triggers for referral of a person with dementia to SPC:

- Increase in intensity of symptoms, e.g. pain, dyspnoea, terminal agitation, that cannot be managed or controlled by referring team.
- Assistance with the introduction of advance directives, or clarification regarding certain treatment decisions [173].

6.3.3 HEART FAILURE REFERRAL TRIGGERS

When the following clinical indicators are present in patients with heart failure they should be considered for SPC review:

- Persistence at NYHA Stage III or IV [56] 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 the patients referred to SPC.

6.4 DISCHARGE FROM SPECIALIST PALLIATIVE CARE

SPC needs can change over time. As a result of therapeutic intervention or re-investigation, a patient may not be in a state of active, progressive or advanced disease and would not require ongoing SPC support. Similarly, after a period of time in contact with SPC services, the extraordinary needs of a patient may become ordinary needs and unless there is a monitoring requirement, patients should be referred back to their original health care team [171].

Discharging patients from SPC services is frequently raised as a contentious issue. It appears that some specialist nursing teams discharge patients at the earliest opportunity and are open to re-referral, while others retain patients as “pending”, i.e. patients do not receive regular contact or intervention but remain on the caseload until a need arises. This anomaly arises due to the lack of evidence of good practice in the discharge of patients who no longer have specialist needs [174]. The rationale for discharging a patient can pose particular difficulties where the primary, secondary or tertiary care supports are not in place to respond to the total needs of the patient or family members. This can frequently be the cause of communication difficulties which can generate further stress on the patient and family [175, 176]. It has

been recommended that there is a need for more rigorous assessment of discharge procedure and outcomes across SPC teams in order to develop validated audit tools and to create the evidence on which to base discharge decisions.

It must be recognised that any delay in discharging a person who no longer requires SPC services will potentially limit access to SPC for patients with more significant needs. Clearly defined admission and discharge procedures for SPC are recommended for inclusion when introducing standards in palliative care services [77, 84, 127]. Such guidelines would provide the much needed clarity for the patient, family, referring team and SPC staff.

6.4.1 DEVELOPING A DISCHARGE POLICY

Several SPC services in Ireland have developed their own discharge policies. An example of a policy that is under development in Our Lady's Hospice in Dublin is highlighted below.

A patient may be discharged from SPC if one or more of the following criteria are met:

1. There is a change in disease status such that the patient no longer has any SPC needs e.g:
 - Investigations reveal less advanced disease than previously thought
 - Following response to treatment
 - Disease evident as only slowly progressive.
 2. There is symptomatic improvement such that the patient no longer has SPC needs.
 3. Following initial SPC assessment, it is agreed that they do not have SPC needs and ongoing needs are more appropriately met by other health care agencies.
 4. The patient, following informed discussion, expressly requests discharge from SPC.
 5. The patient or family persistently prevent effective SPC input e.g. restricting access for assessment.
- The SPC team are, however, always available to offer support to involved health care professionals.

If a patient meets any of the above criteria, it is appropriate to consider discharge with ongoing care from other health care providers including GP, hospital team etc. Such decisions will be made following multi-professional discussion, with the patient and family being involved in the discharge process. The patient, the referring team and all relevant health care professionals must be advised in advance of the decision to discharge. It is important to note that patients can be re-referred should they develop SPC needs once more [177].

The Leeds Eligibility Criteria, outlined above, could also be used as a baseline for discharging from SPC services [171].

6.5 SHARING RESPONSIBILITY FOR ENSURING ALL LEVELS OF PALLIATIVE CARE IS AVAILABLE

Palliative care services, both non-specialist and specialist, should be available in all care settings, and should be a component of care between diagnosis and death, with close integration in hospital and community services [1]. However the information in earlier chapters of this report has identified that non-specialist palliative care services are under-developed within the disease-specific services and primary care in Ireland, with lack of policy direction in this area [11, 12, 22]. It is helpful to reflect where the responsibility lies for bringing about the necessary change in this area, as there are many potential conduits and inhibitors that can influence the development of access to palliative care for people with non-malignant conditions.

The report of the NACPC clarifies that the SPC team has a role with regard to the provision of advice, support, information and education updates to other health care professionals, patients and families in both acute and community settings, with a specific mention in relation to symptom control. This view is supported by several other publications, with the acknowledgment that SPC often leads research and development agendas, as well as being major providers of education in end-of-life care [24, 163]. However it is also recognised that family physicians and nurses should lead the way in instigating a palliative care approach for patients with life-limiting illness, as this approach is consistent with the holistic person-centred approach that is advocated by primary care [73, 139].

International disease-specific professional groups have also clarified their responsibility in this area. Specific leadership has been shown by the American Thoracic Society [71], European Respiratory Society [70], Alzheimer Europe [121], European Society of Cardiology [57], American College of Cardiology [125] and Heart Failure Society of America [69] in acknowledging the need to integrate appropriate levels of palliative care within routine care. Of particular relevance are the guidelines from the European Society of Cardiology which recommend that a collaborative approach between cardiologists and SPC is required to address the palliative care needs of patients with end-stage heart failure [123].

Taking account of this information, there is appears to be consensus amongst a wide body of professional groups and health service providers that they all have a role in ensuring palliative care is available to patients with life-limiting illness throughout their disease trajectory. Developing a solid bridge of communication between primary, secondary and tertiary care will enhance the ability for collaboration, support, and education, so that patients can receive a reassuring professional presence in the face of death [62, 162]. Leadership is required from all the relevant stakeholders within service delivery, education, policy and academia to ensure that the necessary steps are taken to ensure that this can be achieved.

BEREAVEMENT SUPPORT



Bereavement support is an essential aspect of palliative care. It should begin early in the disease process, before the death of a patient and be available in all care settings. Appropriately trained staff including social workers, psychologists, nurses and professional counsellors may each play a role in bereavement support in these different settings. Although the majority of bereaved people are able to manage the grief and loss they experience with the help of family and friends, a small minority of people may require some bereavement counselling [1]. It is recognised that there are three levels of bereavement support, firstly through the provision of information. The next level is more formalised support from trained volunteers or via the social work department. A very small minority of people may consider seeking more professional help [164, 165]. Implicit in these three levels of support is the use of a bereavement risk assessment, which should be used to guide discussions with individuals or families about the level of bereavement care that might be most suitable to them [1]. Bereavement services have been identified as a component of palliative and end-of-life care for people with cardiopulmonary disease and their families [166] as well as for patients with dementia and their relatives [167].

6.6

KEY POINTS

Role and timing of palliative care

- Non-specialist palliative care should be anticipatory care which meets all dimensions of needs of a patient with a life-limiting illness.
- The provision of education, training and support measures for staff are necessary to ensure that the palliative care needs of people with diseases other than cancer are appropriately met.

Eligibility criteria

- 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 strengthen the identity of the SPC service.

Specialist palliative care referral triggers

- Disease-specific referral triggers are to be used to assist in identifying the need for referral to SPC, and the use of such triggers should be reviewed.

Discharge criteria

- The use of discharge criteria is recommended to assist in the management to SPC services.

Delivering palliative care in all care settings

- The responsibility for ensuring all levels of palliative care rests with all those involved in the management and delivery of care as well as relevant bodies within education and policy.

Implementing Change

This section includes a summary of the main points identified in this report, lists the overarching and disease-specific recommendations that are required to address the challenges identified and outlines the plan for the implementation of these recommendations.

Chapter Seven

Summary

7 OVERVIEW

Since 2001 Irish government health policy has indicated that palliative care should be available in all care settings and should consider the needs of patients with malignant and non-malignant diseases. However policy commitments relating to management of life-limiting diseases other than cancer are only emerging. Specifically HSE working groups have been recently established on COPD, Dementia and Heart Failure. Following submissions arising from the work of the Extending Access Study it is anticipated that finally palliative care needs will be recognised and referenced in future policy frameworks for people with non-malignant, life-limiting diseases. One of the future challenges will be to implement such policy directions as well as to ensure that palliative care is referenced in all disease management frameworks at policy and operational level.

International practice in this area has demonstrated that collaboration between SPC and disease-specific specialists is the most effective method to achieve delivery of all levels of palliative care. The requirement for SPC to educate their colleagues with regard to aspects of non-specialist palliative care is coupled with the need for joint expertise when dealing with the SPC needs of people with non-malignant diseases. The development of disease-specific strategies and end-of-life programmes in other countries can provide some direction for non-specialist care needs to be responded to appropriately.

7.1 NON-SPECIALIST PALLIATIVE CARE AND NON-MALIGNANT DISEASES

When seeking to determine how non-specialist palliative care can be integrated into disease-specific frameworks this report identified a number of challenges and barriers as follows:

- The lack of awareness of the role of palliative care for people with life-limiting, non-malignant illness
- The lack of evidence-based service models or research in this area
- The lack of training and education provision in palliative care for staff working with people with life-limiting, non-malignant diseases
- The need for further monitoring and governance systems in this area
- The sense of apprehension expressed about introducing non-specialist palliative care
- The lack of policy framework for people with life-limiting, non-malignant diseases
- The absence of comprehensive service frameworks for people with COPD, dementia and heart failure at primary, secondary and tertiary levels.

7.2 SPECIALIST PALLIATIVE CARE AND NON-MALIGNANT DISEASES

Although it has been recognised that SPC services in Ireland are well developed by international standards, it is difficult to obtain accurate data on the specific level of access of SPC for people with COPD, dementia and heart failure.

Eleven percent of SPC services indicate that they provide services only to people with cancer, MND and people with AIDS and 19% of services limit in some way the care provided to patients with non-malignant conditions. The limited availability of education and training in this area, the lack of standardised eligibility and discharge criteria and the uncertainty of the disease trajectory of non-malignant diseases have been frequently cited as barriers to development of SPC in this area. The need to determine referral triggers to assist with the timing of referral to SPC has also been suggested as helpful.

As part of its deliberations the study sought to address some of these barriers, as well as seeking to estimate the service level of non-malignant access for which SPC services need to plan. The outcomes of these determinations are summarised as follows:

- Projections for access to SPC services for people with diseases other than cancer appear to be lower than anticipated in earlier reports. This is based on examination of recent Irish and UK literature and data from a number of Irish SPC services that have reported an open referral system based on needs rather than diagnosis. It is accepted that standardised data collection is required to determine more accurate projections in this area.
- 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 strengthen the identity of the SPC service. It is recommended that SPC services and their representative professional bodies consider and agree on a mechanism to determine and introduce eligibility criteria for SPC services in Ireland.
- The importance of developing a discharge policy for all patients in SPC was emphasised and criteria for such policy have been outlined in Chapter 6. However as primary care and specialist services outside of palliative care are under-developed it is acknowledged that discharging people from SPC can be problematic.
- Disease-specific triggers for referral to SPC are helpful in generating awareness of the role of SPC for people with non-malignant diseases.

7.4 ADDRESSING THE CHALLENGES

Bringing about change within health care provision is particularly challenging because of the complex relationships that exist between a wide variety of organisations, professional groups, patients and carers and the HSE [178]. Seeking to extend palliative care to people with non-malignant diseases is no exception. The challenges listed above must be accepted by a wide variety of stakeholders, from policy makers, education providers, health care providers – both statutory and voluntary – and patients and their carers. There needs to be openness from all those who have responsibility for management and delivery of care for people with life-limiting, non-malignant diseases to work collaboratively to overcome these challenges.

The recommendations which follow seek to identify how these conclusions, barriers and challenges can be addressed. Each of the Extending Access Working Groups has specifically prioritised recommendations relating to the development of service models. It is acknowledged that a strong implementation plan is critical to ensure that the recommendations are progressed.

Recommendations

The Extending Access Study has identified a number of overarching recommendations that are common to the development of palliative care for all people with life-limiting diseases.

Disease-specific recommendations have also been identified to ensure that appropriate levels of palliative care are available to people with COPD, dementia and heart failure.

Detailed rationale for the recommendations on COPD, dementia and heart failure can be found in Appendix 1, 2 and 3 respectively.

All of the recommendations are grouped under the headings Policy, Education, Service Model and Research.

Chapter Eight

Recommendations

Overarching Recommendations

Policy

1. Current government health policy that refers to people with life-limiting non-malignant diseases does not make reference to the need for palliative care.

All policy documents that refer to life-limiting diseases are to include plans for access to appropriate non-specialist and specialist palliative care.

Department of Health and Children

2. Although the HSE currently funds the majority of SPC services in Ireland, and Government policy states that SPC services should be available to all patients, a small number of SPC services restrict their services to people with malignant disease, MND, HIV and AIDS.

- a) The recommendations of the 2001 report of the NACPC are fully implemented.
Health Service Executive / Department of Health and Children
- b) Governance and monitoring systems to be introduced to ensure that SPC is provided on the basis of need rather than diagnosis to all patients with life-limiting illness.
Health Information and Quality Authority / Health Service Executive

3. As palliative care seeks to focus on quality of life and adopts a holistic approach to patient care which encompasses both the person diagnosed with a life-limiting disease and those that matter to them, it can be helpful to embrace these principles in a variety of end-of-life programmes within a population health approach.

The introduction of an end-of-life strategy⁹ to support and guide all health service staff who work with people who are near end-of-life, in order that all people can maximise quality of life and die with dignity and comfort.

Department of Health and Children / Health Service Executive / Irish Hospice Foundation

Education

4. It is vital that the changing nature of palliative care needs is addressed in all levels of palliative care education and this should be considered in formal education provision and informal educational opportunities. 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 the recommendations below.

- a) Organisations associated with formal education of professionals working with people with life-limiting illness to include palliative components in their training curriculum.
Health Service Executive / Palliative Care Education Taskforce / Medical Education Training and Research Unit and relevant educational institutions
- b) The generation of educational material providing information on the role of palliative care for all people with life-limiting non-malignant diseases is required, including disease-specific referral triggers for SPC. Such material should be based on information in this report.
Health Service Executive / Irish Hospice Foundation

⁹ End-of-life strategies have been developed in other countries as a mechanism to deliver increased choice to all patients, regardless of their disease, about where they live and die. Such strategies seek to provide patients with the support to make this possible, and enhance co-ordination between all relevant service providers in this area.

- c) Education and training opportunities to be encouraged for all SPC staff who wish to gain a greater depth of understanding of palliative care for people with life-limiting non-malignant diseases. Further research would also be helpful to ascertain the learning needs of SPC teams in this area.

Health Service Executive / Palliative Care Education Taskforce / Medical Education Training and Research Unit and relevant educational institutions

- d) All allied health professionals and healthcare staff to be trained in palliative care relevant to their specialty and grade, so that appropriate levels of palliative care can be delivered when required by all staff.

Health Service Executive / Palliative Care Education Taskforce / Medical Education Training and Research Unit and relevant educational institutions

5. In seeking to develop quality of services for older people HIQA have recently launched National Quality Standards for Residential Care Settings for Older People. Standard 16 seeks to ensure that each resident continues to receive care at the end of his/her life which meets his/her physical, emotional, social and spiritual needs and respects his/her dignity and autonomy [85].

Develop education and training service initiatives at level 1 and level 2 of the 5-level palliative care educational framework to skill staff within residential care settings for older people so they can provide non-specialist palliative care as specified in the HIQA standards.

Health Service Executive / Specialist Palliative Care / Education Departments with support from Irish Hospice Foundation

Service Model

6. International evidence indicates that people with non-malignant diseases benefit most when palliative care service models are based on a collaborative and/or shared care approach between the disease-specific specialist, primary care staff and the specialists in palliative care. The recommendations in this section will be augmented by the service model recommendations outlined in the disease-specific appendices (Page 55 – C.1; page 57 – D.1; page 59 – H.1).

All health staff who care for patients with life-limiting non-malignant diseases, including those in SPC, disease-specific specialties and primary care, should work in a collaborative manner so that the patients' palliative care needs are met in appropriate settings.

Health Service Executive / Specialist Palliative Care

7. It is recognised that the majority of patients can have their palliative care needs addressed by primary care and disease-specific services where there is appropriate training and support from SPC. In a minority of cases the particular circumstances may necessitate SPC services becoming involved in a more direct way. Care of the imminently dying patient at home is one situation where, on occasion, only the SPC services may have the expertise and structures in place to ensure timely and appropriate care.

Patients who are thought to be dying imminently and have chosen to do so at home should be able to avail of SPC if required.

Specialist Palliative Care / Health Service Executive

8. The use of standardised eligibility criteria for entry into and exit from SPC services will assist in providing clarity and equity of access for those patients with SPC needs and strengthen the identity of the SPC service. The establishment of referral criteria for SPC can assist in identifying appropriate referrals.

- a) SPC services and their representative professional bodies to consider and agree on a mechanism to determine and introduce eligibility criteria for SPC services in Ireland.
Irish Association of Palliative Care / Irish Palliative Medicine Consultants Association / CEO Hospice Groups / Health Service Executive
- b) All SPC services to introduce discharge guidelines for all patients in receipt of their service.
Specialist Palliative Care
- c) SPC referral triggers to be developed for other non-malignant life-limiting diseases, for example those with chronic kidney disease, scleroderma, pulmonary fibrosis and cystic fibrosis.
Irish Hospice Foundation / Specialist Palliative Care / Health Service Executive and relevant professional organisations

Research

9. Services for people with life-limiting non-malignant illness at primary, secondary and tertiary levels have always endeavoured to respond to patients who are facing death within the limited resources they have.

An extensive mapping exercise is required to determine the extent and range of service delivery initiatives that support people with life-limiting diseases other than cancer who are in the advanced stage of their illness. Such an exercise should include primary care, acute care and residential settings, and should determine if such initiatives have been evaluated.
Health Service Executive / Irish Hospice Foundation

10. There is a dearth of evidence-based service models and clinical interventions relating to palliative care for people with non-malignant diseases, particularly COPD, dementia and heart failure. The following developments are required to progress this.

- a) Research is required to determine the impact of palliative care for people with illnesses other than cancer focussing on clinical management and service delivery.
Health Research Board / Health Service Executive / Irish Hospice Foundation
- b) It would be beneficial for universities and third level institutions to consider developments in palliative care as areas for on-going research.
Medical Education Training and Research Unit
- c) Research for palliative care requires additional financial support.
Health Service Executive / Health Research Board

Disease-Specific Recommendations

The disease-specific recommendations emanate directly from the deliberations of the Extending Access Working Groups on COPD, dementia and heart failure. The rationale for these recommendations can be found in the detailed disease-specific Appendices 1, 2 and 3 of this report.

CHRONIC OBSTRUCTIVE PULMONARY DISEASE

For palliative care to be embedded in the COPD patient's care pathway a multifaceted approach is required to address the challenges. In addition to speedy development of COPD services which integrate palliative care in primary, secondary and tertiary healthcare, the Extending Access Study identified that there is a need for greater clarity and raised awareness of the role of all levels of palliative care for people with COPD. The recommendations outlined are prioritised in relation to service model development, education, policy and research. They seek to ensure a greater awareness of the role of palliative care – both specialist and non-specialist – for patients with COPD so their palliative care needs can be identified and met regardless of their care setting. Further background to the COPD recommendations can be found in Appendix 1.

C.1 Service Model

- a) A project group is to be established to devise, plan and oversee a proposed Model of Care for patients with COPD who have reached stage III or IV disease classification within a designated health location encompassing an AGH, 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 COPD 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; it 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 respiratory health initiatives within AGH, Primary care and SPC.
Health Service Executive with support from Irish Hospice Foundation and Irish Thoracic Society
- b) All Pulmonary Rehabilitation programmes should include a palliative component.
Health Service Executive / Irish Association of Pulmonary Rehabilitation
- c) A series of fact sheets are to be produced to encourage and assist patients with COPD in their self management and their overall understanding of their disease.
Irish Thoracic Society / Irish Hospice Foundation

C.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 and education initiatives such as meetings, annual study days, journals clubs etc, between respiratory and palliative care professionals are required to enhance understanding and promote collaboration in this area.
Irish Thoracic Society with support from Health Service Executive / Irish Association of Palliative Care / Irish Hospice Foundation
- b) Post graduate education for staff working in respiratory medicine should have a defined palliative care component.
Health Service Executive / Palliative Care Education Taskforce / Medical Education Training and Research Unit and relevant educational institutions

- c) An information leaflet on the triggers for referral to SPC and role of palliative care for people with COPD should be produced to assist in generating awareness for all staff working in this area. (See also recommendation 4b).

The Irish Hospice Foundation with support from Irish Thoracic Society / Health Service Executive / Irish Association of Palliative Care

C.3 Policy

All service and policy developments relating to COPD should reference the need for palliative care to be part of the COPD service framework.

Department of Health and Children / Health Service Executive

C.4 Research

- a) Emerging COPD treatment interventions which have a palliative care element should include evaluation which will assist in determining evidence-based information on the timing and impact of palliative care for people with COPD.

Health Service Executive / Health Research Board / Irish Hospice Foundation

- b) Monitor Hospital Inpatient Enquiry System (HIPE) data to determine if a frequency of three or more admissions to hospital can be used as an additional trigger for referral to SPC.

Health Service Executive

- c) Further examination is required regarding the palliative care needs of people with other respiratory diseases.

Health Service Executive / Irish Hospice Foundation / Irish Thoracic Society

DEMENTIA

It is accepted that palliative care should be included in the care pathway for people with dementia, and that the person-centred approach that is advocated for dementia services integrates well with palliative care principles. However there are a number of challenges associated with the implementation of palliative care for people with dementia, including ethical considerations, education and timing of palliative care interventions. The recommendations which follow arise from an identified need for better structured and more widely available dementia-specific services which include access to palliative care, as well as evaluating and building on those services which have already specifically included non-specialist palliative care within their service framework. The need for evidence-based information and clarity about the role of palliative care in dementia is addressed as is the issue of training and education for all healthcare professionals and support staff who care for people with dementia. Further context to these recommendations can be found in Appendix 2 of this report.

D.1 Service Model

- a) A project group is to be established to devise, plan and oversee a proposed Model of Care outlining the palliative interventions required for patients diagnosed with dementia within a designated health location ideally encompassing an AGH, residential facility, 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 dementia. 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 as well as family members and the person with dementia; 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 initiatives relating to care of persons with dementia in residential care settings, Primary Care and AGH.

Health Service Executive / Irish Hospice Foundation with support from Alzheimer Society of Ireland / Dementia Services Information and Development Centre

- b) Every effort should be made to ensure that people with dementia die in an environment and amongst staff that they are familiar with.

Health Service Executive

D.2 Research

Research should be carried out to:

- a) Prepare and validate clinical standards for assessment and treatment of end-of-life symptoms of people with dementia.

Health Service Executive / Irish Hospice Foundation with support from Dementia Services Information and Development Centre / Alzheimer Society of Ireland

- b) Devise a practical framework for the classification of terminal dementia.

Health Service Executive / Health Research Board with support from academic institutions

D.3 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) Host study days to generate greater awareness and understanding on the role of palliative care within dementia services.
Specialist Palliative Care / Older Persons Services, Psychiatry of Old Age / Irish Hospice Foundation / Health Service Executive with support from Alzheimer Society of Ireland / Dementia Services Information and Development Centre
- b) Post graduate education for all staff working in the area of dementia should have a defined palliative care component suitable to their skill level, and SPC staff working in this area should be able to access training in this area, so that palliative care needs of people with dementia can be identified and responded to at appropriate levels.
Health Service Executive / Palliative Care Education Taskforce / Medical Education Training and Research Unit and relevant educational institutions
- c) Provide opportunities for distance learning Continuing Professional Education in dementia and palliative care.
Health Service Executive / Dementia Services Information and Development Centre / Palliative Care Education Taskforce and relevant educational institutions.

D.4 Policy

- a) The HSE National Working Group on Dementia should consider recommendations of this report.
Health Service Executive
- b) Future monitoring of services should consider the introduction of an ageing in place policy so that people with dementia live in an environment which adapts to their changing needs throughout the course of their illness.
Health Service Executive / Department of Health and Children

HEART FAILURE

People with heart failure are living longer and the prevalence of this disease is increasing in Ireland. A national comprehensive heart failure service which includes access to palliative care is urgently required. The Extending Access Study identified that many of the palliative care needs of heart failure patients can be met from within a comprehensive heart failure service with collaborative models benefiting patients where SPC needs are identified. While current cardio-vascular policy is well developed no current policy or strategy recognises palliative care needs of this patient group. The recommendations seek to establish links between heart failure and SPC services to respond to patients' SPC needs; to heighten awareness of and provide clarity on the role of non-specialist palliative care in the heart failure patient's journey; support education initiatives and to build on existing Irish research in this area. Further context for these recommendations can be found in Appendix 3 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 institutions
- 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, must have a community component and include access to appropriate levels of palliative care.
Health Service Executive / Specialist Palliative Care

Chapter Nine

Implementation

IMPLEMENTATION PLAN

The implementation of the recommendations of this report requires engagement and commitment from a wide variety of stakeholders. The views expressed during the consultation phase of the study demonstrated that ownership and responsibility for the delivery in this area needs further debate and clarification and that funding must be linked to the implementation plan.

The palliative care needs of the patients with life-limiting illness and their families must remain the constant focus of any plan. The expectations for the roll-out of the recommendations need to be realistic, complement the HSE organisational changes that are taking place, and processed in such a way that they can be embedded within service delivery. They must also impact on education, policy and research outcomes to ensure that the palliative care needs of people with life-limiting diseases will be fully addressed and integrated within disease management frameworks in the future. Some of the recommendations may require a shift in terms of the focus of service delivery and change in attitudes. They may also be dependent on an element of skill acquisition and the introduction of audit and evidence-based systems to ensure that change is delivering the desired results.

DELIVERING ON PALLIATIVE CARE FOR ALL

Following the publication of this report a forum, entitled Delivering on Palliative Care for All, will be held to discuss the impact of the report and clarify areas of responsibility and actions required for the implementation of its recommendations. This forum will facilitate the development of an action plan based on identifying and prioritising the recommendations and taking into consideration the funding, capacity and emerging HSE integrated structure of service delivery units. All those who have been identified as having a role in delivering palliative care services for people with non-malignant diseases will be invited to attend.

This forum will also provide an opportunity to allow the wide range of services providers, educational institutions, professional groups, voluntary bodies and individuals to examine and discuss the findings the report.

The agreed action plan arising from the forum will be published and circulated and will form the basis of the implementation plan for this report. The action plan will refer to the principles underlying the HSE Change Model and the National Integration modifications that are planned as part of the Transformation Programme [179]. The HSE will have ultimate responsibility for monitoring this plan.

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Appendix One

Palliative Care and Chronic Obstructive Pulmonary Disease

Appendix One

Palliative Care and Chronic Obstructive Pulmonary Disease

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PREFACE TO APPENDIX 1: PALLIATIVE CARE AND CHRONIC OBSTRUCTIVE PULMONARY DISEASE

“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).

CHRONIC OBSTRUCTIVE PULMONARY DISEASE WORKING GROUP MEMBERSHIP:

Angela Edghill
IHF Project Team

Dr. Stephen Higgins
Consultant in Palliative Medicine

Geralyn Hynes
HRB Clinical Nursing & Midwifery Fellow, School of Nursing & Midwifery, Trinity College Dublin

Marian Johnson
Clinical Specialist in Respiratory Physiotherapy

Anna Marie Lynch (Chair)
Clinical Nurse Specialist in Palliative Care

Marie Lynch
IHF Project Team

Patricia McLaughlin
Respiratory Clinical Nurse Specialist

Catherine Meagher
Lecturer, School of Nursing & Midwifery NUIG, Practice Nurse Representative

Dr. Eithne Mulloy
Consultant Respiratory Physician

Palliative Care and Chronic Obstructive Pulmonary Disease

1. INTRODUCTION

This Appendix outlines the prevalence and manifestations of COPD, examines international developments with regard to COPD and palliative care and explores potential service models where palliative care services can be included as part of comprehensive management of COPD based on an Irish context. The appendix concludes with deliberations and recommendations of the Extending Access Working Group on COPD and palliative care. These recommendations should be considered with regard to the overarching recommendations in the main body of this report.

2. WHAT IS CHRONIC OBSTRUCTIVE PULMONARY DISEASE?

Definition and Background

COPD is a term used for a number of diseases including chronic bronchitis and emphysema which are now included within the diagnosis of COPD. This disease is preventable and treatable, and it generally leads to damaged airways in the lungs, causing them to become narrower and making it harder to breathe. This constriction is not fully reversible and is usually progressive. The disease may follow different patterns from person to person. Some people experience a rapid progressive decline in lung function with increasing morbidity and early death, while others present with a progressive decline in lung function that, whilst more severe, nonetheless mimics the downward curve of lung function associated with ageing. COPD is associated with acute exacerbations and there is a positive correlation between the frequency of exacerbations and accelerated decline in lung function [3].

The Global Initiative for Chronic Obstructive Lung Disease document classifies four stages of COPD which are outlined in the table below [4].

Stage		Symptoms	Pulmonary Function Tests with a Forced Expiratory Volume (FEV1) result of:
Stage I	Mild	Often minimal shortness of breath with or without cough and/or sputum. Individual usually unaware that lung function is abnormal.	> 80% of predicted values/performance
Stage II	Moderate	Often moderate or severe shortness of breath on exertion, with or without cough or sputum. This is typically the first stage at which patients seek medical attention due to chronic respiratory symptoms or an exacerbation of their disease.	50-80% of predicted values/performance
Stage III	Severe	More severe shortness of breath, reduced exercise capacity, fatigue and repeated exacerbations which usually impact on patients' quality of life.	30-50% of predicted values/performance
Stage IV	Very Severe	Very appreciably impaired quality of life due to shortness of breath. Possible exacerbations may be life threatening. Respiratory failure may lead to right heart failure.	Less than 30% of predicted values/performance – or less than 50% with chronic respiratory failure

2.1 EPIDEMIOLOGY AND MORTALITY

The prevalence of COPD internationally is generally thought to be between 5% and 10% of population, based on European and US Population studies, with approximately 44 million cases worldwide [5, 6]. It is a leading cause of morbidity and mortality and it is expected that by 2020 it will be the third leading cause of death. Approximately 250,000 people die each year in Europe because of COPD.

A European Community Respiratory Health Survey showed an 8% prevalence of chronic bronchitis in those aged 20-44 years in Ireland, and this survey showed that Ireland was second only to Spain in terms of the prevalence of chronic bronchitis also referred to as COPD [3]. Given the prevalence of smoking among young adults it is unlikely that mortality from COPD will fall dramatically in the medium term and therefore Ireland is likely to continue to have one of the highest mortality rates in Europe from this disease [7-9].

COPD accounts for 22% of total respiratory mortality, is the third leading cause of respiratory death after pneumonia and lung cancer and kills one in five people in this country [8, 10]. COPD also disproportionately affects those from poorer socio-economic classes in Ireland [11]. Mortality in severe COPD is between 36% and 50% at two years after admission for an acute exacerbation [12].

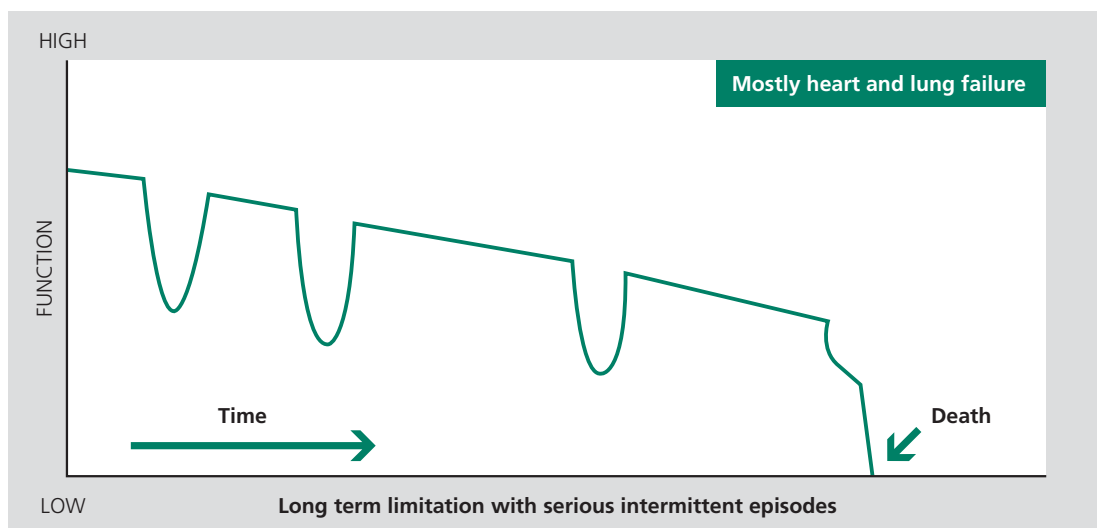
2.2 SYMPTOM BURDEN

The main symptoms of COPD are breathlessness, cough and sputum production, along with chest tightness, wheezing and airway irritability. Fatigue, poor appetite and weight loss are more common in advanced disease [13], with low mood, poor sleep quality, severe pain, panic attacks, depression and functional limitations in the activities of daily living also strongly associated with the disease [12]. People who have COPD frequently have a range of other co-morbidities that need to be considered in their care pathway.

Studies suggest that COPD patients suffer longer than patients with malignant lung disease because of the disease trajectory associated with COPD, have a significantly poorer physical, social and emotional health status and greater difficulty with activities of daily living [14]. In advanced stages of the disease, as each exacerbation could result in death, the individuals may confront the fear of dying on a number of occasions [15, 16]. This disease trajectory is illustrated in Diagram 1.

DIAGRAM 1:

DISEASE TRAJECTORY MOST COMMON IN HEART AND LUNG FAILURE REFLECTING PROGRESSIVE DECLINE AND ACUTE EXACERBATIONS [60]¹¹



¹¹ © Diagram 1 is reproduced with the permission of RAND Health

The considerable uncertainty surrounding the disease trajectory in advanced disease makes it difficult for physicians and patients to broach the topic of death and it is extremely difficult to identify whether an exacerbation will prove fatal. Patient studies have identified that the uncertainty concerning their illness and prognosis generates a sense of isolation from their physicians and creates communication difficulties and unmet information needs [17].

Seamark et al indicated that patients with severe COPD have considerable impairment of quality of life and physical and psychological needs at least as severe as patients with lung cancer. This supports conclusions drawn by Ahmedzai in 2004 and Russell in 2007 that while the symptom burden for cancer and COPD patients is equal, the accumulated suffering for COPD patients is greater, compounded by the fact they continually face complex and important decisions over a longer period of time [14, 18-21].

Studies and research in this area list the following factors associated with COPD as additional burdens to those people with the disease: depression and anxiety, social isolation and being confined to the house, fear and uncertainty regarding illness trajectory, severe breathlessness on minimal exertion, loss of autonomy and independence and diminished social identity and friendships [19]. The other related burden is the association between COPD and smoking. As 90% of COPD patients are smokers or ex-smokers they are likely to experience stigma associated with smoking-related illness. This could also contribute to their disease burden [8, 9, 22].

The burden of COPD also extends to quality of life issues for the family and carers, and the impact can be seen on health services, work absenteeism, and disability [23]. Brennan and O'Connor note that that in Ireland respiratory disease is the most common reason for patients to visit the GP. It has been shown that in the last two years of life people with COPD have frequent admissions to and spend increasing lengths of time in hospital [8, 23].

2.3 END-STAGE OF CHRONIC OBSTRUCTIVE PULMONARY DISEASE

End-stage COPD has been defined as: When forced expiratory volume in one second (FEV1) <30% predicted accompanied by severely limited and declining performance status, plus at least one of the following criteria: 1) advanced age; 2) presence of multiple morbidities; and 3) severe systemic manifestations/complications of COPD [15, 23-26].

The above definition is helpful as it stresses the importance of co-morbidities and draws a distinction between severe COPD, as defined in classification and management guidelines, and end-stage COPD requiring palliative care interventions. Nevertheless it remains the case that predicting death or estimating prognosis in COPD is notoriously difficult [4-6, 27].

Progressive COPD and associated co-morbidities in older patients result in significant disease burden on individual sufferers and on hospital services [19]. Lynn et al found that those patients who died from COPD spent one fifth of their final six months of life in hospital [15].

3. PALLIATIVE CARE FOR PEOPLE WITH CHRONIC OBSTRUCTIVE PULMONARY DISEASE

The palliative care needs of people with COPD have been recognised in international studies for over a decade, and more recently the role of palliative care has been acknowledged in international health guidelines which are examined in some detail below. Subsequent sections of this appendix will explore the studies and service developments in this area.

3.1 INTERNATIONAL POLICY AND GUIDELINES

The American Thoracic Society (ATS) and the European Respiratory Society (ERS) produced joint COPD guidelines in 2004. These stress the concept of integrated care for patients with COPD. They note that

patients with advanced COPD suffering from disabling symptoms benefit from integrating palliative care into routine care, especially to relieve dyspnoea (breathlessness) and to address emotional and spiritual issues, whether at home, in a hospital or in a nursing facility. They state that the caregivers should become informed about end-of-life planning and palliative care, and that those most closely involved with the patient's care should initiate advance care planning discussions with the patient in stable periods of health. This can be done by providing information on probable outcomes and the existence of palliative interventions, such as dyspnoea management and terminal sedation. They note that neglect in offering patients and their families appropriate information and resources for end-of-life care can result in unnecessary admissions to acute care hospitals for worsening respiratory symptoms [28].

The ATS/ERS statement on Pulmonary Rehabilitation in 2006 notes that pulmonary rehabilitation programmes provide an important opportunity to assist advance care planning for patients with moderate to severe COPD. Educational programmes on advance care planning within pulmonary rehabilitation increase the adoption rate for patient-physician discussion about end-of-life care and preparing advance care directives. It is reported that most co-ordinators of pulmonary rehabilitation consider end-of-life education as an appropriate aspect of their programme [29].

More recently (2007) the ATS produced an official clinical policy statement endorsing the concept that palliative care should be available to patients at all stages of illness and recommending that respiratory clinicians should have basic competencies in palliative care and should consult with their SPC colleagues where appropriate. The statement includes the ATS professional values and principles related to palliative care and a list of core competencies in palliative care for pulmonary physicians [30].

The UK NICE COPD (2004) guidelines recommend that patients with end-stage COPD and their family and carers should have access to the full range of services offered by multidisciplinary palliative care teams, including admission to specialist inpatient units. They also detail palliative pharmacology treatment [31].

In 2006 the Welsh Assembly produced a consultative document on commissioning directives for respiratory diseases. This document proposes full access to multi disciplinary palliative care services for people with respiratory disease – including their families and carers – at all stages of their illness and in all care settings [32].

3.2 ROLE OF PALLIATIVE CARE FOR PEOPLE WITH CHRONIC OBSTRUCTIVE PULMONARY DISEASE

The very nature of this chronic, life-limiting illness means that the care of most COPD patients will have been shared between primary and secondary and/or tertiary health care. A model for palliative care for COPD would need to address such an interface. This section outlines the specific role of palliative care for people with COPD, with some reference to developing service models. It describes the challenges that present when implementing such programmes, and finally proposes the components required for a successful integrated care model.

In 2001 Addington Hall suggested that the role of SPC in non-malignancy was to provide a coherent approach to assessment, facilitate access to community services and help in management of symptoms. Then there would be gradual development of the role of palliative care for people with COPD as opportunities for training and education in this area become available and a greater understanding as to the role of palliative care emerges [33].

Blackler et al in 2004 list the specific palliative care needs of patients with severe COPD, as follows:

- Information and educational needs to include the non curative nature of disease, the various treatment options, discussion of non-invasive ventilation and future directives with regard to their treatment
- Physical needs – management of dyspnoea, pain, fatigue, nutrition, sleep, chest secretions and management of potential adverse effects of medication
- Psychological and emotional needs – depression, anxiety, uncertainty, social isolation, anticipatory grief
- Spiritual needs
- Privacy, dignity and patient confidentiality
- Equity
- Safety [34].

Yohannes (2007) illustrates how providing palliative care for patients with COPD will provide an opportunity for better communication with patient, family and physician in order to plan appropriate treatment strategies. These could include advance care planning and patient preferences with regard to choice of end-of-life care, withholding or withdrawing medical treatment and place of care. The psychosocial support and the health and professional care and attention may help to overcome the disproportionate fear brought about by dyspnoea on exertion and may help to engage the patient in routine daily activities [35].

In 2007 Russell described how communicating with a depressed COPD patient about difficult end-of-life decisions raises further challenges for the practitioner and patient in terms of assessing whether their decisions are based on clinical depression, emotional well being, how the conversations are carried out or how individual patients are experiencing their illness at a given time. A patient or family may use denial as a temporary and acceptable coping mechanism or as a conscious desire not to plan for the future. This has consequences for care and decision-making such as advance directives. Some of the theories within the sociology of death and dying can help staff and patients consider these concepts [19].

A recent study by Taylor et al explored the views of patients following hospitalisation for exacerbation of their COPD on how and with whom they would like to discuss end-of-life issues. The study concluded that communication on end-of-life issues are important to patients, and needs to be sensitively handled and tailored to individual needs where possible. Patients did not want to have such discussions while experiencing an exacerbation. They expressed a preference for such discussions to be held with the respiratory consultant, respiratory nurse or GP, and some said that information booklets or DVDs provided in advance may help to facilitate the discussion [36].

A small number of pilot programmes in the UK have been identified where palliative care was included in COPD services. These include the Lincolnshire Countywide COPD steering group which in 2006 established criteria for identifying patients with end-stage COPD to flag possible action and a small scale pilot project where respiratory nurse specialists work within the community [37, 38].

In 2004 a review of end-of-life care was carried out in Luton and South Bedfordshire. This involved collaboration between healthcare providers and people with COPD whose prognosis was less than six months. The review sought to identify needs and preferences, raise awareness of end-of-life care as an issue for COPD patients and enable more choice in preferred place of care for such patients.

At a workshop for patients and carers it was agreed that the hallmarks of “perfect” palliative care for COPD patients were:

- Patients should feel well prepared and their care should contain no surprises.
- That care should be comprehensive, coordinated and customised to reflect personal preferences.
- Patients should never feel overwhelmed by their symptoms [39, 40].

One of the challenges in introducing palliative care for people with severe COPD is the fact that active treatment and palliative treatment may need to run concurrently throughout the course of living with COPD. This dual approach may be contrary to local service ethos and expectations. However outcomes include improvements in patient reviews and planning, better MDT working in relation to palliative care and significant reduction in the number of admissions and readmissions to hospital in the last years of the patients' lives [10]. In addition there is evidence that SPC services may be reluctant to adapt to the needs of people with COPD, and studies have shown that both medical and nursing staff are unlikely to identify COPD patients as having palliative care needs in spite of their medical documentation. This is illustrated by Exley et al who demonstrated that, even in Primary Health Care Teams committed to the delivery of palliative care, people dying with end-stage cardio-respiratory disease are less likely than those with cancer to receive full, easily understood information on their disease or to be aware that they are dying [41, 42].

Other challenges which inhibit the development of a palliative care approach for people with COPD are a lack of communication between specialists and GPs [10, 41-43] and a need for more information about the disease manifestations. This knowledge deficit generates a passive approach resulting in patients not reporting their symptoms to their doctor [18, 33, 37, 40, 42]. An additional challenge is the stigma associated with smoking-related illness, coupled with the expectation that nothing more can be done and utter loss of hope [18, 19, 41].

The management of patients with COPD should be based on an integrated care model, with a collaborative approach which establishes strong communication and co-ordination between the primary and secondary care providers, with full access to the MDT [14, 35, 40, 42]. In situations where SPC services are well established the integrated care model should emanate from this source [31, 44]. In the absence of a specialised respiratory service in primary care, patient support will be based in secondary care, either hospital inpatient or outpatient service, with optimum utilisation of resources. Building on the pulmonary rehabilitation model there needs to be enhanced information, face to face communication and education to promote self management. These require necessary physical and psychological support [10] to facilitate the advance planning that is advocated for people with COPD [31, 44].

A survey of palliative and respiratory physicians in the UK in 2007 indicated that SPC physicians view the support from respiratory teams as crucial to their intervention with a patient with advanced respiratory disease, and agreed roles would also be helpful [43].

The studies referred to in this section have demonstrated the need to have a seamless integrated care approach to people with COPD, between the primary, secondary and tertiary care. The policy implications arising from the weight of evidence of unmet palliative care needs among patients with COPD indicates the need for a palliative approach to care while continuing with active disease management. A palliative care approach needs to interface in all these services areas, with an emphasis on provision of information on disease trajectory, promotion of patient autonomy and self management. Gaps in service usually occur between the primary care and hospital services, because of the under development of primary care services. It is also worth noting that despite the recognition of the benefits of pulmonary rehabilitation programmes, these are not available to or suitable for all patients with COPD; and such programmes should not be the only method of discussion on issues related to end-of-life for people with COPD.

4. CHRONIC OBSTRUCTIVE PULMONARY DISEASE SERVICES IN IRELAND

4.1 POLICY

Until recently there has been very little recognition of the specific needs of people with COPD in health strategies and policy documents in Ireland. However since 2006 there has been some indication that the needs of this population group have been acknowledged and these developments are outlined below.

In 2006 the HSE published a document outlining the prevalence of chronic disease in Ireland including COPD. This report lists a summary of pulmonary programmes throughout the country, some which are specifically targeted towards COPD [22].

As part of the recent HSE Strategy Transformation for Change, Programme Four is seeking to implement a model for the prevention and management of chronic illness including evidence-based prevention programmes and treatments for people with COPD [45]. One of the initiatives arising from Programme Four is the establishment of a Steering Group to develop a national strategy for the management of COPD aiming to reduce the burden of disease in terms of adverse impact on quality of life, avoidable illness, disability and death. The report of this group is due in 2008 and will include references to the palliative care needs of people with COPD, as well as providing an updated audit of COPD services available throughout the country.

The 2008 National HSE service plan anticipates that the COPD strategy will ensure that best evidence care is provided in a structured manner to patients, that their care is provided as close to home as possible [46].

4.2 SERVICE PROVISION

People with COPD in Ireland are cared for largely by their GP. However, the majority of GPs do not have access to a fast-track system of referral to key multi-disciplinary services including spirometry, pulmonary rehabilitation and specialist nursing services. Very few specialist respiratory nurses working within the hospital-based multi-disciplinary respiratory teams are available to visit their patients in the community. Practice Nurses who may have additional qualifications in respiratory care work only within their employer GPs' surgeries [47]. Many patients with COPD, who experience an acute exacerbation, have to access hospital services via Accident and Emergency. They will be seen by the consultant on call, who may then refer to the respiratory physician, if available. Currently several hospitals in Ireland do not have specialist respiratory consultants. The existing deficits in respiratory services militate against good respiratory care for people with advanced COPD, and inhibit the opportunities for introducing palliative care for these patients.

There are SPC teams in most acute general hospitals (AGH). Some patients with COPD are referred to hospital SPC teams for advice and support in the final phase of their illness. In such situations, the SPC team does not take over the patient's care. Some hospitals may provide SPC outpatient care on a joint basis with medical teams from other specialties though this practice is not widespread.

In recent years programmes such as Respiratory Outreach Programmes have been developed by the HSE in an attempt to address the fragmentation between primary, secondary and tertiary healthcare services. These programmes seek to address acute care needs in the home allowing patients who meet specific criteria to be discharged early from hospital or be discharged from Emergency Departments. In Respiratory Outreach Programmes, patients are visited at home by hospital based specialist respiratory nurses.

4.3 SNAPSHOT PICTURE OF IRISH PATIENTS WITH CHRONIC OBSTRUCTIVE PULMONARY DISEASE

To assist in the picture of Irish patients with end-stage COPD fifteen patients who attend the Outpatients Department of an AGH were interviewed by a Respiratory Nurse Specialist in September 2007.

A summary of the findings is outlined below.

Age breakdown				Gender breakdown	
65 – 69	70 – 74	75 – 79	80 – 84	Male	Female
13%	33%	26%	26%	9	6

- 20% reported they received none of the supports generally associated with people with advanced COPD
- 6% reported they had access to a Palliative Care Nurse
- Significant shortness of breath was experienced by all and insomnia, fear and production of sputum by 26%, with many experiencing at least 3 distressing symptoms
- 53% of the respondents requested new drugs to alleviate their symptoms
- 13% said they would like “to end it all” [48].

This small unpublished analysis highlights the deficits and capacity issues in the services available to people in the terminal phase of COPD, and reinforces the need for a comprehensive respiratory service which would include a palliative care component.

4.4 KEY POINTS

While the strategy and service developments outlined above are welcome, community and primary care services are currently under-developed in Ireland and progress on the roll out of primary care teams has been slower than anticipated. These factors, added to the lack of nationwide comprehensive community and hospital specialist respiratory services which incorporate a palliative care element, indicate that it will be some time before people with COPD in Ireland can access an integrated respiratory service, and have their palliative care needs met regardless of their care setting.

5. IRISH CHRONIC OBSTRUCTIVE PULMONARY DISEASE SERVICES WITH PALLIATIVE CARE

The Extending Access Study has identified a small number of initiatives which seek to address the non-specialist palliative care needs of patients with COPD. A number of AGH have included a palliative care component in their pulmonary rehabilitation programmes, and the Irish Association of Pulmonary Rehabilitation is seeking to standardise the format for such programmes. One teaching hospital has commenced a small scale outreach project for people with severe COPD with encouraging results. These examples (which are not intended to be exhaustive) are summarised below.

In addition a number of teaching hospitals have introduced models similar to the Liverpool Care Pathway. [49] for terminal care of people in their last 48 hours in hospital. Such care pathways could benefit people with COPD who are dying in hospital. They are detailed in Chapter 6.

CHRONIC OBSTRUCTIVE PULMONARY DISEASE SERVICES AT ST. JAMES'S HOSPITAL

St. James's Hospital (SJH) Respiratory Assessment Unit (RAU) developed a pilot COPD Outreach Programme which included elements of chronic disease management such as early hospital discharge, self-management and pulmonary rehabilitation.

Palliative Approach

The palliative element for the programme arose from patient desire to return home from hospital, or not to be readmitted during their end-stage of COPD. A number of patients who had opted not to have invasive treatment were managed at home and since the latter half of 2007, ten patients were supported in their wish to be cared for and to die at home. To date it has been not possible to access SPC in the community for these patients.

Criteria

Patients who were under the care of a SJH Respiratory Consultant were included in the programme if they had family support and their social circumstances permitted. The medical criteria for inclusion in the programme were: diagnosis of advanced/end-stage COPD, severe debility, severe and worsening symptoms despite maximum treatment, evidence of respiratory failure and the absence of significant co-morbidity that is difficult to manage.

Services

The Respiratory CNS assessed the patient and home visits were provided as necessary. Patients and their family were assisted in symptom management and worries and concerns addressed. The Respiratory CNS liaised with the Respiratory Consultant for optimal management. Bereavement follow up was provided to the families/carers as required.

Problems/barriers/developments

It was an unfunded pilot project available to a small number of patients only and will require a shared approach in the future. This project has stopped taking referrals and is currently being evaluated after its first year in operation. This evaluation will provide the basis for a funding application to integrate this aspect of care into the overall service. RAU staff are actively engaged with key players in primary and secondary care to advance this project.

Source: Bettina Korn, Respiratory Nurse Specialist, St. James's Hospital

5.2

PULMONARY REHABILITATION AT THE ADELAIDE AND MEATH HOSPITAL INCORPORATING THE NATIONAL CHILDREN'S HOSPITAL (AMNCH), TALLAGHT

The pulmonary rehabilitation programmes in AMNCH, is an eight-week, 16-session programme.

Services

The Pulmonary Rehabilitation Team Medical Director is a respiratory consultant. The team also includes a palliative medicine consultant, two physiotherapists, a psychiatrist, nurse, pharmacist, nutritionist, occupational therapist and social worker. Each session includes exercise and a lecture. Up to 24 patients attend each session.

Criteria

Criteria for participation in the programme include a clinical diagnosis of COPD, a high degree of motivation and engagement with smoking cessation.

Palliation

The palliative care consultant currently delivers a session on end-of-life issues as part of the pulmonary rehabilitation programme. Topics discussed include the progressive nature of COPD, cardiopulmonary resuscitation, living wills and a general description of the symptom control options available.

Source: Marian Johnson, Clinical Specialist in Respiratory Physiotherapy, AMNCH

5.3

PULMONARY REHABILITATION SERVICE, LETTERKENNY GENERAL HOSPITAL

The aim of service is to assist in the management of patients with chronic respiratory diseases, improve exercise endurance, to improve quality of life

Services

This is an education and exercise programme, over eight-weeks with three-classes, per week, eight clients per class, and is co-ordinated by respiratory nurse specialist and senior physiotherapist in respiratory care. Each class includes input from the following areas: palliative care, occupational therapy, dietician, respiratory medical team, respiratory nurse, smoking cessation, pharmacy, anaesthetist, clinical psychologist.

Palliation

The palliative care component comprises an interactive group discussion by the CNS in palliative care, with explanations on palliative care and the role of CNS in palliative care for people with non-malignant diseases.

Patient Group

This programme is targeted at people with chronic lung disease including people with COPD, and commenced in September 2007.

Source: Patricia McLaughlin, Respiratory Nurse Specialist, Letterkenny Hospital

5.4 IRISH ASSOCIATION OF PULMONARY REHABILITATION

This group is working to seek consensus on and develop a suitable end-of-life tool that can be used with COPD patients within the pulmonary rehabilitation programmes.

5.5 CURRENT IRISH RESEARCH IN CHRONIC OBSTRUCTIVE PULMONARY DISEASE AND PALLIATIVE CARE

There are a number of research projects underway in both the Republic of Ireland and Northern Ireland in the area of palliative care and COPD. The outcomes of research will assist and inform emerging Irish respiratory models of care.

5.5.1 ADDRESSING THE PALLIATIVE CARE NEEDS OF PATIENTS WITH CHRONIC OBSTRUCTIVE PULMONARY DISEASE THROUGH DEVELOPMENT OF RESPIRATORY NURSING PRACTICE

Researchers: Geralyn Hynes, Mary McCarron, Karen Cox, Trinity College Dublin, supported through a HRB Clinical Fellowship in Nursing and Midwifery. The aim of this project is to inform and develop respiratory nursing practice specifically in relation to palliative care for patients with advanced disease COPD through identifying and addressing unmet needs. The project will bring together the specialist knowledge of palliative and respiratory nurse specialists, and experiences of patients with COPD.

5.5.2 DEVELOPING RESPIRATORY NURSING PRACTICE TO ADDRESS PALLIATIVE CARE NEEDS OF PATIENTS WITH CHRONIC OBSTRUCTIVE PULMONARY DISEASE: EXPLORING THE LAY-CARER EXPERT KNOWLEDGE AND EXPERIENCE

Researchers: Mary McCarron, Geralyn Hynes, Ann Stokes. Supported by the Irish Hospice Foundation. The purpose of this study is to develop an understanding of informal carers' experiences of caring for a person with advanced or severe COPD. This research will inform a larger study that is looking at out how nurses can best respond to the needs of people who have advanced COPD.

5.5.3 NORTHERN IRELAND HOSPICE CARE IN COLLABORATION WITH THE UNIVERSITY OF ULSTER

They are currently undertaking a study of palliative care needs and service provision for people with advanced COPD. Early findings indicate that:

- The principles of holistic palliative care should be inclusive of people with COPD and their carers.
- Appropriate information must be provided earlier in the illness trajectory to ensure patients and their carers are aware of the implications of COPD.
- There is currently a reactive model of service provision which must become more proactive in meeting the needs of patients with COPD and their carers.
- Consideration should be given towards the development of networks and services to ensure carers are prepared and supported for their role.
- The provision of palliative care requires effective resources and staff development and training to promote collaborative partnerships across health and social care pathways.
- There is a deficit in the area of bereavement support for families and carers of people with COPD [50].

6 KEY FINDINGS AND CONSIDERATIONS IN PROVIDING PALLIATIVE CARE FOR PEOPLE WITH COPD IN IRELAND

Despite the high mortality rates for people with COPD in Ireland, there is very little awareness of the potential role of palliative care. This section summarises the challenges and barriers that present in relation to service models and structures, education, policy and research, and concludes with some direction relating to how these can be overcome.

6.1 SERVICE MODEL AND STRUCTURE

In order to respond to the palliative care needs of people with COPD, there needs to be greater interface between existing respiratory and SPC services. It would be helpful for all professionals involved to agree on a model of care which would highlight how a person with advancing COPD could, if required, access the different levels of palliative care as their illness progresses.

Currently access to SPC for people with COPD is variable throughout the country. Some SPC services do not accept referrals and others offer the services of their home care team but limit access to specialist inpatient units [51]. This inconsistent access generates some uncertainty as to the role of SPC for people with COPD. Identification of triggers for referral of people with advanced COPD to SPC would assist in providing clarification of the role of SPC. The development of common eligibility and discharge criteria for SPC would encourage SPC services to provide their service in a standardised manner and would also assist in providing transparency regarding the role of SPC for people with advanced COPD for both staff and patients.

It is encouraging to note that the IAPR is seeking consensus to develop a standardised end-of-life tool which can be used as part of a pulmonary rehabilitation programme. It would be helpful if the SPC profession collaborated with this group in relation to this development. Such a partnership would also assist in ensuring palliative care would be a core component of the various respiratory initiatives including the pulmonary rehabilitation programmes and other respiratory outreach services.

It is recognised that patients with COPD experience increasing levels of isolation and anxiety as their disease progresses. This is compounded by the tendency for these patients to adopt a passive approach to the management of their disease, the prevalence of the lower socio-economic cohort that this patient group represents and the lack of an advocacy organisation to represent the health and social needs of the COPD population. There is an urgent requirement to implement a range of self-management patient programmes to inform and equip people with COPD to develop coping strategies to deal with the symptom burden and issues relating to end-of-life that they may experience. The development of a comprehensive series of fact sheets about COPD including reference to palliative care would assist in responding to this identified need.

6.2 EDUCATION

Formal education initiatives at both under-graduate and post-graduate level are required to assist in the provision of palliative care to people with COPD as well as those with other life-limiting chronic diseases. These are referred to in detail in the overarching recommendations of the main body of this report as well as Appendix 4, and this education requirement is relevant to professionals within both respiratory and SPC services.

Informal education responses could include the establishment of joint training initiatives between palliative care and respiratory representative bodies such as the Irish Thoracic Society (ITS) and specialist palliative care representative bodies with input from Irish College of General Practitioners and HSE and Irish Hospice Foundation. This could begin with a joint study day to debate the issues that have been presented in this report particularly those relating to the timing of discussion on end-of-life issues and the

skills required to assist in the physical and psychological symptom burden that people with COPD experience. This should assist in generating consensus about how future service developments in COPD and palliative care can fully attend to the palliative care needs of people with COPD.

6.3 POLICY

Currently services for people with COPD in Ireland are underdeveloped, and the recent initiatives for community-based respiratory programmes do not have a palliative component. There are no formal structures in place for delivery of standardised COPD services, and the services on the ground appear to be fragmented and poorly co-ordinated, with minimal or non-existent home/respice supports. Very few people in Ireland with COPD have access to a MDT, and where they exist it is difficult to discern the extent to which these teams have a palliative component.

It is essential that the COPD Strategy, the relevant programmes emanating from the HSE Transformation for Change and all other appropriate stakeholders charged with the advancement of COPD services address palliative care needs in policy and guideline documents

There are a number of other respiratory diseases which are life-limiting. These include cystic fibrosis and pulmonary fibrosis, and these groups also have palliative care needs that are often either unrecognised or neglected. Respiratory and SPC services should consider how best to address these needs and staff working in these areas would benefit from further education and training.

6.4 RESEARCH

There is a dearth of information available as to the role of palliative care for people with COPD. For example, more information is required as to the disease trajectory and best timing of palliative care interventions. It would also be beneficial to discover more about the experience of families who have had a family member die from COPD. The relationship between the incidence of unplanned admissions to an AGH and mortality rate of people with COPD might help in generating a trigger for referral to SPC.

It would also be helpful to research and develop guidelines and frameworks for further developments in this area. A useful starting point could be generated from a comprehensive audit of SPC services to people with COPD in community, AGH and hospice-based settings in Ireland, particularly where there is evidence of a commitment to accommodate these patients' needs.

6.5 PALLIATIVE CARE: TIMING, ELIGIBILITY AND REFERRAL TRIGGERS FOR PEOPLE WITH CHRONIC OBSTRUCTIVE PULMONARY DISEASE

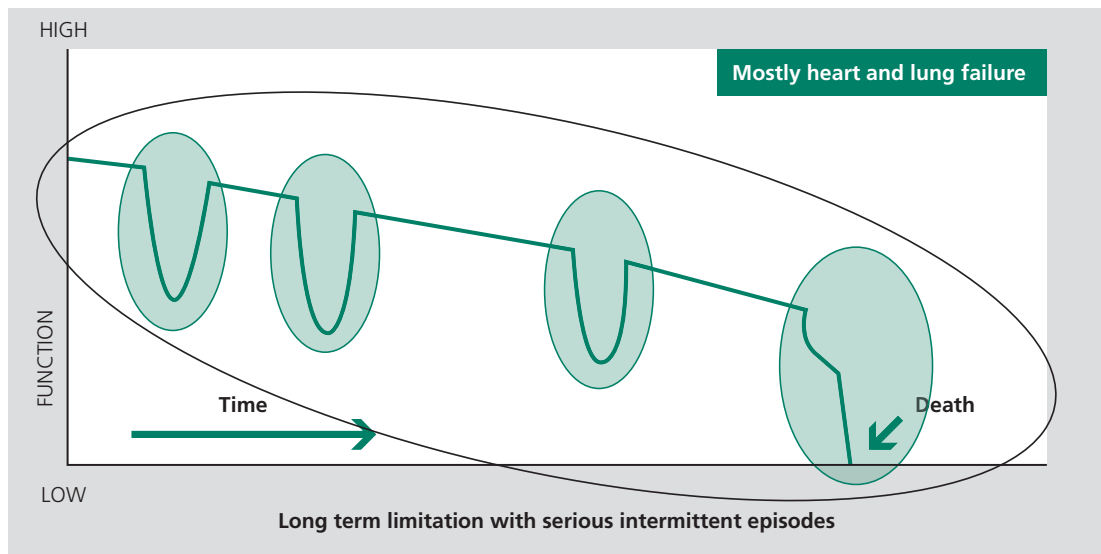
The need to clarify the role of SPC and eligibility for access to SPC for people with COPD presented as a recurring challenge throughout the study.



Diagram 5 is an adaptation of Diagram 1 on page 79 to demonstrate how an understanding of the disease trajectory for people with COPD can be helpful to illustrate the timing and necessary relationship between respiratory services in delivering non-specialist palliative care and SPC where required.

In Diagram 5 the large oval suggests that non-specialist palliative care should be included early in the disease trajectory, with particular consideration of:

- a) Symptom management, including dyspnoea, pain, fatigue
- b) Responding to anxiety and depression that is prevalent with the disease
- c) Assisting in understanding the disease trajectory and advice and support relating to advanced planning [16, 52].

DIAGRAM 5:
TIMING OF PALLIATIVE CARE IN DISEASE TRAJECTORY MOST COMMON IN HEART AND LUNG FAILURE [ADAPTED FROM 60]¹²



-  Large oval indicates timing for non-specialist palliative care
-  Green ovals indicate potential timing for SPC

Staff addressing needs with patients may 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 COPD and/or complex co-morbidity). Wherever extraordinary need arises in the disease trajectory which cannot be addressed by the respiratory team, referral to SPC should be considered.

¹² © Diagram 5 is an adaptation of a diagram reproduced with the permission of RAND Health

6.5.1 TRIGGERS FOR CONSIDERATION OF REFERRAL TO SPECIALIST PALLIATIVE CARE

Triggers for referral to SPC would generally relate to the recognition of end-stage of COPD. However, as mentioned earlier, there is no agreed definition of end-stage COPD and it is difficult to determine. Kimathianaki, Mitrouska et al propose the following definition which can be used as triggers for consideration for referral to SPC [23]:

- Forced expiratory volume in one second (FEV1) <30% predicted accompanied by severely limited and declining performance status.
- Increased intensity of symptoms despite optimal treatment.
- Plus at least one of the following criteria:
 - advanced age
 - presence of multiple morbidities
 - severe systemic manifestations/complications of COPD [23,53].

These are similar to indicators used by the UK Gold Standards Framework [53].

Any referral for SPC for patients with advanced or end-stage disease should only be made as a result of a respiratory assessment carried by respiratory physician where available [54].

6.5.2 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.

7

RECOMMENDATIONS

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

C.1 Service Model

- a) A project group is to be established to devise, plan and oversee a proposed Model of Care for patients with COPD who have reached stage III or IV disease classification within a designated health location encompassing an AGH, 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 COPD 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; it 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 respiratory health initiatives within AGH, Primary care and SPC.
Health Service Executive with support from Irish Hospice Foundation and Irish Thoracic Society
- b) All Pulmonary Rehabilitation programmes should include a palliative component.
Health Service Executive / Irish Association of Pulmonary Rehabilitation
- c) A series of fact sheets are to be produced to encourage and assist patients with COPD in their self management and their overall understanding of their disease.
Irish Thoracic Society / Irish Hospice Foundation

C.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 and education initiatives such as meetings, annual study days, journals clubs etc, between respiratory and palliative care professionals are required to enhance understanding and promote collaboration in this area.
Irish Thoracic Society with support from Health Service Executive / Irish Association of Palliative Care / Irish Hospice Foundation
- b) Post graduate education for staff working in respiratory medicine should have a defined palliative care component.
Health Service Executive / Palliative Care Education Taskforce / Medical Education Training and Research Unit and relevant educational institutions
- c) An information leaflet on the triggers for referral to SPC and role of palliative care for people with COPD should be produced to assist in generating awareness for all staff working in this area. (See also recommendation 4b).
The Irish Hospice Foundation with support from Irish Thoracic Society / Health Service Executive / Irish Association of Palliative Care

C.3 Policy

All service and policy developments relating to COPD should reference the need for palliative care to be part of the COPD service framework.

[Department of Health and Children / Health Service Executive](#)

C.4 Research

a) Emerging COPD treatment interventions which have a palliative care element should include evaluation which will assist in determining evidence based information on the timing and impact of palliative care for people with COPD.

[Health Service Executive / Health Research Board / Irish Hospice Foundation](#)

b) Monitor Hospital Inpatient Enquiry system (HIPE) data to determine if a frequency of three or more admissions to hospital can be used as an additional trigger for referral to SPC.

[Health Service Executive](#)

c) Further examination is required regarding the palliative care needs of people with other respiratory diseases.

[Health Service Executive / Irish Hospice Foundation / Irish Thoracic Society](#)

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Appendix Two

Palliative Care and Dementia

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Palliative Care and Dementia

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PREFACE TO APPENDIX 2: PALLIATIVE CARE AND DEMENTIA

“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).

DEMENTIA WORKING GROUP MEMBERSHIP

Maeve Clark

Education Officer, DSIDC (Dementia Services Information & Development Centre)

Dr. Mary Cosgrave

Consultant Psychiatrist in Psychiatry of Old Age

Dr. Joan Cunningham

Consultant in Palliative Medicine

Angela Edghill

IHF Project Team

Cecelia Hayden

Clinical Nurse Specialist, Dementia Care

Marie Lynch

IHF Project Team

Mary Mannix

Clinical Nurse Specialist, Psychiatry of Old Age

Professor Mary McCarron

Associate Professor of Nursing, School of Nursing & Midwifery, Trinity College Dublin

Paschal Moynihan

Specialist, Services for Older People, HSE West

Maurice O'Connell (Chair)

Chief Executive, Alzheimer Society of Ireland

Dr. Isweri Pillay

Consultant Geriatrician

Barbara Whyte

Clinical Nurse Specialist, Palliative Care

Palliative Care and Dementia

1. INTRODUCTION

The first section gives a synopsis of the epidemiology and prognosis patterns for dementia, and charts the issues and advances related to the introduction of palliative care for people with dementia based on international research and development work in this area. The document then focuses on palliative care and dementia within an Irish policy and development context. The final section presents the findings of the Extending Access Working Group on dementia and palliative care and outlines a number of recommendations that will assist in implementing the necessary changes to allow for the inclusion of palliative care for people with dementia in Ireland. These recommendations should be considered with regard to the overarching recommendations in the main body of this report.

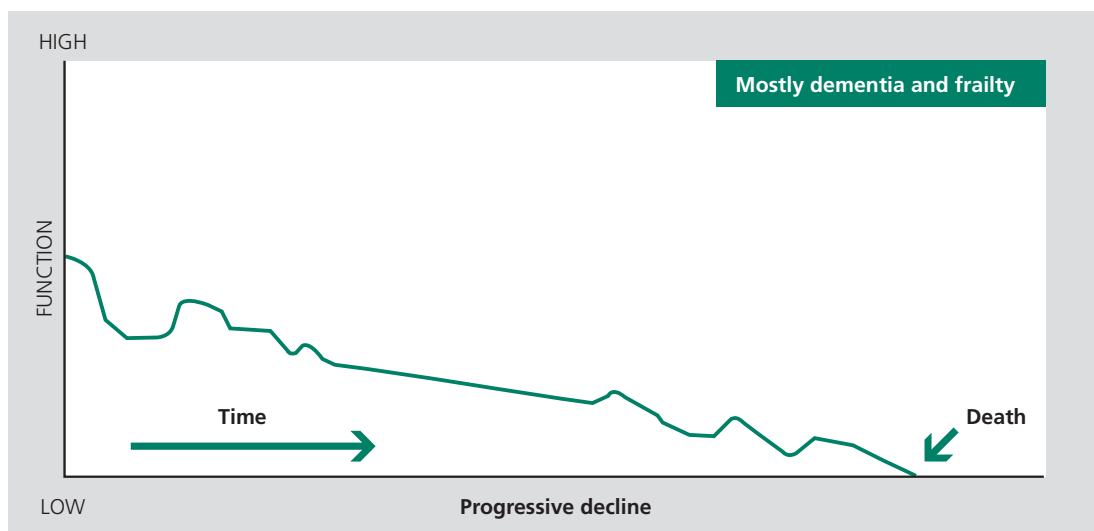
2. WHAT IS DEMENTIA?

Dementia is a disease characterised by impairment in memory, intellect, judgement, language, insight and deterioration in social skills. The individual diagnosed with dementia may also demonstrate an acute sensitivity to his or her social environment and a high level of stress. While over 100 different diseases will produce the symptoms of dementia, it is known that Alzheimer's Disease is by far the most common cause of dementia, accounting for more than 50% of all cases. Other common causes include vascular brain disease (Multi-Infarct or Vascular Dementia), mixed dementias (a mix of two or more dementia types with one predominating, commonly Alzheimer's Disease and Vascular Dementia) and Dementia with Lewy Bodies. Less common dementias include fronto-temporal dementia, particularly in the under 65-year age group, alcohol related dementias, Huntingdon's Disease, Creutzfeldt Jakob Disease and AIDS related dementia [3].

During the course of the disease the person will, in general, undergo a gradual and progressive deterioration in their symptoms. As an individual progresses through the mild, moderate and severe stages of their illness, so their requirement for care increases. Symptoms range from initial difficulty with complex tasks and forgetfulness, to the stage where the person with dementia cannot carry out basic functions such as walking or eating, loses their ability to communicate meaningfully and their behaviour may become more challenging for carers. While care in the final stages of dementia is often provided in nursing homes or continuing care facilities, some individuals are also cared for at home, and family members have a critical role in the life cycle of care of a person with dementia regardless of their care setting. The disease trajectory is a gradual, sometimes slow, decline, as illustrated in Diagram 2.

DIAGRAM 2:

DISEASE TRAJECTORY MOST COMMON IN DEMENTIA AND FRAILITY [60]¹³



¹³ © Diagram 2 is reproduced with the permission of RAND Health

The quality of the care people with dementia receive will affect the way they experience their disease and the impact of its progress. Kitwood (1997) would argue that the experience of dementia is unique to the individual and depends upon the interaction of five key factors, namely: the person's personality, their biography, their physical health, their neurological impairment and the social psychology of the environment in which they live [5]. Neglect of any one of these areas is likely to result in a poor quality of life and death for the person with dementia. It must be stressed that people in all stages of dementia still express many emotions. The ability to communicate is not totally lost but requires increasingly sensitive perception by the carer. Respectful and inclusive care at all stages of the illness can be achieved when the true essence of person-centred care is adopted.

The complexity and uniqueness of each person's experience of dementia may be underestimated when the focus of examination is on average or usual symptom burdens. Individual differences need to be taken into account in the planning of services to meet the needs of people with dementia and their carers. The importance of an integrated and co-ordinated model of service provision that has the flexibility to adapt and respond to individual circumstances cannot be over emphasised [6].

2.1 EPIDEMIOLOGY

Today, more than 38,000 people in Ireland have dementia, of which Alzheimer's Disease is the most common form. The risk of developing Alzheimer's Disease increases with age with its prevalence rising from approximately 1% in people under 65 years old to more than 20% for those over 80 years. Although Alzheimer's Disease is more commonly associated with older age, it can also occur in people in their 40s and 50s. The application of Eurodem prevalence rates to Ireland suggests that there are approximately 2,000 people under the age of sixty with dementia; with an expected increase to 2,500 by 2016 [7-9]. The recent HSE report on residential services for people with dementia indicates that the number of people with dementia in Ireland is likely to increase to 49,153 in 2016, and 70,115 by 2026 [10].

2.2 PROGNOSIS

The life expectancy of a person newly diagnosed with dementia may vary depending on age at diagnosis and stage of dementia when diagnosis is made as well as other co-morbidities. It is generally recognised that survival in dementia is highly variable and may range from five to twenty years. Kelly et al (2007) also highlights that in comparison, persons with intellectual disabilities receiving a diagnosis of dementia have substantially decreased life expectancies. The median survival from initial diagnosis was 4.2 years for men and 5.7 years for women with dementia [11, 12]. It is also reported that men have a poorer survival across all age groups compared with females [12].

2.3 END-STAGE DEMENTIA

It is useful to identify the final phase of a disease when considering palliative care. Abbey (2006) identifies the following groups of symptoms and behaviours that can signify this phase for a person who has dementia:

- There is often a progressive worsening of memory resulting in increased confusion and disorientation.
- Speech and the ability to communicate often deteriorate to the point where the person may eventually become incoherent or completely mute.
- Behavioural changes may occur which can lead to a person being belligerent, sobbing or screaming, or strikingly passive and quiet, immobile and detached.
- The person's ability or desire to move independently can decline, leaving them bed/chair bound.
- The person's capacity for self-care progressively diminishes, making them totally dependent on carers.
- The person's ability to eat independently gradually disappears, often in association with a diminished ability to swallow and increased risk of aspiration. A progressive loss of appetite almost always follows.

- Other complications can include bowel and bladder incontinence, muscle atrophy and contractures, increased susceptibility to delirium, recurrent infections, pneumonia, pain, peripheral shutdown, bedsores and general skin breakdown. Delirium can result in increased restlessness and agitation [13].

The prevalence of these symptoms will vary between individuals because of differing disease processes, individual differences and co-existing diseases such as cardiac failure, diabetes or cancer [13]. It is recognised that infections such as pneumonia, urinary tract infections and septicaemia are not uncommon in late stages of dementia and these are the most frequent causes of death in the final stages of the disease [14].

It must be emphasised that end-of-life issues for a person with dementia can be further complicated by their inability to communicate verbally, the difficulty for caregivers in interpreting symptoms and care needs, and the variability in the disease trajectory.

All health care workers, family members and informal carers need to be aware of the person with dementia's progressive inability to address their own psychological and social needs. Education and training will help such carers to improve the support they provide to the person with advanced dementia and ensure that the principles of person-centred care, with a continued focus on comfort, attachment and inclusion, are maintained [5].

2.4 KEY POINTS

Dementia is an increasingly prevalent, progressive disease without cure and with known manifestations that require specialised care from staff and families. The final phase is particularly challenging given its length, the deterioration of the individual and the progressive inability of the person with dementia to communicate and participate in decision-making about their care. Maintaining person-centred care and comfort will require incorporation of palliative approaches and training for health care workers and informal carers.

3. DEMENTIA, INTELLECTUAL DISABILITY AND PALLIATIVE CARE

People with intellectual disability, particularly persons with Down syndrome, show much higher rates of dementia compared to the general population. General population prevalence is between 1% and 25% and intellectual disability prevalence between 2% and 54% with higher incidence at younger ages. In response to these trends there have been a number of developments in Ireland in education and service delivery for palliative care for people with intellectual disability and dementia. These are examined in the shaded section below as a distinct entity, and consideration should be given as to how dementia services for people in the general population can learn from these developments.

DEMENTIA, INTELLECTUAL DISABILITY AND PALLIATIVE CARE

Epidemiology

People with intellectual disability, and particularly persons with Down syndrome, are at increased risk of developing dementia compared to the generic population. Age specific rates are estimated to be 36.1% in persons aged 50-59 years and 54.5 % in persons aged 60-69 years [10]. The recent study by Fahey-McCarthy et al (2008) would suggest that services are challenged in addressing the complex needs often evidenced at the end-stage of dementia [15].

Prognosis

For persons with Down syndrome prognosis may be complicated. Decline is often more compressed with a mean duration of dementia estimated to be between 3-5 years [12], with more recent studies indicating that people appear to be surviving longer at a more advanced stage [15]. It should be noted that many persons with intellectual disability may have different pre-morbid levels of functioning than the general population which will mean that it is not possible or appropriate to use independence levels or MMSE (Mini Mental State Examination) scores to estimate stage of dementia [16, 17].

Service Models

This study has identified a number of service models of dementia care for people with intellectual disability which includes palliative care. One of these service models is highlighted below:

In 2005 the Daughters of Charity Service responded to the challenges of dementia and produced a Strategic Plan on Dementia which recognised that:

- As dementia progresses, medical and nursing needs become more complex and maintaining adequate hydration and nutrition, pain management and end-of-life care decisions are paramount.
- People with dementia – and their families if appropriate – require information, guidance and support to make informed decisions that will guide end-of-life care plans.
- There is a need to offer high quality nursing and appropriate palliative care for persons with advanced dementia, their peers, the staff and families.
- End-of-life care plans will be developed in conjunction with the person (where possible), staff and families, to support care.
- Bereavement support groups for clients/peers and for staff need to be established or expanded [18].

As part of their strategic plan the Daughters of Charity have developed a comprehensive education programme for those supporting people with dementia. Staff throughout the service receive training in principles of person-centred dementia care and skills in comfort care.

Education and Training needs

Following a recent study a recommendation has been made in this area about the development and piloting of a joint educational intervention between intellectual disability services and specialist palliative care services to address key care concerns raised by participants in supporting persons with intellectual disability and advanced dementia [15].

Key Points

These developments provide a useful foundation when considering how to introduce palliative care for people in the general population. However application to the general population would require changes in guidelines and protocols developed, given the different ability levels of people with intellectual disability.

4 OVERVIEW OF POLICY, STUDIES AND SERVICE DEVELOPMENTS

In considering how to extend palliative care to people with dementia, it is helpful to examine research and policy developments in this area from an international and national perspective. For sometime it has been accepted internationally [15, 19, 20] that palliative care has a role to play in the treatment and care pathway of people with dementia. In 2001 Addington Hall documented how people with end-stage dementia exhibited similar care needs to people with advanced cancer, although it has been noted that for people with dementia the end-stage lasts longer [20]. Hughes (2005) suggests that the difficulty in obtaining ethical approval in patients who are unable to give informed ethical consent has impeded research on the efficacy of palliative care in dementia [21].

It is acknowledged that introducing palliative care in supporting persons with end-stage dementia will challenge the way clinical and palliative services are traditionally delivered, because of the variability in dementia presentation, ethical and consent issues, communication difficulties [22] as well as difficulties in identifying the end-stage of this disease [23]. This is supported by studies which have indicated that palliative care services for persons with advanced dementia have not been initiated because death was not seen as imminent [24]. Other studies suggest that where a palliative approach was not incorporated in end-of-life care of persons with dementia, analgesia was infrequently used, the dying phase was not recognised, and antibiotics were inappropriately used in the last days of life [25]. Families gain particular benefit from additional information with regard to symptom management and treatments for advanced dementia to help guide decision making [26].

Reports from the UK and Australia provide guidance and direction on the role and potential utility of palliative care interventions for people with advanced dementia [13, 19, 27]. In 2006 Abbey stated that “high quality palliative care in terminal dementia is facilitated when both the person with dementia and their family have together explored issues related to treatment and management” (Pg 6).

Abbey recommends that the following components be included as part of a non-specialist palliative care for people with advanced dementia:

- Care environment
- Symptom management – pain, nutrition, hydration and antibiotics
- Provision of personal care, covering invasive procedures and restraint
- Personal comfort measures, including personal hygiene, mouth care, difficulty with breathing, skin care, bowel movement, mobilisation, personal support including emotional and psychosocial needs
- Spiritual care
- Cultural issues
- Death
- Family carers and decision making
- Negotiating care with service providers [13].

The UK NICE guidelines on supporting people with dementia and their carers agree that dementia care should incorporate palliative care from the time of diagnosis until death. They specifically state that the aim should be to support the quality of life of people with dementia, to enable them to die with dignity and in the place of their choosing, while also supporting carers during their bereavement, which may both anticipate and follow death [19]. It is imperative that such services should include the person-centred approach and respectful principles underpinning good dementia care.

The 2007 report from the National Audit Office UK states that early diagnosis for people with dementia gives people the opportunity to make choices and plan for the future while they are still relatively well. This may include decisions about treatment and end-of-life care (including artificial feeding and resuscitation), the writing of wills and/or advance directives, setting up of enduring power of attorney or the appointment of advocates [27].

The Lighting Up Lives study in Scotland investigated whether the palliative care needs of people with end-stage dementia were met. Thirty percent of carers reported that pain was an issue when questioned about the standard of physical care. Care home managers reported that there was a lack of medical information provided by GPs and hospitals which impacted on the effectiveness of the care the care homes were able to provide. The relationship between carers and relatives was reflected poorly. Over 50% of care staff interviewed expressed a negative image of relatives, and equally over 50% of informal carers did not feel the care home had sufficient information on their relative. The majority had not been regularly involved in a review of the persons care, despite their requests for this [28].

An educational project called Beyond Barriers has been developed by Alzheimer Scotland to respond to the needs identified in this study. This programme is being funded by the Scottish Government as a response to their commitment to palliative care for people with non-malignant diseases. The educational project is offered to both carers and relatives and has an action learning element to assist with embedding practices in the work place. Evaluation of this project will be available in early 2009 [29].

In Peterborough, UK, a palliative care dementia group has been formed in a specialist care home for the elderly mentally ill, with representatives from the local hospice, the GP and other health and social care staff in the area. Core aspects of the service that is provided from this group include advance care planning, avoidance of unnecessary admissions, and use of a modified end-of-life care pathway. Training and support for staff in the use of pain assessment and syringe drivers plays a critical role. Practical sessions are held with relatives to inform and discuss a range of issues that arise as part of this service [30].

St. Christopher's Hospice, London, has established and evaluated a new model of working to meet the palliative care needs of people with advanced dementia and their families. Early findings have indicated that most people with dementia can be cared for at the end of their lives by staff who are not specialists in palliative care, once there is access to specialist support. Intervention from SPC included symptom control, psychosocial support, terminal care and support for families, carers and staff [30].

Alzheimer Europe are preparing a position paper on guidelines on end-of-life care for people with dementia, and this will include specific guidelines on a wide range of care issues that present for people with advanced dementia, including pain management, feeding and swallowing, as well as the moments preceding and following death. It will also consider the ethical issues related to care of people with dementia [31].

The specific rationale, practice and interventions of SPC for people with advanced dementia were described by Shuster (2000) and more recently by Hughes (2005). Shuster outlines the specific challenges to adopting palliative care with advanced dementia care, and suggests that, in keeping with the person-centred approach, discussions are initiated about treatment preferences as early as possible in the trajectory of the illness and ideally when the person is still capable of meaningful participation [32]. Supportive discussion on decisions and options about appropriate care provision can help to relieve guilt and distress that is commonly experienced by family members and caregivers [21].

More recent work by Hughes acknowledges that palliative care fits well within the philosophy of person-centred dementia care but that care and symptom management at end-of-life is poor because few dementia staff have training in end-of-life care and few palliative care staff have training in dementia. He advocates for a liaison role for SPC staff with community, nursing home and hospital-based dementia service providers. He believes palliative care will facilitate discussion on and the development of advance planning about end-of-life and thus subsequent care will be based on previously agreed goals. He also sees a role in supporting families in bereavement [33].

At the 2007 European Association of Palliative Care conference the following interventions from UK research were listed by Thune for inclusion in plans to improve the end-of-life care for persons with advanced dementia:

- A thorough palliative care needs assessment of patients, especially focusing on the presence/absence of pain.
- Advance care planning discussions with relatives to improve knowledge and understanding of end-stage dementia, how the illness may progress and to support them in making realistic end-of-life care decisions.
- Education for health care professionals to improve their understanding of advanced dementia and issues surrounding appropriate care and treatment [26].

The McCarron et al study in 2008 suggests that the principles of person-centred dementia care mirror the broad principles of palliative care. SPC participants interviewed as part of the study recognised that they did not have the resources or expertise to deal with many of the care issues/challenges which often need to be addressed at an earlier stage of dementia and even questioned its feasibility. It was clearly evident too that many of the participants working in intellectual disability services supporting persons with advanced dementia often lacked the necessary skills and knowledge required in providing optimal end-of-life care. There was limited experience in supporting people who were dying. Difficulties were often compounded by lack of guidelines and specialist support to guide decision making at end-of-life. There were additional training needs to be met particularly in the area of pain and symptom management and the maintenance of nutrition and hydration. There was a consensus that the optimal care of persons with advanced dementia could be greatly enhanced by close collaboration, guidance and support from SPC particularly in the areas of advanced planning, symptom management, grief and bereavement support [15].

The views of service users are an integral part of health service delivery. Services for people with dementia need to recognise that people with dementia can make choices and express opinions. The UK NICE guidelines underline the importance of allowing time for effective consultation with service users and families.

4.1 KEY POINTS

- It is evident that the introduction of palliative care in advanced dementia care can raise specific ethical challenges. However there is general agreement that opportunities for advance planning should be given to persons with dementia and their families as early as possible as this will facilitate how the individual wishes to live with dementia.
- The policy developments in other countries which have included palliative care as part of services for people with dementia provide guidance and direction for developing Irish policy in this area. These ideas need to be embedded in the person-centred approach to dementia care that should be available from the time of diagnosis up to the final phase, and death.
- The evidence-based models identified support the need to develop collaborative practice and to concentrate on the development of local initiatives.

5 CONTEXT OF DELIVERY OF SERVICES FOR DEMENTIA IN IRELAND

5.1 CURRENT SERVICE PROVIDERS

Within the HSE the role of Medicine for the Elderly lies with both the diagnosis of dementia and the assessment and management of people with dementia who have medical problems. Many geriatricians take a proactive approach to the development of dementia services. About 50% of the work of Psychiatry of Old Age services – also referred to as Mental Health Services for Older Persons – is in the area of dementia, where they have specific responsibility for people with dementia who have severe behavioural problems. This team also has a role in diagnosis, but their continued involvement in such cases usually only occurs where there are associated behavioural or psychiatric symptoms [6]. Neurologists are often involved in the assessment and diagnosis of younger persons with dementia. Services for Older People are an integral part of the HSE. These services are provided in a variety of care settings and frequently respond to the needs of people with dementia [34].

When fully implemented, the Memory Clinic Model [6] provides a diagnosis of dementia following a full assessment, and follow up is offered where the degree of progression is assessed, and opportunities are provided for continued support. While some clinical services have developed memory clinics and carers' groups their availability is variable throughout the country.

Currently there is a lack of dementia-specific services at hospital and community levels. In general, outside of the dedicated dementia services, post diagnosis care is mediated by the public health nurse in conjunction with the primary care physician. The transition from home to living with a carer to admission to long-term care is usually overseen by the primary care team. This team provides advice and support regarding the ongoing issues presented during the course of the disease. Issues with regard to artificial feeding, use of measures designed to prolong life such as treatment of recurrent infection and end-of-life issues are referred to a specialist such as a geriatrician or, in the case of behavioural disturbance, to psychiatry of old age. However there are pockets of evidence of developing alliances between palliative care teams and services for people with dementia.

A survey of Irish GPs by Cahill et al found that the rate of disclosure of dementia by Irish GPs is low compared with similar patterns in other countries and this survey determined that there is an urgent need to develop active and more systematic approaches to GP training and dementia care. Failure to disclose diagnosis is a barrier to exploring issues, support and to future planning [35].

5.2 POLICY AND REPORTS RELEVANT TO DEMENTIA SERVICES IN IRELAND

Evidence of challenges in delivery of dementia services has been documented in a number of reports over the past decade [6, 10, 36]. These reports have also outlined the proposed model of practice for dementia service with a strong emphasis on the person-centred model [6]. The Alzheimer Society of Ireland (ASI) has initiated many of these reports and has stressed that the current fragmentation between the elderly, disability and mental health services inhibits development of the seamless, person-centred continuum of service that is fundamental for people with dementia. ASI has also emphasised that people who have early onset dementia are at further disadvantage in that they are often excluded from dementia-specific services because of their age [36].

Recently there have been a number of strategic initiatives which have focussed on services for people with dementia. These include the Expert Advisory Group (EAG) on older persons, established by the HSE in 2006 [37], and the National Working Group on Dementia which was convened at the end of 2007, and it is anticipated that the latter will include a reference to palliative care within in its brief [38].

5.3 PALLIATIVE CARE AND DEMENTIA – IRISH POLICY CONTEXT

The Vision for Change report (2006) notes that the issue of palliative care in dementia is of singular importance; however this report does not explore how palliative care should be incorporated into existing services for people with dementia [41].

An unpublished HSE report (2007) on residential services for people with dementia acknowledges that end-of-life issues in dementia care in Ireland have received little focus to date. It notes that training staff in non-specialist palliative care is critical for best practice for staff working with residents/patients with dementia in long-term care and in the acute sector. It also underlines the importance of training on ethical issues including the use (or non-use) of naso-gastric and percutaneous endoscopic gastrostomy feeding at the end-stage of dementia [10].

In 2008 standards for residential care settings, including supplementary criteria applicable to units that specialise in dementia care, were launched by the Health Information and Quality Authority (HIQA) [42]. As an estimated 60-70% of people in residential and nursing homes have dementia [41] it is appropriate that these criteria cross reference with Standard 16 which deals with end-of-life care needs for people in residential settings [42].

The 2008 report by O'Shea et al, End-of-Life Care for Older People in Acute and Long-Stay Settings in Ireland, notes that while dementia is an increasing cause of death among older people, it is not generally recorded as the primary cause of death. The result is a lack of awareness of the life-threatening nature of the disease in its advanced stages and a failure to integrate end-of-life care and gerontological care [41].

In 2007 O'Shea's report on dementia care noted that there is a responsibility on the family or staff who support people with dementia to get to know the person and how that person conveys their wishes, be it distress or comfort. The development of a life-long, inter-generational understanding of dying and death is also necessary for good quality care to emerge at the end-of-life for people with dementia, and this should be incorporated in integrated care pathways [44].

Despite the limited policy direction in this area, there is evidence that the HSE recognises that the services for people with dementia are underdeveloped, and of commitment that emerging frameworks/models will include a palliative care component.

6 PALLIATIVE CARE AND DEMENTIA – EXAMPLES OF IRISH SERVICE MODELS AND EDUCATION INITIATIVES

Understandably very little evidence could be found where the palliative care is fully integrated into established dementia services. Some examples of service models and education initiatives in the area of dementia services which reference palliative care are outlined below. This is not intended to be an exhaustive list but serves to represent the service developments in this area.

- Staff in Le Cheile, St. Vincents Hospital, Athy, Co. Kildare, which is a ten-bedded dedicated dementia unit, have all received training in palliative care, and they have a person-centred approach to all aspects of their care, including their end-of-life care. SPC input is requested for complex symptom management.
- The Clonakilty Community Hospital has a 14-bedded dementia unit, which includes two purpose-built apartments for people with dementia who are in the final phase of their illness. A person-centred approach is adopted as the service model. The local SPC team provide support to these patients as required.

- St. Patrick's Unit in Cashel is currently re-configuring its dementia services which will include a purpose built dementia unit, including dedicated end-of-life beds. This is being led out by an Advanced Nurse Practitioner (ANP) in Dementia Care, who has received training in Palliative Care. The SPC provide support to patients as required.
- One Psychiatry of Old Age team reported extensive involvement with their local SPC services. The example was given where the SPC team had visited the acute and long-stay wards and directly helped with the care of two persons dying with dementia. This SPC team has also offered support to patients in the general hospital who were dying with advanced dementia. However no other dementia-care team reported direct dealings with SPC team.
- Several AGH have SPC teams that offer services to people with dementia, and one such AGH team has listed 4% of patients with co-morbidities of dementia in 2007, and 5% with dementia as their primary diagnosis in their service.
- Other than the Higher Diploma in Specialist Nursing in intellectual disability and dementia in the School of Nursing and Midwifery in Trinity College in which one of four specialist modules addresses palliative care, there is little interdisciplinary post-graduate educational provision on palliative care in dementia care [45].
- The Dementia Services Information and Development Centre (DSIDC) has included papers on end-of-life issues in its National Conferences and has facilitated discussions at a local level during staff training days. DSIDC are currently developing a module on palliative care in dementia for nurses and health care assistants in residential care settings.

7 KEY FINDINGS AND CONSIDERATIONS FOR THE PROVISION OF PALLIATIVE CARE FOR PEOPLE WITH DEMENTIA IN IRELAND

Internationally studies have demonstrated that good quality palliative care in end-stage dementia is where the person with dementia and their family can explore the issues related to their treatment and management. This planning and discussion needs to take place as early in the disease trajectory as possible so the person with dementia is capable of meaningful participation. Despite the increased projections of dementia population in Ireland there is currently no agreed service framework for people with dementia, and there is very little evidence-based practice of palliative care incorporated into dementia-specific services.

This section outlines the issues that present in delivering palliative care for people with dementia in relation to service models and structure, research, policy and education and seeks to identify ways to meet these challenges.

7.1 SERVICE MODEL AND STRUCTURE

It is accepted that palliative care should be included in the care pathway for people with dementia, and that the person-centred approach that is advocated for people with dementia integrates well with the palliative care principles. However there are a number of challenges associated with the implementation of palliative care for people with dementia. These include the timing of introduction of palliative care, clarity with regard to the role of palliative care, addressing the ethical dilemmas that can present at end-of-life for people with dementia, the ability to communicate with people with advanced dementia and the role of advance directives in care pathways.

In Ireland the current baseline for services for people with dementia is extremely poor, and the structure of service provision is fragmented. Despite this there have been a few advances in implementing person-centred dementia care provision in Ireland which have specifically included palliative care within their service framework. An evaluation of these emerging models would inform any future developments as well as providing guidance from an education, policy and research perspective.

As a high proportion of people with mid to end-stage dementia are in residential care in Ireland, it is imperative that private and public institutions develop dementia-specific services which include non-specialist palliative care. The role of SPC for people with dementia also requires attention. There is a lack of awareness amongst many professionals of the role and responsibility of SPC in this area, and access to SPC for people with dementia in Ireland is variable throughout the country. The establishment of referral triggers and eligibility criteria for access to SPC would assist in providing clarity in this area.

As services for people with dementia are evolving, specific consideration needs to be given to ensure that people with dementia in the final phase of their illness can die in the care of staff that are familiar with their needs, and in an appropriate environment. Greater support in the community from appropriately-resourced multi-disciplinary teams (MDT) from Services for Older Persons could help to prevent inappropriate admissions to Accident and Emergency. It would also be helpful to provide guidelines and fact sheets for patients, families and staff at diagnosis of dementia and as the illness progresses and also consider the role of an independent advocacy service where family members are not involved in decision making re the care of a person with dementia. These guidelines should ensure that the person with dementia and their families are informed and involved as appropriate about all aspects of their care and related decision making. They should include a description of services available and issues for consideration by patients and families. Such developments must also refer to the added complexities associated with end-of-life issues for a person with a dementia due to their inability to communicate verbally, the difficulty for care-givers in interpreting symptoms and needs and the variability in the disease trajectory.

7.2 RESEARCH

It has been acknowledged that palliative care in dementia can raise specific ethical challenges, and consequently more evidenced-based information would be helpful to practitioners when considering how to introduce aspects of palliative care for people with dementia, notwithstanding the fact that this area is a particularly sensitive area in which to carry out research.

The particular areas that would benefit from research are:

- The timing of introduction of palliative care.
- The need to determine the classification of end-stage dementia to assist the timely intervention of the SPC team.
- The need to provide information on and validation of clinical standards for assessment of treatment of end-of-life symptoms of people with dementia.
- The need to learn more about the impact a palliative care service within a dementia-specific service has made to the person, the families and the staff involved.

An audit and profile of the current provision of palliative care services for dementia in all health care settings in Ireland would provide some guidance as to emerging practices and assist in providing a database of activity.

7.3 EDUCATION

All staff who work with people with dementia require specific formal and informal training and education in end-of-life issues. Special efforts should be made to develop collaborative approaches between SPC and staff working directly with people with dementia, to help overcome the communication difficulties that present and to ensure a person-centred approach is maintained.

Opportunities for dementia-specific training are very limited in Ireland, and it is imperative that emerging under-graduate and post-graduate training curricula in this area include significant content on end-of-life and aspects related to palliative care. The development of distance-learning modules for education accumulating to certificate, diploma, or degree would be another method to respond to the education demands in this area. Staff in residential units, AGH and nursing homes would benefit from modules including dementia, challenging behaviours, palliative care, communication, nutrition and pain management.

An opportunity to present and debate the issues arising from this report would be helpful in raising awareness and understanding of palliative care and dementia.

7.4 POLICY

The HSE National Working Group on Dementia, convened at the end of 2007, must consider and address the palliative care needs of people with dementia that have been identified in this report.

Particular consideration should be given to the difficulties that can arise from existing structural and staffing difficulties in nursing homes and long-term care facilities in Ireland, as there is potential for inappropriate transfers of people with dementia from their primary place of care to accident and emergency units at end-of-life. If such transfers occur, people with dementia may die surrounded by strangers who are not familiar with or able to respond to their needs. There is a need for appropriate planning and resources to cater for impending death of a person with dementia and to overcome relatives' concerns and those of legal formalities arising from death in a long stay institution.¹⁴

Equally, health care provision must respect the traditions associated with the cultures it now represents, particularly with regard to death, dying and bereavement, and although this is particularly poignant for people with dementia when in their terminal phase, it is relevant for all people diagnosed with a life-limiting disease.

8 PALLIATIVE CARE: ELIGIBILITY CRITERIA AND REFERRAL TRIGGERS FOR PEOPLE WITH DEMENTIA

8.1 TIMING OF PALLIATIVE CARE AND DEMENTIA

The lack of clarity of the role of non-specialist palliative care in dementia services and eligibility and access to SPC for people with dementia is a recurring theme of the Extending Access Study.

Diagram 6 is an adaptation of the diagram used earlier to demonstrate how understanding the disease trajectory for people with dementia can be helpful to illustrate the timing and necessary relationship between dementia services in delivering non-specialist and specialist palliative care where required.

In Diagram 6 the large oval suggests that non-specialist palliative care should be included early in the disease trajectory, prompting queries relating to advance planning, spiritual and psychosocial matters and any unmet physical symptoms. Services for Older Persons can play a pivotal role in advising on avoiding burdensome interventions for patients with advanced dementia. Staff addressing these 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. Non-specialist palliative care

¹⁴ Currently if a person with dementia dies when they are in a nursing home or a mental health facility, their death must be reported to the Coroner, who may in turn request that an inquest be held.

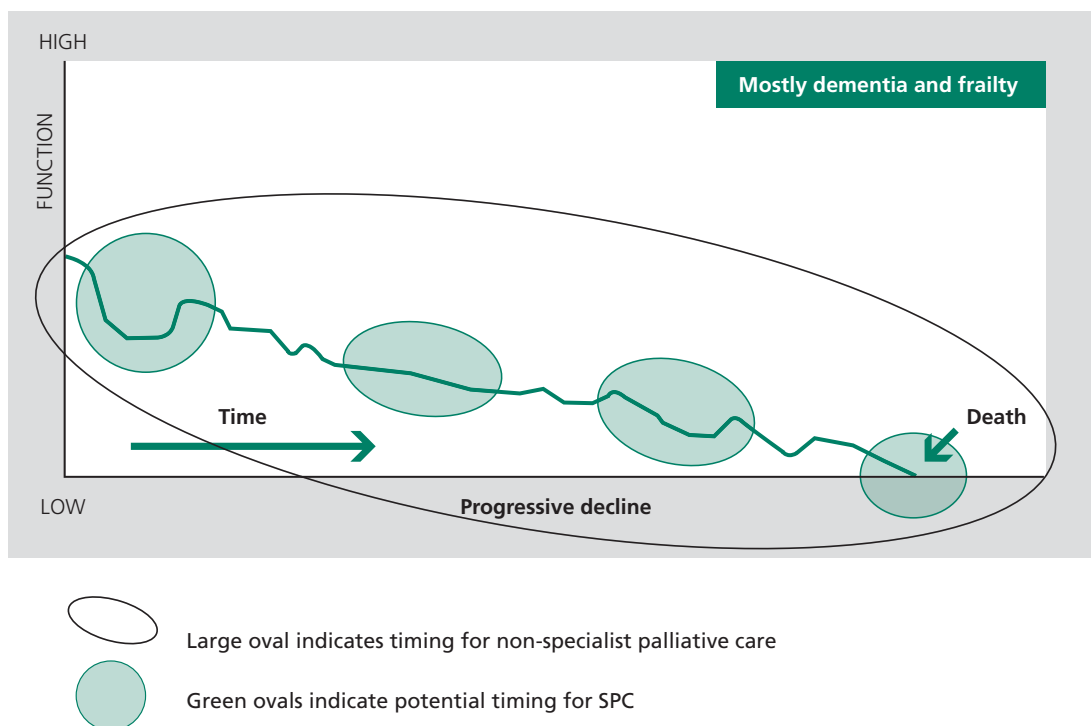
needs can extend beyond death of a patient, as often the primary care services remain involved with the family during the bereavement process. They specifically have a role in relation to:

- Symptom management and pain
- Community and home care support to address increasing disability
- Anxiety and depression that is prevalent with the disease
- Understanding of the disease trajectory and advice and support relating to advanced planning
- Prompt access to SPC at advanced stage of illness, particularly in the community.

The smaller ovals indicate where particular consideration of the need to refer to and discharge from SPC may occur. Referral to SPC could arise from complex/extraordinary needs relating to physical, emotional and/or spiritual needs of patients throughout their disease trajectory which cannot be met by the dementia team. (See 8.2).

DIAGRAM 6:

TIMING OF PALLIATIVE CARE IN DISEASE TRAJECTORY MOST COMMON IN DEMENTIA AND FRAILITY [ADAPTED FROM 60]¹⁵



The insidious nature of decline for people with dementia makes it more difficult to determine triggers to predict referral to SPC. Nevertheless the relationship between dementia professionals providing care on a daily basis and SPC teams should be similar to those for people with a disease trajectory exhibiting more distinct exacerbations and remissions. The SPC consultation for people with dementia may be once off assessment, and should generally be based on a collaborative approach recognising the need for ongoing input from dementia-specialist team. The referral to SPC could be for clinical management from a medical or nursing perspective or else the management of needs that can be met by the SPC MDT.

It is accepted that the full application of this model would be dependent on a fully resourced dementia service framework. However, as has been demonstrated earlier, some dementia services in Ireland are delivering on aspects of this model.

¹⁵ © Diagram 6 is an adaptation of a diagram reproduced with the permission of RAND Health

8.2 TRIGGERS FOR REFERRAL TO SPECIALIST PALLIATIVE CARE

SPC is largely inappropriate for persons with dementia with stable, inactive disease. While the final phase of dementia is difficult to discern, a referral to SPC would be recommended where there has been an acute medical event, with an increase of intensity of symptoms which have become intractable despite active treatment.

The following indicators may be used as triggers for referral of a person with dementia to SPC:

- Increase of intensity of symptoms, e.g., pain, dyspnoea, terminal agitation, that cannot be managed or controlled by referring team.
- Assistance with the introduction of advanced directives, or clarification regarding certain treatment decisions [46].

8.3 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.

D.1 Service Model

- a) A project group is to be established to devise, plan and oversee a proposed Model of Care outlining the palliative interventions required for patients diagnosed with dementia within a designated health location ideally encompassing an AGH, residential facility, 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 dementia. 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 as well as family members and the person with dementia; 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 initiatives relating to care of persons with dementia in residential care settings, Primary Care and AGH.

Health Service Executive / Irish Hospice Foundation with support from Alzheimer Society of Ireland / Dementia Services Information and Development Centre

- b) Every effort should be made to ensure that people with dementia die in an environment and amongst staff that they are familiar with.

Health Service Executive

D.2 Research

Research should be carried out to:

- a) Prepare and validate clinical standards for assessment and treatment of end-of-life symptoms of people with dementia.

Health Service Executive / Irish Hospice Foundation with support from Dementia Services Information and Development Centre / Alzheimer Society of Ireland

- b) b) Devise a practical framework for the classification of terminal dementia.

Health Service Executive / HRB with support from academic institutions

D.3 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) Host study days to generate greater awareness and understanding on the role of palliative care within dementia services.

Specialist Palliative Care / Older Persons Services, Psychiatry of Old Age / Irish Hospice Foundation / Health Service Executive with support from Alzheimer Society of Ireland / Dementia Services Information and Development Centre

- b) Post graduate education for all staff working in the area of dementia should have a defined palliative care component suitable to their skill level, and SPC staff working in this area should be able to access training in this area, so that palliative care needs of people with dementia can be identified and responded to at appropriate levels.

Health Service Executive / Palliative Care Education Taskforce / Medical Education Training and Research Unit and relevant educational institutions

- c) Provide opportunities for distance learning Continuing Professional Education in dementia and palliative care.

Health Service Executive / Dementia Services Information and Development Centre / Palliative Care Education Taskforce and relevant educational institutions

D.4 Policy

- a) The HSE National Working Group on Dementia should consider recommendations of this report.
Health Service Executive
- b) Future monitoring of services should consider the introduction of an ageing in place policy so that people with dementia live in an environment which adapts to their changing needs throughout the course of their illness.
Health Service Executive / Department of Health and Children

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Appendix Three

Palliative Care and Heart Failure

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).

HEART FAILURE WORKING GROUP MEMBERSHIP:

Phil Pyne Daly
Cognitive Psychotherapist

Angela Edghill
IHF Project Team

Dr. Paul Gregan (Chair)
GP and Consultant in Palliative Medicine

Marie Lynch
IHF Project Team

Fidelma MacHale
National Hospitals Office, HSE

Kathy McSharry
Practice Nurse representative, Professional Development Coordinator for Practice Nurses

Dr. Niamh Murphy
Cardiologist/Lecturer in Cardiovascular Medicine

Dr. Norma O'Leary¹⁶ (Chair)
Research Fellow, Palliative Care

Sheila Ryan
Clinical Nurse Specialist, Palliative Care

Mary Ryder
Advanced Nurse Practitioner in Heart Failure

Dr. David Weakliam
Consultant in Public Health Medicine, HSE

¹⁶ Dr. Norma O'Leary chaired the Working Group until October 2007. The Group was chaired thereafter by Dr. Paul Gregan.

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.

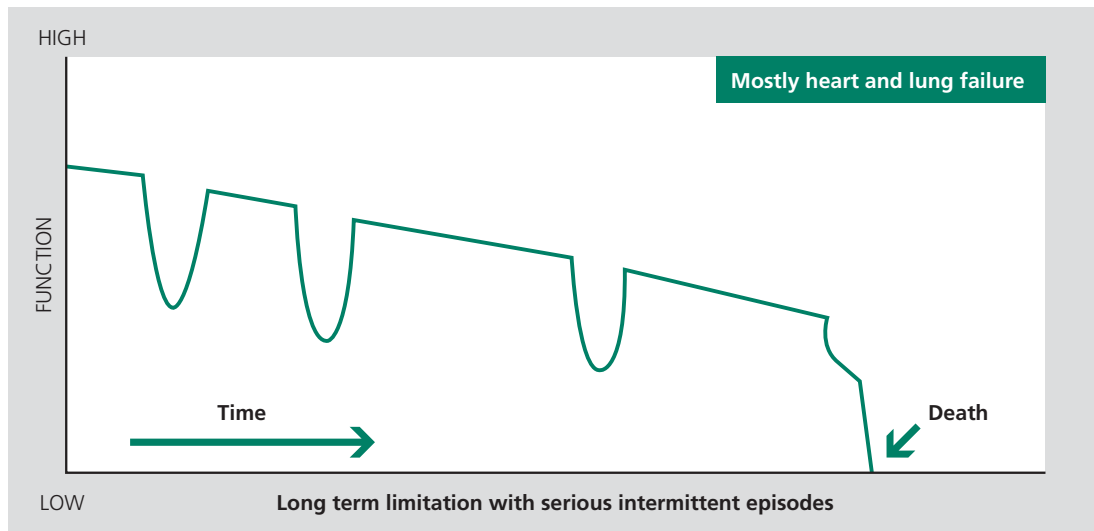
As heart failure is considered a mode, not a cause, of death, it is not notable on death certificates in Ireland, and it is therefore difficult to determine mortality rates.

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:

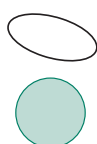
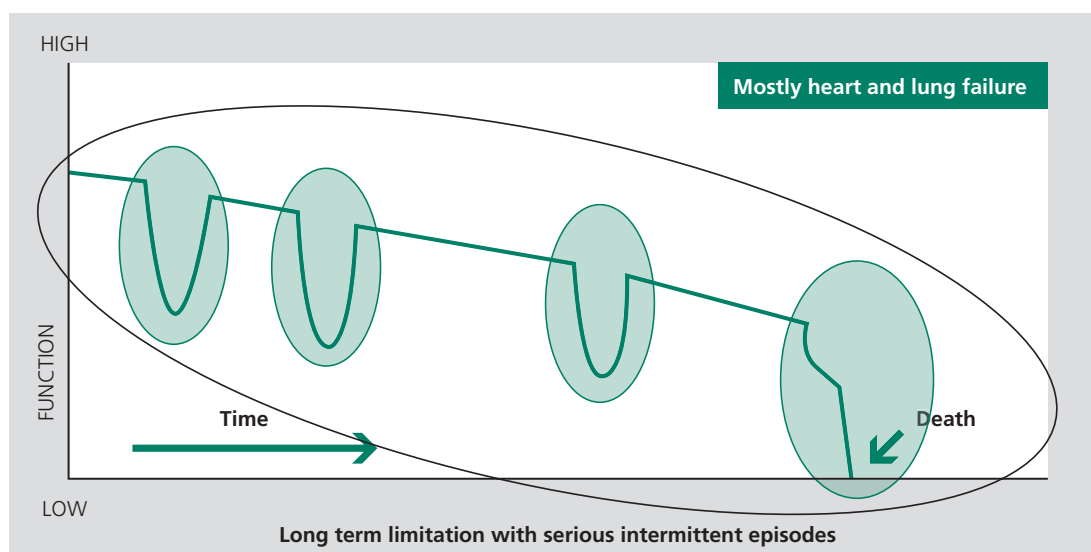
- The unpredictable disease trajectory and prognostication which makes the identification of end-stage heart failure difficult.
- Uncertainty about when discussions on sensitive end-of-life issues could be introduced is compounded by time pressures intrinsic in the high patient population in cardiology, 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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Appendix Four

Submission sent to
Palliative Care Education
Taskforce

Appendix Four

Submission sent to Palliative Care Education Task Force

The recently established Palliative Care Education Taskforce (PCET) is working on a five-level palliative care education framework [1]. In recognition of this, the formal education requirements identified during the course of the study have been combined and presented to the PCET for consideration in their work. It is hoped that PCET will work closely with the developing HSE Medical Education, Training and Research Unit (METR) to progress palliative care education and training [2]. The work of the PCET, the five-level education framework and METR are described in more detail in Chapter 3 of this report.

One of the principal findings of the Extending Access Study is that in order to successfully integrate palliative care into the care plan for people with non-malignant diseases there must be increased educational opportunities for all healthcare staff, including those in SPC.

Healthcare staff require specific support and training in aspects of palliative care to address the needs of patients in their care, and refer patients to SPC as appropriate. As SPC staff increasingly respond to the needs of people with life-limiting illness other than cancer, they also require additional skills and training on the specific needs of these patients.

The particular educational and training needs identified relate to:

- Understanding physical and psychological symptom burden
- Communication issues relating to dying
- Ethical issues surrounding care of the those diagnosed with life-limiting disease
- Advance planning and symptom control.

LEVEL 1 PRE-QUALIFICATION PROFESSIONAL TRAINING, THE FOUNDATION OF A PALLIATIVE CARE APPROACH

The Schools of Medicine attached to the Irish universities should ensure that the palliative care core principles for people with cancer and those with diseases other than cancer are made explicit in undergraduate medical curricula.

It is recommended that **third-level education providers of pre-registration nursing programmes** make explicit in the curricula the learning objectives and subject content regarding teaching of palliative care core principles for people with cancer and those with diseases other than cancer. It is also recommended that palliative care core principles be made explicit in the curricula of undergraduate midwifery programmes.

Universities and colleges that are responsible for education and training of **allied health professionals** should ensure that palliative care core principles are made explicit in the undergraduate curriculum appropriate to each discipline.

It is recommended that when third level pre-qualification programmes are designed and developed that palliative and end-of-life care issues be taught as an inter-disciplinary module/ subject i.e. shared learning between nursing, midwifery, medical and allied health students.

The Health Service Skills Award FETAC Level 5 involves support staff studying five core modules and three elective modules. The Palliative Care Support Module is offered as an elective module. However this module is not offered in all of the Centres of Nursing/Midwifery Education, the internal providers in the HSE for training/educating Health Care Assistants (HCAs). It is imperative that this module be offered as an elective module in all of the Centres of Nursing/Midwifery Education. Ideally it should be offered as a core module.

In addition, it is recommended that HCAs who have already completed the Health Service Skills Award and those who completed the preceding qualification, Health Care Support Award, be facilitated by the HSE to study the Palliative Care Support Module, as an additional module.

LEVEL 2 GENERALIST CONTINUING PROFESSIONAL EDUCATION

- Joint study days between SPC and specialists in disease-specific disciplines are required to assist in the clarification of the role of palliative care for people with diseases other than cancer. These study days will facilitate the development of non-specialist palliative care within the disease-specific management framework, and yield potential for collaborative work. These study days could be a combination of multidisciplinary format and also restricted to individual professional groupings. Responsibility for these study days would lie jointly with the relevant palliative care and other specialist organisations.
- Continuing Professional Education modules on palliative care and specific life-limiting diseases should be available to all health care professionals. It is recommended that the modules be developed in a standardised way, accredited in line with the National Framework of Qualifications and available via distance learning format. Furthermore, it is recommended that the modules be delivered with an inter-disciplinary focus. An example of this is the Princess Alice Programme that Milford Hospice is currently introducing [3, 4]. It is recommended that responsibility for developing, implementing and evaluating the impact of the modules lies with the soon to be established multi-disciplinary HSE Education Training and Research Management Sub-Committee. (See Chapter 3).
- Information on Continuing Professional Education in palliative care topics should be easily accessible and widely distributed.

The Irish Committee on Higher Medical Training: should ensure that the palliative care element incorporating components on communications and breaking bad news is included in the core curriculum for all Specialist Registrars, including cardiology, respiratory, neurology, nephrology and psychiatry of old age.

It is recommended that palliative care principles for people with cancer and diseases other than cancer be included in the curricula of generic modules of postgraduate medical training programmes which are being developed by the postgraduate training bodies and the Irish Medical Council.

The Irish College of General Practitioners: must ensure that core training for GPs includes a palliative care module.

It is recommended that palliative care principles for people with malignant and non-malignant diseases be included in the curricula of **all formal, speciality post-graduate/post-registration nursing programmes.**

It is recommended that palliative care core principles be made explicit in the curricula of **post-registration midwifery programmes.**

It is recommended that all **Employers** of Health Care Assistants who have studied the FETAC level 5 Palliative Care Support Module in either the Health Service Skills Award or the Health Care Support Award facilitate these staff to update their end-of-life and palliative care knowledge and skills.

It is recommended that in-service training on the palliative care approach be mandatory in the induction and on-going education/training programmes of all support and administrative staff.

Provision of fact sheets for health care staff on all levels of palliative care for people with non malignant diseases will assist the necessary ongoing education and awareness in this area.

LEVEL 3 SPECIALIST PREPARATION

The **Irish Committee on Higher Medical Training** should ensure that the management of patients with non-malignant diseases be included in the core curriculum for Specialist Registrars in SPC.

Third level education providers of post-registration/post-graduate palliative care nursing programmes should ensure that the management of patients with non-malignant diseases is included in the curriculum.

The curricula of palliative and end-of-life programmes for **allied health professionals** should make explicit the learning outcomes regarding the management of persons with malignant and non-malignant diseases.

It is recommended that third level specialist palliative care programmes/modules be developed and offered as inter-disciplinary programmes/modules.

LEVEL 4 POST-SPECIALIST SUPPORT FOR LEADERSHIP

The findings from any educational research arising from the implementation of any of the recommendations of this report should be used to inform the development of level 4 education programmes.

LEVEL 5 GENERAL PUBLIC EDUCATION AND INFORMATION

People who have life-limiting diseases and their families require information on their disease trajectory, to assist them with their own autonomy and self management of their diagnosis and any advance planning/future decisions they require.

A public health approach should be adopted in the following projects for all life-limiting diseases:

- Public awareness initiatives
- Education programmes
- Information materials

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Appendix Five

List of Submissions
received during
Consultation Process

Appendix Five

List of submissions received for consideration on draft report of Palliative Care for All during the consultation process.

List of respondents during consultation process

Alzheimer Society of Ireland

Association of Occupational Therapists of Ireland

Thomas Bergin, Internal Cardioverter Defibrillator Users Group

Patricia Boylan CNS, Colette Hemenstall, Assistant Director of Services, Maria Fitzpatrick CNS, Cheeverstown House Services

Michael Bramwell, Psychosocial Bereavement Programme, Dundalk Institute of Technology

Joanne Carr, Development Coordinator, Hospice Friendly Hospitals Programme

Dr. Miriam Colleran, Consultant in Palliative Medicine, Naas General Hospital

Prof. Peter Conlon, Department of Nephrology & Renal Transplantation, Beaumont Hospital

Claire Crehan Dowdall, Family Carer – Dementia

Dr. Gerard Crotty, Consultant Haematologist, Midland Regional Hospital, Tullamore

Cystic Fibrosis Association of Ireland

Dementia Services Information and Development Centre

Directors of Nursing Specialist Palliative Care National Group

Helen Donovan, Hospice Friendly Hospitals Programme

Daphne Doran, Hospice Friendly Hospitals Programme

Mary Dowling, HSE Clinical Risk Manager, Carlow Kilkenny

Elizabeth Doyle, Transformation Development Officer PCCC, HSE

Sheila Doyle, Care of Older Persons, Nursing and Midwifery Planning and Development Unit

Dr. Andrew Eustace, Consultant in Old Age Psychiatry

Margaret Feeney

Ann Marie Fitzgerald, Clinical Specialist Physiotherapist, Chair of the Irish Association of Pulmonary Rehabilitation

Mary Flanagan, Director of Nursing HSE, LHO Dublin North

Dr. Ita Harnett, Consultant in Palliative Medicine, Galway Hospice & Mayo General Hospital

Health Information and Quality Authority

HSE Steering Group on National Action Plan for Heart Failure

HSE West Palliative Care Consultative Committee

Philip Hendrick, Air Products Ireland Limited

Hospice and Palliative Care Social Work Group

Irish Association of Palliative Care

Irish Heart Foundation

Irish Nephrology Nurses Association

Irish Practice Nurses Association

Irish Nephrology Society

Irish Raynaud's and Scleroderma Society

Irish Society of Physicians in Geriatric Medicine

Irish Society of Chartered Physiotherapists

Irish Thoracic Society

Dr. Kate Irving, Lecturer in Nursing, Dublin City University

Letterkenny General Hospital

Marymount Hospice, Cork

Helen MacMahon, Palliative Care Nurse Manager/Ass. Director of Nursing, Donegal Hospice

Claire McArthur, Senior Dietician, Milford Care Centre, Limerick

Melinda McCabe, Physiotherapist Manager, Daughters of Charity

Mary McDermott, Palliative Care CNM3, Athlone

Dr. Eithne Mulloy, Respiratory Consultant, St. John's Hospital, Limerick

National Council for the Professional Development of Nursing and Midwifery

National Council for Specialist Palliative Care

Nursing Department, Kerry General Hospital

Deirdre O'Connell, Clinical Placement Co-ordinator, Cardiology, Beaumont Hospital

Rob O'Farrell, Senior Cardiopulmonary Physiotherapist, Mercy University Hospital, Cork

Palliative Care Education Taskforce

Palliative Care Service, Beaumont Hospital

Pastoral Care Department, Kerry General Hospital

St. Francis Hospice, Dublin

South Tipperary Hospice Movement

Standing Committee on Death, Dying and Bereavement, Beaumont Hospital

Standing Committee on Dying, Death and Bereavement, University Hospitals Galway.

The Adelaide and Meath Hospital incorporating the National Children's Hospital

Therapy Advisory Unit, Department of Health and Children

Marian Wyer, Professional Development Coordinator for Practice Nurses

Irish Hospice Foundation
Morrison Chambers
32, Nassau Street
Dublin 2

www.hospice-foundation.ie

Health Service Executive
Oak House, Limetree Avenue
Millennium Park, Naas
Co. Kildare

www.hse.ie