Report of the

National Advisory Committee on PALLIATIVE CARE



DEPARTMENT OF HEALTH AND CHILDREN

AN ROINN SLÁINTE AGUS LEANAÍ

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Chairman's Preface

We emerge deserving of little credit; we who are capable of ignoring the conditions which make muted people suffer. The dissatisfied dead cannot noise abroad the negligence they have experienced.

J Hinton[1]

Welcome to the Report of the National Advisory Committee on Palliative Care. On behalf of the members of the Committee, I am pleased to present this report to the Minister for Health and Children.

Over thirty years ago, Prof. John Hinton voiced his criticisms of the standard of medical care offered to patients with advanced and life-threatening conditions. In the decades that followed, we have witnessed a remarkable renaissance in terms of our understanding of the needs of patients in the final stages of life. Developments in therapeutics and in our knowledge of pain and symptom management have spearheaded a quiet but very effective revolution. In parallel with developments in medical science, we have developed a much deeper understanding of the complex psychosocial and spiritual needs of patients and their families, as they seek to cope with the pain and suffering associated with progressive and inevitable loss.

Loss is a universal human experience. To observe at close quarter the capacity of the human spirit to mature, develop and triumph in the context of intense suffering and adversity is one of the most humbling and rewarding of human experiences. As a society, perhaps the most sensitive measurement of our maturity is the manner in which we care for those who are facing the ultimate challenge - the loss of life.

Palliative care is sometimes described as a new speciality. In fact, it is probably the oldest of all medical specialities. This anonymous 16th century writing summarises much of the palliative care experience:

To cure, occasionally; to relieve, often; to comfort, always!

In essence, palliative care is primarily concerned with quality of life; it is dedicated to a form of active treatment that is designed to ensure that patients are enabled and encouraged to live their lives to the greatest possible extent, in the manner and in the setting of their choice.

Inspired by the pioneering work of Dame Cicely Saunders at St. Christopher's Hospice in London, health care professionals across the world have rediscovered the very essence of good medical care: the union of all that scientific medicine has to offer with a caring and dedicated commitment to the varied needs of each individual patient and his or her family. To achieve an optimal level of pain and symptom control, we must harness the expertise of a wide range of medical, nursing and paramedical disciplines. Ireland has a long and proud tradition in achieving excellence in nursing and medical care and it is from this foundation that we wish to move forward.



Palliative care is about people; it is concerned with ordinary people who find themselves facing extraordinarily difficult situations: the loss of independence, the loss of financial security, the loss of all that is safe and familiar, the loss of friends and family, the loss of future and ultimately, the loss of life. It is in part concerned with providing answers, and in greater part is concerned with being there for people when there are no answers. It is in part concerned with accompanying people to a place where few are comfortable, and being there for them. It is more often dealing with uncertainty than certainty and fundamentally it seeks to respect the individual for who they are, rather than what they do or have achieved. Dame Cicely Saunders wrote:

"You matter because you are you, and you matter all the days of your life"

In the context of palliative care, we do not always get a second chance to get things right. We have a duty of care to our patients and we also recognise the need to address the pain and suffering inevitably experienced by family members. By achieving and maintaining an optimal level of pain and symptom control for our patients, we create the space and opportunity where they are free to address the many personal issues that inevitably surface at this time of life. For their families, we need to ensure that as they begin to undertake the demanding work of grieving, and it is hard work, that they are at least comforted by the knowledge that their loved one was well cared for, and that they themselves had the opportunity to be heard and understood. The work of bereavement support begins not after the patient has died, but at the point of first contact. All of us, in sickness and in health, have a basic need to be heard and to be understood.

The Irish authorities have shown leadership and direction in this facet of medical care. It is worth noting that in 1995, Ireland was the second country in Europe to recognise palliative medicine as a distinct medical specialty. We now have a unique opportunity to ensure that every person in Ireland who requires palliative care, will be able to access with ease a level of service and expertise that is appropriate to their individual needs. Such services must be provided by a highly trained and co-ordinated inter-professional team, and delivered at a time and in a place that will be determined by the specific needs and personal preferences of each individual patient.

Although comforted by the developments that have occurred to date, we are ever mindful of the level of unmet need in our society. Our task is not confined to providing the necessary structures and resources that will properly support a modern palliative care service. There is also an urgent need to address some of the understandable fears and anxieties associated with specialist palliative care or hospice programmes. The need for a basic attitudinal change was highlighted by Dr. Michael Kearney[2] when he wrote:

"Patients with incurable illness must no longer be viewed as medical failures for whom nothing more can be done. They need palliative care, which does not mean a hand-holding, second-rate, soft option, but treatment that most people will need at some point in their lives, and many from the time of diagnosis, demanding as much skill and commitment as is normally brought into preventing, investigating and curing illness."



The members of the National Advisory Committee on Palliative Care had a complex and wide-ranging brief. In many instances, we were confronted by a lack of current and relevant data. We invited submissions from interested parties in Ireland and abroad. All submissions and representations made to us were very carefully considered and we are indebted to all those who shared their knowledge and expertise with us so willingly and with such courtesy and enthusiasm.

The implementation of this report will have very significant funding implications. We recognise the many demands placed on our health budget and we appreciate that the implementation of all of the recommendations in this report will require time and patience. The voluntary sector has contributed enormously to the development of services in Ireland to date and I am confident, that within the proposed framework, it will be possible for us all to move forward in a spirit of partnership, mutual understanding and respect, in the interest of patient care.

Over the years to come, the success or failure of this report will not be judged solely by the number or diversity of our specialist palliative care programmes, nor by any set of pre-determined statistics documenting our activities. The success of this report will be judged by the extent to which we all learn to recognise and respond to the complex and challenging needs of our palliative care patients and their families. For the future, I hope that this report will ensure that all health boards are in a position to provide a level and a quality of service that both reflects and defines best international practice. Our patients and their families require and deserve nothing less.

On a personal note, I wish to express my sincere thanks and appreciation to all the committee members for their dedication, commitment, hard work and good humour. My thanks also to all those who contributed to our discussions and deliberations in any way whatsoever. A special word of thanks to Dr. Gene Collins who undertook the demanding task of researcher and report co-ordinator with characteristic enthusiasm and professionalism.

Dr. Tony O'Brien M.B., F.R.C.P.I.
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Executive Summary



CHAPTER ONE: BACKGROUND

Palliative care is the continuing active total care of patients and their families, at a time when the medical expectation is no longer cure. Palliative care responds to physical, psychological, social and spiritual needs, and extends to support in bereavement. The goal of palliative care is the highest possible quality of life for both patient and family.

Specialist palliative care 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.

The Government's commitment to this area of care was first reflected in the National Health Strategy in 1994, which recognised the important role of palliative care services in improving quality of life. It gave a commitment to the continued development of these services in a structured manner, in order to achieve the highest possible quality of life for patients and their families.

The Minister for Health and Children established the National Advisory Committee on Palliative Care in the Summer of 1999 with a view to preparing a report on palliative care services in Ireland. The work of the Committee has resulted in the publication of this report.

CHAPTER TWO: AN OVERVIEW

Palliative care services are structured in three levels of ascending specialisation. These levels refer to the expertise of the staff providing the service.

Level one – Palliative Care Approach: Palliative care principles should be appropriately applied by all health care professionals.

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.

Level three – Specialist Palliative Care: Specialist palliative care services are those services whose core activity is limited to the provision of palliative care.

In each health board area, all three levels of service provision should be available and all patients should be able to engage easily with the level of expertise most appropriate to their needs.

Palliative care services, both specialist and non-specialist, should be available in all care settings, including acute general hospitals and the community. Services should be sufficiently flexible to allow movement of patients from one care setting to another, depending on their clinical situation and personal preferences.

There is limited information available regarding the current delivery of palliative care services in Ireland. However, it is apparent that there is wide variation in the type and level of service provision within each health board area. This issue is addressed in subsequent chapters of this report, and recommendations are made to ensure the equitable delivery of palliative care services in all health board areas.



CHAPTER THREE: THE NEED FOR SPECIALIST PALLIATIVE CARE

It is anticipated that the need for palliative care services will increase in coming years. Population projections indicate that between 1996 and 2031 the population aged 65 years and over is expected to more than double. Currently, over 95% of all patients availing of palliative care services suffer from cancer. The number of people dying from cancer is expected to rise in future years, due to the ageing population.

Concerns about equity have fuelled the debate regarding the extension of specialist palliative care services to patients with advanced disease of non-cancer aetiology. Patients with cardiovascular and respiratory diseases would make up the bulk of these non-cancer patients requiring specialist palliative care. The number of patients with multiple sclerosis, motor neurone disease and similar disorders are small, but these diseases have a much longer course than many of the cancers. It has been estimated that the inclusion of non-cancer patients within the scope of specialist palliative care services would at least double the need for specialist services.

Ethnic and cultural diversity is now a demographic reality within most western societies and cannot be ignored by specialist palliative care services. All cultures and religions have particular beliefs relating to dying, death and bereavement. The Irish traveller community also has different ways of looking at death and bereavement. Palliative care professionals should recognise and facilitate cultural difference.

Palliative care for children differs from palliative care for adults in that many children requiring palliative care have life-limiting conditions, as opposed to advanced terminal conditions. Children may survive many years with these conditions. The needs of these children differ from the needs of adults. A significant proportion have long-term needs, and many live with severe disability. The needs of their families may also be more complex. Respite care is an important element in the care of children with life-limiting conditions. Children also have a need for continuing education. An expert committee, established by the Faculty of Paediatrics, is currently examining the future delivery of palliative care services to children in Ireland.

In determining the need for specialist palliative care services, other population groups with particular needs should also be considered. These include people with intellectual, physical and sensory disabilities. Prisoners and intravenous drug abusers also have particular needs in relation to health care. The needs of these groups should be addressed by each health board when planning the future delivery of specialist palliative care services.

CHAPTER FOUR: PATIENTS AND CARERS PERCEPTIONS

Increasingly, the views of patients and carers are sought in the planning and evaluation of services worldwide. Many studies have been undertaken in the area of palliative care to establish how patients and carers perceive palliative care services.

Studies of different models of service delivery consistently favoured hospice care over hospital care, particularly in relation to psychosocial aspects of care and the quality of communication. Hospice inpatients reported lower levels of pain compared to their hospital counterparts in some studies. Reducing family distress and controlling symptoms were the areas where relatives felt the specialist palliative care service made a big difference. Communication also improved with specialist palliative care involvement.

Consumer views on inpatient hospital care found a wide range of problems. Poor communication was reported as a particular problem in several studies. Lack of privacy for consultation was another important issue. Access to hospital inpatient services was frequently delayed, and long delays were widely experienced at hospital outpatient clinics and in Accident and Emergency departments.

Studies of palliative care in the community found practical support in the home was lacking for many carers. They identified the need for more overnight support, more help in the home, more day care, and easier access to respite care as the main priorities. Other areas identified for improvement include better communication, the provision of information on services and entitlements, bereavement support and counselling.

CHAPTER FIVE: SPECIALIST PALLIATIVE CARE SERVICES

Specialist palliative care services are those services with palliative care as their core specialty. Specialist palliative care services are analogous to secondary or tertiary health care services.

All specialist palliative care services should have an essential minimum core of professionally trained staff with recognised post-qualification specialist training and clinical experience in palliative care services. These include medical and nursing staff, and an appropriate complement of physiotherapists, occupational therapists, social workers, speech and language therapists, pharmacists and clinical nutritionists.

The specialist palliative care service also requires staff specifically trained to meet the psychosocial needs of the patient, family and carers, and suitably trained and experienced members of staff who will be responsible for bereavement services. Other requirements include a co-ordinator of spiritual care and a volunteer co-ordinator.

Each health board area should have a comprehensive specialist palliative care service to meet the needs of patients and families in the area. This service should support the patient wherever the patient may be - at home, in hospital, in residential care, or in a specialist palliative care unit.

Specialist palliative care services have an important role in supporting other health care providers at hospital and community level. All health care professionals should be able to access advice and support from specialist palliative care service providers when required.

CHAPTER SIX: SPECIALIST PALLIATIVE CARE UNITS

The specialist palliative care inpatient unit should be the core essential element of the specialist palliative care service. This unit should act as a co-ordinating centre for the delivery of specialist palliative care services in all care settings, including hospitals and the community.

The specialist palliative care inpatient unit should provide a wide range of specialist services to patients and families, including medical, nursing, psychosocial and spiritual care. Reasons for admission would ordinarily include complex symptom management, psychosocial problems, and intensive rehabilitation. The specialist unit should also act as a resource for other health professionals in the area, by providing support and advice when needed. The specialist unit should also provide facilities for research and education in palliative care.

The National Advisory Committee recommends that there should be at least one specialist palliative care inpatient unit in each health board area. Specialist palliative care units should, where possible, be based close to the acute general hospital with the broadest range of specialist services, including radiotherapy and oncology, in the area.

In keeping with the principle of equity, it may be necessary to establish a satellite specialist palliative care inpatient unit in some health board areas with a wide geographical spread. The satellite inpatient unit would function as an extension of the lead specialist palliative care unit in the region. There should be no more than one satellite inpatient unit in any health board area.

In areas where the population density is low, it may be necessary to establish satellite community bases, from where specialist palliative care staff could provide services to patients in the community.

Day care centres attached to specialist palliative care units provide access to all specialist palliative care services. Patients may attend day care programmes for medical and nursing care or for rehabilitation. The Committee recommends that all specialist palliative care inpatient units should provide day care facilities for patients.

The physical structure and environment of a specialist palliative care inpatient unit should be appropriate to the needs of patients and staff, and should also be sensitive to the needs of families and friends. The National Advisory Committee recommends that an Expert Group on Design Guides for Specialist Palliative Care Settings should be established, which would ensure a national consistency of standards for all specialist palliative care centres.

CHAPTER SEVEN: SPECIALIST PALLIATIVE CARE IN ACUTE GENERAL HOSPITALS

The majority of patients dying from cancer are admitted to hospital in the last year of life. These patients, and others with active progressive non-malignant disease would benefit from the advice and support of specialist palliative care services. These services are currently at an early stage of development in Ireland. A number of hospitals have medically led specialist palliative care teams, while others are developing links with local palliative care units and home care services.

The National Advisory Committee recommends that all acute general hospitals should have a specialist palliative care service. This service should be provided by an inter-disciplinary team and should be led by a consultant in palliative medicine, who would be available for a defined minimum number of sessions per week. The specialist palliative care team should consist of at least a specialist palliative care nurse, a social worker, and a secretary. Hospital specialist palliative care teams would offer advice and support to other professional health care providers regarding the management of patients with advanced and progressive disease. Such teams would function as an extension of the lead specialist palliative care unit for the region.

In smaller general hospitals, where it may not be feasible to employ a full-time specialist palliative care team, the specialist palliative care team serving the community should provide a service to patients in the hospital.

Hospital admission policies should be sensitive to the needs of patients with advanced disease. There should be minimum delay in waiting times for a hospital bed. There should be one point of entry to hospital services for palliative care patients, and subsequent referrals should be speedily organised. Arrangements should be made to “fast-track” outpatient appointments for patients receiving palliative care.

Joint outpatient clinics should be established in acute general hospitals, allowing the specialist palliative care team to become involved, as appropriate, in patient care at an earlier stage in the disease process.

CHAPTER EIGHT: PALLIATIVE CARE IN THE COMMUNITY

The majority of general palliative care in the community is provided by the general practitioner and public health nurse. Other disciplines are also involved in the care of patients in the community to varying degrees. These include the physiotherapist, the occupational therapist, the speech and language therapist and the social worker.

Increasingly, the palliative care nurse has become involved in the care of patients with advanced disease. The role of the palliative care nurse is to provide information, advice and support to patients and families, and extends to bereavement support, where appropriate, following the death of a patient.

The evolution of specialist palliative care in Ireland has resulted in the development of specialist palliative care teams in the community. The specialist palliative care team should be an inter-disciplinary consultant-led team, consisting of nursing staff and at least a physiotherapist, an occupational therapist and a social worker. All team members should be trained in specialist palliative care.

The specialist palliative care team should be based in, and led by, the specialist palliative care unit in the area. In areas with a wide geographical spread, the specialist palliative care team working in the community may be based in satellite units, which maintain close clinical, educational and administrative links with the lead specialist palliative care unit.

Specialist palliative care services should be available to all people living in the community, be it at home, in a nursing home, or in a community hospital. There should be a specialist palliative care team working in the community in all health board areas. Specialist palliative care nurses should provide a seven-day service to patients in the community.

Support beds for palliative care patients are provided in a number of community hospitals around the country. They provide an intermediate level of inpatient care for patients. The specialist palliative care team working in the community may be involved in the patient's care when appropriate.

Although palliative care in the community has improved greatly over recent years, deficits still exist. These include lack of domestic support, lack of respite care, and difficulties with transport. Other obstacles to care in the community include difficulty in accessing community-based services, and accessing equipment or medicines in the community. These issues are addressed in the text.

CHAPTER NINE: BEREAVEMENT SUPPORT

Bereavement support is an integral part of palliative care and should be incorporated into all specialist palliative care programmes. Bereavement support should be available in all settings where specialist palliative care is offered. Prevention of complex bereavement problems is an important component of specialist palliative care services. Bereavement support should begin early in the disease process, long before the death of the patient.

The aim of bereavement support is to rehabilitate individuals and families before and after the death of a loved one. Not every family member or friend of a deceased person needs bereavement counselling. The majority of bereaved people are able to manage with the help of family and friends.



All specialist palliative care staff offer a general level of bereavement support to individuals and families. Specialist palliative care nurses play an important role in bereavement support in the community. Volunteers may be trained to provide general bereavement support to family and carers. For those who require extra support, appropriately trained staff such as social workers, psychologists or professional counsellors should be available. An appropriate member of staff should act as bereavement service co-ordinator.

CHAPTER TEN: EDUCATION, TRAINING AND RESEARCH

Education is a core component of specialist palliative care. The culture of continuing professional education and development should be promoted among health care professionals in all disciplines that are involved in the delivery of palliative care.

Academic departments of palliative medicine should be established in each medical faculty to support and develop education and research in all disciplines. Specific university courses should be developed in collaboration with service providers to meet the needs of nurses and paramedical staff wishing to acquire different levels of academic education. A core curriculum for medical, nursing and paramedical undergraduates should be developed and should be introduced throughout medical undergraduate training.

Each specialist palliative care unit should set up a nursing practice development unit to develop, implement, and monitor nursing practice in the unit. A clinical practice development co-ordinator should be employed in each specialist palliative care unit.

The application of research findings encourages the growth and development of a specialty and is a critical element in defining a specialist palliative care service. All health care professionals working in palliative care should have the opportunity to engage in research. Research should be included in all nursing and medical curricula.

There should be a major public funding allocation to promote palliative care research in Ireland, and to put in place the necessary infrastructure to allow this to happen. A number of research centres, which would be linked to academic departments, should be established. These should have access to all the specialties necessary to carry out quality research.

CHAPTER ELEVEN: COMMUNICATION

Failure by health service staff to communicate effectively has been identified in a number of studies as a major impediment to the quality of care for patients and families. This failure to communicate occurs at several levels in different care settings – communication with patients and their families, communication within the hospital services, communication within community services, and communication between hospital and community health care professionals.

All staff involved in the care of patients with progressive disease and their families should receive specific training in communication skills. Structures should be put in place to support this recommendation. Suitable space and facilities to allow privacy during conversations between doctors and patients and their families should also be provided.

Discharge planning, including early communication with health care professionals in the community, should be encouraged in all hospitals to facilitate the seamless transfer of patients to the community. The concept of "shared care" should be promoted among health care professionals in the community.

CHAPTER TWELVE: STANDARDS IN PALLIATIVE CARE

Increasing emphasis is being placed on the importance of evaluating health care services. It is now recognised that a systematic approach to evaluating and improving quality of care should be central to any service.

Every specialist palliative care service should have an explicit commitment to quality improvement. A culture of delivering the best possible quality should be promoted in all disciplines and be assumed by all staff. Standards should be set in all dimensions of service provision in relation to the structure, process and outcome of care. These should also encompass aspects of training and development of services. Systems should be developed to evaluate the quality of specialist palliative care services.

A Minimum Data Set should be developed at a national level, which should provide standardised information on all patients of the specialist palliative care services. Standardised performance indicators and outcome measures should be utilised in specialist palliative care services in order to evaluate and maintain quality standards.

CHAPTER THIRTEEN: FUNDING AND ACCOUNTABILITY

The level of financial support available from individual health boards for palliative care services varies from one health board area to another. This has arisen mainly due to the absence of a policy on palliative care services at national level. The future development of specialist palliative care services requires a commitment to the ongoing provision of an adequate level of public funding, with a corresponding commitment to quality and accountability from service providers.

Statutory funding should be made available on a phased basis to meet the core running costs of all specialist palliative care services, in all care settings. All proposals for specialist palliative care services, including capital developments, should be prepared within the context of national policy, regional plans, agreed priorities and local needs.

There should be a separate protected budget for specialist palliative care services, administered by a senior officer of the health board. The funding of specialist palliative care services should be determined at health board level. All day-to-day expenditure should be met by the health board palliative care budget.

Health boards should work in partnership with the voluntary service providers in their areas. Partnerships should be formalised by way of service agreements. The process should respect the independent identity and operational autonomy of individual voluntary service providers. However, the process should also respect the statutory, regulatory and public accountability responsibilities of the health boards, the Department of Health and Children, and the Minister for Health and Children.



CHAPTER FOURTEEN: PLANNING AND DEVELOPMENT

The Minister for Health and Children should establish a National Council for Specialist Palliative Care with a view to advising the Minister on national policy. The National Council should be broadly based and have representatives from the appropriate statutory and voluntary agencies. Its membership should be appointed by the Minister for Health and Children.

Each health board should establish two regional committees on palliative care - a Regional Consultative Committee and a Regional Development Committee.

The Regional Consultative Committee should be an advisory committee. It should provide a broadly based forum for the exchange of information and ideas on all matters pertaining to palliative care, both specialist and non-specialist, in the region. It should advise the Regional Development Committee on any matters relating to the provision of palliative care services in the region, including new developments.

The Regional Development Committee should prepare an agreed development plan for the region, within the policy guidelines issued by the Department of Health and Children, and having regard to the recommendations of the National Council and the Regional Consultative Committee. It should advise the Chief Executive Officer on the allocation of all statutory resources, both capital and revenue, provided for new and developing services.

CHAPTER FIFTEEN: PRIORITIES, TIMEFRAMES AND COSTS

Palliative medicine is a new and developing specialty. This report describes a comprehensive specialist palliative care service and acts as a blueprint for its development.

As a first step, a national policy on palliative care should be formulated. An Expert Group on Design Guides for Specialist Palliative Care Settings should be established to inform all relevant parties to the facilities procurement process, and to ensure a national consistency of standards for all specialist palliative care centres. At a regional level, all health boards should undertake a needs assessment to define the palliative care needs in their area.

Priorities for the development of a specialist palliative care service should be based on national policy and should be decided by health boards at regional level, based on the need for services, as defined by the recommended needs assessment, and also taking account of advice provided by the regional committees on palliative care. The implementation of this report's recommendations should occur within a five year period.

The estimated costs of the recommendations made in the report are detailed in this chapter.

Section 1

Background





Chapter 1

Historical Background



Chapter 1

1.1 INTRODUCTION

Palliative care is the continuing active total care of patients and their families, at a time when the medical expectation is no longer cure. Palliative care responds to physical, psychological, social and spiritual needs, and extends to support in bereavement.

The goal of palliative care is the highest possible quality of life for both patient and family. The principles of palliative care apply to all patients with advanced progressive disease regardless of aetiology, and are applicable in all care settings.

This chapter describes the background to the development of palliative care services in Ireland and documents the Government's commitment to the further development of palliative care. It acknowledges the important role played by the voluntary sector in the development of palliative care. It describes the current strengths and weaknesses of palliative care service delivery. It emphasises the increasing need for specialist palliative care services in Ireland, and highlights issues that need to be addressed in the future development of palliative care service delivery.

Finally, it describes the background to the establishment of the National Advisory Committee on Palliative Care, documents its terms of reference, and briefly describes the work of the Committee, which resulted in the publication of this report.

1.2 DEFINITIONS

In the interests of clarity, accuracy and consistency, the following definitions are adopted for use in this report.

Palliative Care is defined by the World Health Organisation (WHO) as the active, total care of patients whose disease is no longer responsive to curative treatment.[1] Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is the achievement of the best possible quality of life for patients and their families.

Palliative care:

- affirms life and regards dying as a normal process
- neither hastens nor postpones death
- provides relief from pain and other distressing symptoms
- 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

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.[2]



Palliative medicine is the appropriate medical care of patients with active, progressive and advanced disease, for whom the prognosis is limited, and the focus of care is the quality of life. Palliative medicine includes consideration of the family's needs before and after the patient's death.[2]

Specialist palliative care 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.

Terminal care is a continuum of palliative care and is usually used to describe the care that is offered during the period when death is imminent, and life expectancy is limited to a short number of days, hours or less.

Hospice care is a term that is often used to describe the care offered to patients when the disease process is at an advanced stage. The term may be used to describe both a place of care (i.e. institution) or a philosophy of care, which may be applied in a wide range of care settings. In this report, the term "palliative care" will be used in preference to "hospice care", when appropriate. However, when referring to other research or reports, the word "hospice" may be used at times.

In the context of palliative care, the **family** is defined as any person who is significant to the patient.

KEY POINTS

Palliative care is the total active care of patients and their families, at a time when the medical expectation is no longer cure.

Palliative care integrates the psychological, physical, social and spiritual aspects of a patient's care.

The goal of palliative care is the highest possible quality of life for the patient and family.

1.3 THE MODERN PALLIATIVE CARE MOVEMENT

"Hospice care" in Ireland originated in the late 19th century with the establishment of Our Lady's Hospice in Dublin and St. Patrick's Hospital in Cork by the Sisters of Charity. Originally, the term "hospice" referred to a house of hospitality for pilgrims, dating back to the Christian era of the 4th century. However, by the late 1800's these institutions became associated with the care of the dying, and were often known locally as the "hospice for the dying" or the "home for the incurables".

Modern palliative care originated with the development of St. Christopher's Hospice in London in 1967. Since then, thousands of palliative care programmes have been established in many communities in the western world, particularly Great Britain, Canada, the United States, Australia and Scandinavia.[3] The modern palliative care movement in Ireland began to gather momentum in the early 1980's. The unique contribution of the Sisters of Charity to this area of care in Ireland is acknowledged.[4]

The Irish Hospice Foundation was established in 1986 as a voluntary support organisation for the development and improvement of hospice services. It played a significant role in identifying and responding to local need for palliative care services. It has acted as an advocate and catalyst for the continuing development of palliative care services in Ireland.

The Irish Cancer Society also played an important role in the development of palliative care services in Ireland. Its role in palliative care is centred on patient-related services, particularly the development of home-care nursing services in the community.

Important initiatives in specialist palliative care have taken place in Ireland, as part of the modern palliative care movement. The Irish Association for Palliative Care was established in the early 1990's to promote the development of palliative care throughout Ireland. The Medical Council approved the recognition of the speciality of palliative medicine in 1995.

Several important reports and policy documents[5-8] have influenced the development of palliative care services in the UK over the past two decades. The World Health Organisation made palliative care a priority in its Global Cancer Control Programme.[9] The World Summit against Cancer for the New Millennium[10] recommended improvement in the comprehensive care of people with cancer, including supportive care and palliation, and stated that this should be recognised at clinical and policy level.

1.4 GOVERNMENT COMMITMENT TO PALLIATIVE CARE

The Department of Health and Children has adopted a very proactive and supportive role in promoting the appropriate and structured development of specialist palliative care services in Ireland. The Department's commitment to this area of care was first reflected in the National Health Strategy[11] in 1994, which recognised the important role of palliative care services in improving quality of life. It gave a commitment to the continued development of these services in a structured manner.

The development of a National Cancer Strategy[12] in 1996 added further impetus to an already rapidly evolving area of care. The Cancer Strategy sought to promote appropriate models of care that would best address the palliative care needs of patients and their families. It gave an undertaking that there would be a programme of phased development of specialist palliative care in regional cancer services, in consultation with health boards and others involved in palliative care. Since 1997, an additional £10 million (approx.) has been made available to the palliative care services through the National Cancer Strategy.

Palliative medicine was represented on the first National Cancer Forum and has attracted a great deal of help and support from Forum members.

The Government Action Programme for the Millennium[13] also contained a commitment to develop a national palliative care plan.

1.5 STRENGTHS OF THE IRISH PALLIATIVE CARE SERVICES

The agreed goal of developments in palliative care is that good palliative care should be available to all who need it, when and where they need it. Success in meeting this goal is most likely if planned developments are based on the strengths that are already apparent in this area of health care in Ireland.

These include the long established tradition of caring for those with advanced and terminal illness, the strong family and community support that exists for many patients, the massive fund of public goodwill towards the goals of the palliative care movement, along with the network of doctors, nurses and other health care professionals who possess a high level of skills in palliative care, and are committed to ongoing training and education in this area.

Furthermore, there is a positive spirit of co-operation between voluntary and statutory agencies, and a firm commitment from the Department of Health and Children to the continued, structured development of palliative care services nationally.

1.6 WEAKNESSES OF THE IRISH PALLIATIVE CARE SERVICES

Palliative care services were established around the country due largely to the strong and concerted efforts of various voluntary organisations. This, however, has led to an ad-hoc development of services nationwide. There may be a number of different and independent organisations working within each health board area. The relationship between these bodies themselves, and between these bodies and the health boards, is variable. Issues of responsibility, reporting structures and funding may be of an ad-hoc nature, leading to unsatisfactory and often divisive arrangements.

The Health Strategy[11] also identified several weaknesses in the Irish health care system. Among these were fragmentation of services, inadequate linkages between services, community-based services were underdeveloped, waiting times for services were too long and systems for measuring effectiveness were either unavailable or under-utilised.

1.7 THE VOLUNTARY SECTOR

The key role played to date by the voluntary sector in the provision of healthcare services in Ireland is fully acknowledged within the Health Strategy.[11] Voluntary (non-statutory) organisations have been to the forefront in identifying needs in the community and responding to such needs. Much of this development has taken place in co-operation and partnership with local health boards.

The Irish Hospice Foundation has contributed a major funding allocation to the development of palliative care services in Ireland over recent years, and continues to offer financial support to fund many palliative care initiatives. Its current operation is centred mainly on bereavement services, focusing on education, training and research. It also supports hospital-based palliative care services, and acts as a support for the Voluntary Hospice Movement, which is an affiliation of voluntary hospice support groups in Ireland.

The Irish Cancer Society is a national charity, which is dedicated to eliminating cancer as a major health problem, and improving the quality of life of those living with cancer. It has made significant contributions to the development of home-care nursing services, including night-nursing services, for patients with terminal cancer.

The ongoing involvement of the voluntary sector in the planning and delivery of specialist palliative care services in Ireland should be encouraged and facilitated by the development of a structured framework for the planning and implementation of future palliative care services.

1.8 INCREASING NEED FOR PALLIATIVE CARE

The need for palliative care services in Ireland, as in other countries, can be expected to increase in the coming decades as a consequence of several factors.

Ireland has an ageing population. Life expectancy at birth has steadily increased over the past fifty years. Population projections indicate that between 1996 and 2031 the number of people aged 65 years and over is

expected to more than double.

Over 95% of all patients currently availing of palliative care services suffer from cancer.[14] The number of people dying from cancer is expected to rise in future years, due to the ageing population. The number of patients living with cancer is also expected to rise, due to earlier diagnosis, improved treatment and longer survival.[15]

In recent years, the number of non-cancer patients availing of specialist palliative care services has increased, and the spectrum of disease for which patients receive palliative care has broadened. Traditionally, the majority of people availing of specialist palliative care services suffered from cancer or a small number of defined diseases, including motor neurone disease and AIDS.

Increasingly, there is a move to provide specialist palliative care services to patients with end-stage disease of other aetiologies, such as cardiac, respiratory, renal, hepatic and neurological disorders. The impact of providing specialist palliative care services to patients with non-malignant disease is difficult to quantify, but it has been conservatively estimated that demand could increase by up to 80% or more.[16]

Finally, the move towards providing specialist palliative care to patients at an earlier stage in their disease will also have a significant impact on demand for services.

1.9 ISSUES FOR THE FUTURE DEVELOPMENT OF PALLIATIVE CARE

Although specialist palliative care has much to offer patients with progressive disease and their families, there is evidence that there are many unmet needs for these patients and their families.[17] Issues that need to be addressed in order to improve the quality of palliative care services include:

- Access to specialist palliative care services
- Access to paramedical services in the community
- Access to aids, appliances and medicines
- Counselling and bereavement support
- Practical and financial support
- Respite care
- Communication

There is now an increased emphasis on domiciliary and day care services.[18] A recent expert report in the UK[6] placed great emphasis on the involvement of general practitioners and primary care services in the provision of palliative care. Increasing emphasis on community care has also been advocated by the Health Strategy.[11] This will require the input of more resources into the community and better co-ordination of services by the health care professionals involved.

There are several different voluntary agencies involved in the provision of palliative care. There is a need for greater partnership between these agencies and the statutory bodies to ensure a planned and co-ordinated approach to palliative care in the future.

There is now a heightened awareness of consumer opinion among health authorities and health care providers. There is much evidence to suggest that participation by all interest groups, including consumers, in the development of local strategies for the delivery of palliative care increases the acceptability and quality of the service.[8]

The quality of services is becoming increasingly important in all aspects of health care. Structures need to be in place to ensure quality standards in all health care settings. Systems to monitor and evaluate the quality of services are also required. Standardised data sets should be developed, and suitable performance indicators and outcome measures should be identified at a national level in order to achieve this.

The development of a national policy is of paramount importance for the future development of palliative care in Ireland. It is anticipated that this will lead to a phased development of specialist palliative care services in all care settings.

In the current climate of North / South co-operation, it is envisaged that cross-border links will be developed in the area of palliative care. These will further enhance the continuing development of specialist palliative care services throughout the country.

KEY POINTS

The demand for palliative care services in Ireland can be expected to increase in the coming decades.

The development of a national policy on palliative care services is of paramount importance for the future of palliative care in Ireland.

1.10 NATIONAL ADVISORY COMMITTEE ON PALLIATIVE CARE

The Minister for Health and Children established the National Advisory Committee on Palliative Care in the Summer of 1999 with a view to preparing a report on palliative care services in Ireland.

The National Advisory Committee was asked to work within the following terms of reference:

Having regard to—

a) the best interests of patients and their families

b) relevant national and international research, analysis and standards

c) the principles set out in the National Cancer Strategy

d) the policies and recommendations of the National Cancer Forum

e) the palliative care requirements of persons with non-malignant diseases

To examine and make recommendations on:

- The principles underlying the development of specialist and non-specialist palliative care services nationally and regionally
- The organisation and development of an integrated palliative care service involving both statutory and voluntary providers, including the delivery of care in inpatient (hospital, hospice and nursing home), home care, day care, outpatients and other appropriate settings
- Personnel, education and training standards
- Any other matters relating to palliative care which the National Advisory Committee considers appropriate

The National Advisory Committee met on 12 occasions over the period of 14 months. As part of the consultative process, the Committee sought written submissions from several representative groups and organisations, and also placed an advertisement in the national newspapers seeking written submissions from interested parties or individuals (see Appendix One). Several groups were invited to make oral presentations to the Committee in order to clarify issues in relation to their written submission.

Representatives of the National Advisory Committee visited St.Christopher's Hospice in London to meet with a group of experts in palliative care (see Appendix Two). The purpose of the visit was to discuss various issues in relation to palliative care prior to developing this report.



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Chapter 2

Palliative Care - An Overview



Chapter 2

2.1 INTRODUCTION

The purpose of this chapter is to give an overview of palliative care and its application in different care settings. The principles of palliative care are documented, and three levels of specialisation within palliative care are described.

Palliative care, both specialist and non-specialist, is provided in all care settings, including hospitals, specialist palliative care units, and the community. The delivery of palliative care services in these settings is briefly described. The promotion of palliative care within the wider community is also described.

There is very little information available regarding the extent of the current delivery of palliative care services nationally. This is partly because there is no standard information data set for palliative care services in Ireland, and partly because there are numerous service providers, including voluntary organisations, with little co-ordination between the services.

Neither is there much evidence available in the literature regarding the effectiveness of palliative care services. The limited information available is discussed at the end of the chapter.

2.2 PALLIATIVE CARE AND DISEASE

In recent years, the scope of palliative care has broadened to providing palliative care at an earlier stage in the disease trajectory. In 1990 a World Health Organisation expert committee[1] proposed that palliative care should be a gradually increasing component of care from diagnosis to death. The change in name from terminal care to palliative care is, in part, a reflection of this shift in emphasis.[2]

In the context of advancing disease, it is understood that when the progression of the disease cannot be reversed or halted by disease modifying treatment, everything possible should be done to minimise the effects of the disease on the patient.

Even when disease-modifying treatments are no longer appropriate, palliative care remains a medically active therapy. Active interventions such as radiation therapy and chemotherapy are common to alleviate pain and other symptoms.

The relative merits of all approaches to care, including disease-modifying treatment, active medical treatment, and symptomatic and supportive care should be assessed on an individual basis, and treatment schedules should be planned accordingly (see Figure 2.1).

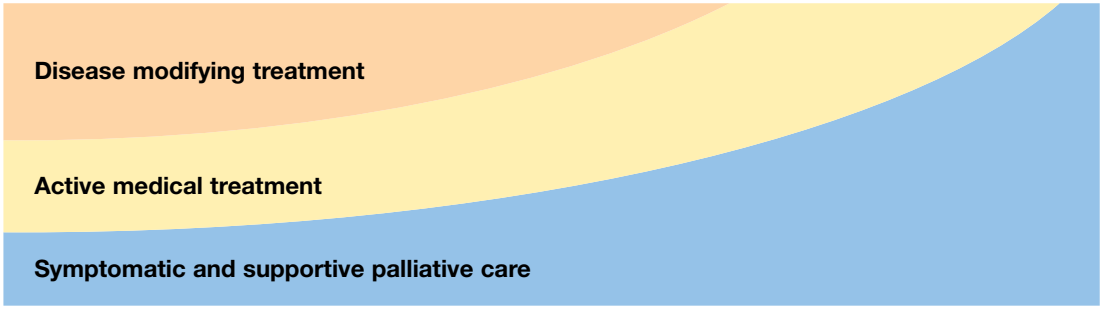


Figure 2.1 *(Adapted from Woodruff [3])*

Rehabilitation is an integral component of palliative care. Rehabilitation of the physical and psychological aspects of a patient's life is vital in order to maintain an optimal level of function in all areas of daily activities.

KEY RECOMMENDATION

Palliative care should be incorporated into the care plan of patients at an early stage of their disease trajectory.

2.3 PRINCIPLES OF PALLIATIVE CARE

The key principles of the palliative care approach include 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 who matter to that person; and an emphasis on open and sensitive communication, which extends to patients, carers and professional colleagues.

Over the past two decades, a number of reports from the UK[4-6] have influenced the development of palliative care services. These reports have identified the following **principles** of care:

- Palliative care is an important part of the work of most health care professionals, and all should have knowledge in this area, and feel confident in the core skills required.
- Primary health care providers in the community have a central role in and responsibility for the provision of palliative care, and accessing specialist palliative care services when required.
- Specialist palliative care should be seen as complementing and not replacing the care provided by other health care professionals in hospital and community settings.
- Specialist palliative care services should be available to all patients in need wherever they are and whatever their disease.
- Specialist palliative care services should be planned, integrated and co-ordinated, and assume responsibility for education, training and research.

The Cancer Strategy[7] sought to promote appropriate models of care that would best address the palliative care needs of patients and their families. The Strategy identified the following **principles** that should be adopted in developing palliative care services:

- Patients should be enabled and encouraged to express their preference about where they wish to be cared for, and where they wish to spend the last period of their life.
- Services should be sufficiently flexible and integrated as to allow movement of patients from one care setting to another, depending on their clinical situation and personal preferences.
- The ultimate aim should be for all patients to have access to specialist palliative care services where these are required.

The National Advisory Committee endorses these principles.

2.4 LEVELS OF PALLIATIVE CARE SPECIALISATION

It is recommended that palliative care services should be structured in three levels of ascending specialisation. These levels refer to the expertise of the health professionals delivering the palliative care services.

Level one – Palliative Care Approach:
Palliative care principles should be practiced by all health care professionals.[8] The palliative care approach should be a core skill of every clinician at hospital and community level.[9] 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.

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.

Health care professionals who wish to undertake additional training in palliative care should be supported in this regard by the health board or other employing authority.

Level three – Specialist Palliative Care:
Specialist palliative care 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. 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.[8]

Within each health board region, the specialist palliative care service should be capable of supporting the delivery of services in all care settings across the region.

All health care professionals should be able to access advice and support from specialist service providers when necessary.[9]

In each health board area, all three levels of palliative care expertise should be available. All patients should be able to engage easily with the level of expertise most appropriate to their needs.

At each level of care, there should be a constant focus on rehabilitation, irrespective of how advanced the condition.

KEY RECOMMENDATIONS

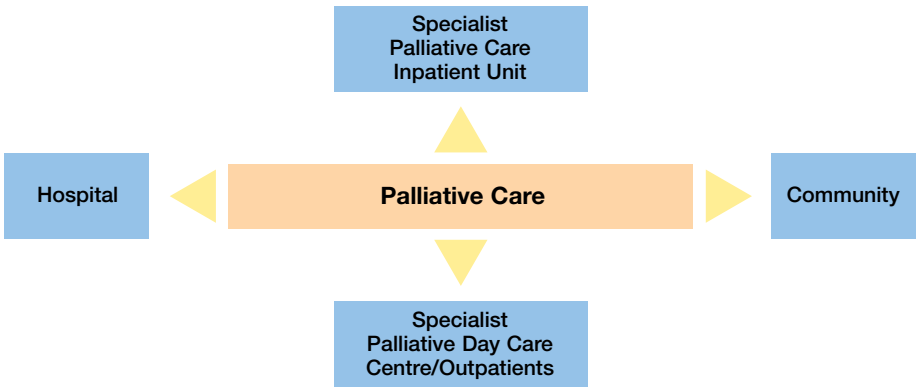
Palliative care services should be structured in three levels of ascending specialisation.

In each health board area all three levels of specialisation should be available.

All patients should be able to engage easily with the level of expertise most appropriate to their needs.

2.5 SETTINGS FOR PALLIATIVE CARE

The principal settings in which both specialist and non-specialist palliative care services are currently provided in Ireland are briefly outlined below. These will be described in more detail in subsequent chapters, and recommendations will be made regarding their future development.



2.5.1 SPECIALIST PALLIATIVE CARE INPATIENT UNITS

The specialist palliative care 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.

The specialist palliative care unit should act as the focal point for the delivery of specialist palliative care services throughout the health board region and should support and complement other service providers at hospital and community level appropriately. The specialist palliative care unit should also act as an important resource, providing facilities for research and education.

2.5.2 SPECIALIST PALLIATIVE DAY CARE CENTRES

Specialist palliative day care centres provide an important service to patients and are a great support to relatives. Day care services attached to specialist palliative care units provide access to specialist care, a change of environment for patients, and respite for their families and carers.

2.5.3 SPECIALIST PALLIATIVE CARE OUTPATIENT CLINICS

Specialist palliative care outpatient clinics allow general practitioners and hospital consultants to obtain specialist advice for their patients. These outpatient clinics are currently provided to a limited degree in Ireland.

2.5.4 SPECIALIST PALLIATIVE CARE SERVICES IN ACUTE GENERAL HOSPITALS

A specialist palliative care service is currently provided in a limited number of acute general hospitals in Ireland. Patients receiving the services of the specialist palliative care hospital team remain on their own wards, under the care of their referring consultant. Specialist palliative care teams in acute general hospitals work in support of, and in collaboration with other hospital teams.

2.5.5 PALLIATIVE CARE IN THE COMMUNITY

General practitioners and public health nurses are the main providers of general palliative care to patients and families in the community. These services may be delivered in the patient's own home, in a local community hospital, in a nursing home or any other setting in the community.

The specialist palliative care team in the community, traditionally known as the "home care team", provides specialist support and advice to patients, families and community-based health care professionals when appropriate. Specialist palliative care services are currently provided to a limited degree in the community.

2.5.6 PALLIATIVE CARE SUPPORT BEDS IN THE COMMUNITY

Palliative care support beds are provided in a number of community hospitals around the country. They provide an intermediate level of inpatient care for patients in a local environment.

Patients are generally admitted to these beds for respite care, for symptom control or for terminal care. The specialist palliative care team working in the community may be involved in the care of these patients when appropriate.

KEY RECOMMENDATIONS

Palliative care services, both specialist and non-specialist, should be available in all care settings.

Services should be sufficiently flexible to allow movement of patients from one care setting to another, depending on their clinical situation and personal preferences.

Experts have predicted that in the ideal future, palliative care will be a gradually increasing component of care between diagnosis and death, and will be more and more closely integrated into hospital and community services.[10] The National Advisory Committee endorses this view.

2.6 THE WIDER COMMUNITY

There is a need to promote the concept of palliative care amongst the community. Self-help groups are an ideal mechanism for interaction with the wider community. The media also has a place in the education of the population in the principles of palliative care. This could include programmes on the television, articles in the newspapers, and possibly websites on the Internet.

School programmes could play an important role in raising the awareness generally of the need of people for palliative care and bereavement support. It is important to promote the palliative care concept among the professionals involved in teaching, as they may be in contact with children receiving palliative care. Similarly, the teachers may be in contact with children who have recently suffered a bereavement. Teacher training programmes could provide the ideal opportunity to train members of the teaching profession in developing the skills to support these children in school, and identify those who may need further professional help.

Other professionals may also be in close contact with people receiving palliative care or who have been bereaved. These would include the police, the clergy and funeral directors. These professionals need some training in the principles of palliative care. Funeral directors, in particular, play an important role in offering

practical help and advice to families of the bereaved. This could extend to offering a package with information on access to all relevant services, including bereavement support.

KEY RECOMMENDATION

The concept of palliative care should be promoted in the wider community.

2.7 CURRENT DELIVERY OF PALLIATIVE CARE SERVICES

There is limited information available regarding the current delivery of palliative care services in Ireland. A national survey[11] was carried out in 1993 to determine the structure and process of all adult palliative care services in Ireland, and to determine, where possible, the costs of providing these services.

The study found a wide variation in the type and level of service provision. There was considerable variation in staffing levels in home care services. Most home care teams had no paramedical staff.

There was also much variation in the funding of palliative care services in the community, with only half of the services receiving direct funding from the health boards. The remaining finance for the home care services was made up from fundraising by local groups, and funds obtained from other voluntary agencies, such as the Irish Cancer Society.

2.7.1 CONSULTANTS IN PALLIATIVE MEDICINE

There are currently seven consultant physicians in palliative medicine in Ireland. There are three in the Eastern Regional Health Authority (ERHA) area, and one each in the Southern Health Board, the Mid Western Health Board, the South Eastern Health Board, and the Western Health Board areas.

Seven consultant posts are in the process of being filled. These include three in the ERHA area, and one each in the Southern, North Western, North Eastern and Midland Health Boards.

2.7.2 SPECIALIST PALLIATIVE CARE UNITS

There are currently five consultant-led specialist palliative care inpatient units in Ireland. These are Marymount Hospice in Cork, Milford Care Centre in Limerick, Our Lady's Hospice in Harold's Cross, Dublin, St. Francis Hospice in Raheny, Dublin and most recently, Galway Hospice.

There is also a palliative care inpatient unit in Sligo, which is currently developing its services.

There is a consultant-led specialist palliative care service in the South Eastern Health Board area, which is based in St. Luke's Hospital, Kilkenny.

The total number of beds currently available in consultant-led specialist inpatient units in Ireland is 118. There were a total of 1,453 admissions to these specialist palliative care inpatient units in 1999. The average length of stay varied from just under 10 days to 24 days in the five units.

Each of these specialist inpatient units has specialist palliative care teams working in the community. Specialist palliative care teams from these units attended 2,073 patients in the community in 1999.

The specialist units each provide a day care service for patients, and also a specialist palliative care service to acute general hospitals in their areas.

2.8 EFFECTIVENESS OF PALLIATIVE CARE SERVICES

There is little evidence available on the effectiveness of different models of palliative care service delivery. Higginson described the evidence of effective palliative care as being like a sieve – there are gaps and holes in our knowledge.[12] However, there is convincing evidence that health care services currently fail to meet the palliative care needs of many patients and families.[13,14]

A recent review of the impact of different models of specialist palliative care[15] found evidence that inpatient specialist palliative care results in better pain control compared with home care or conventional hospital care. A specialist co-ordinated approach to palliative care resulted in similar or improved outcomes, in terms of patient satisfaction, patients being cared for in their place of choice, family satisfaction, control of family anxiety, and patient pain and symptoms.[16]

Those studies that examined health care costs showed a reduction in hospital inpatient days, more time spent at home, and equal or lower costs.[16] Hospice groups used fewer interventional therapies and diagnostic tests compared to conventional care.[17]

Evidence for the effectiveness of hospital teams was very limited. A few studies[18,19] have demonstrated the effectiveness of hospital support teams in terms of their ability to assist in the control of symptoms, and have reported that patients and families have benefited from the service. An Irish study of hospital care in the last year of life[20] found that communication improved with palliative care involvement. Reducing family distress and controlling symptoms were the areas where relatives felt the palliative care service made a big difference.

Studies of home care services are also limited. Some studies have shown that a higher proportion of patients who received services at home died in their own homes.[17]

The National Advisory Committee recommends that further research should be undertaken in Ireland to evaluate the effectiveness of different models of specialist palliative care service delivery.

KEY RECOMMENDATION

Further research should be undertaken in Ireland to evaluate the effectiveness of different models of specialist palliative care service delivery.

2.9 MEDICATIONS

There is now a wide range of opioids available to meet the requirements of palliative care patients in Ireland. However, there have been submissions to the National Advisory Committee regarding the use of diamorphine. This drug is not legally available in Ireland. The Committee, having considered the matter, and in view of the range of prescribing options available, has found no compelling evidence to support a change in legislation at this time. However, it is recommended that this matter be kept under ongoing review.



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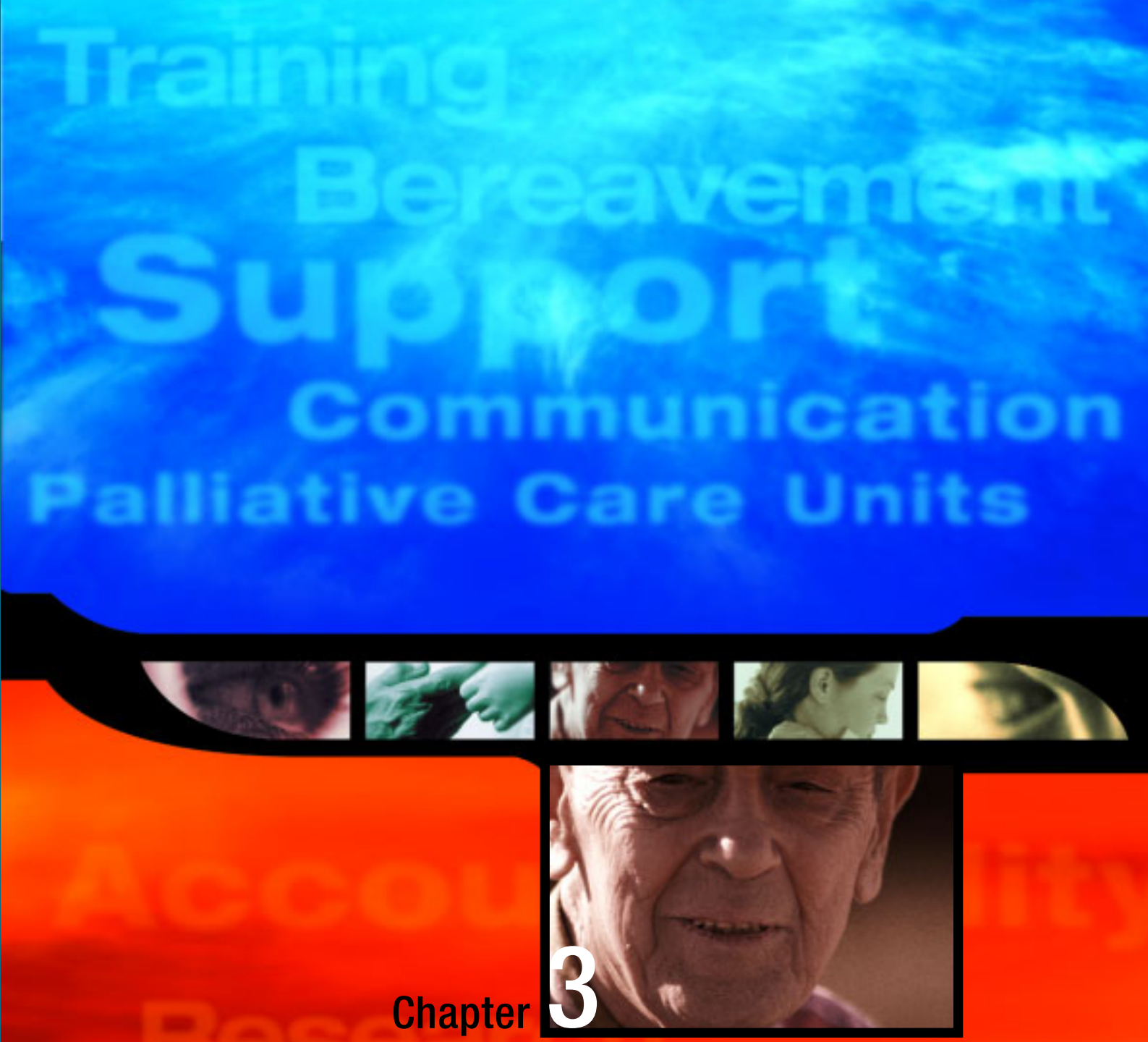
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Chapter 3

The Need for Specialist Palliative Care



Chapter 3

3.1 INTRODUCTION

This chapter examines the need for specialist palliative care services in Ireland. It looks at population projections for the future, which have serious implications for the development of specialist palliative care services. It examines the need for specialist palliative care services of cancer patients, who currently account for over 95% of all patients receiving these services.

Concerns about equity have resulted in much debate and controversy regarding the extension of specialist palliative care services to meet the needs of all patients with advanced progressive disease, not just those with cancer. This issue is explored further, as it has significant implications for the provision of specialist palliative care services.

Finally, the needs of particular population groups, for example - children, ethnic minority groups and others are discussed, as they may have special needs in relation to specialist palliative care services.

3.2 NEEDS ASSESSMENT FOR SPECIALIST PALLIATIVE CARE SERVICES

In recent years, there has been a movement within health authorities towards strategic planning of services. Needs assessment has increasingly been regarded as the foundation upon which health care priority setting and strategic planning should rest.[1]

Population health care need is defined as the population's ability to benefit from health care.[2] Needs assessment requires certain information on the particular population being served, what services are available, and how effective are these services. Considerable difficulty may be experienced in gathering the information required in assessing the needs of palliative care patients.[1] These include the variability in services between different localities; the estimation of the proportion of the population likely to benefit from palliative care input; and the lack of evidence relating to the effectiveness of palliative care.

The broad-based nature of palliative care is also a source of difficulty to health authorities in their attempt to assess needs.[1] Not only does palliative care overlap with other sectors of care (eg. the elderly) but there is also confusion over the boundaries between specialist and non-specialist palliative care.

The Cancer Strategy[3] stated that all health boards would be asked to draw up a set of priorities for the development of palliative care services in their area. As a follow-up to the publication of this report, the National Advisory Committee recommends that a needs assessment for specialist palliative care services should be undertaken by all health boards. This should estimate the current level of service provision in each area, identify gaps in the service, and determine the priorities for future service development. This should be completed within 9 months of publication of this report. Furthermore, each health board should produce a 5-year strategic plan for the development of specialist palliative care services in its area, which should be costed to include all elements of care.

Strong partnership with public health medicine is needed to ensure a systematic and proactive needs assessment for palliative care services.[4] A comprehensive needs assessment for specialist palliative care services was recently undertaken by the Department of Public Health in the Eastern Health Board (EHB) area.[5] The template for needs assessment used by the research team in the EHB may be of assistance to other health boards, and is reproduced in Appendix Three.

KEY RECOMMENDATION

A needs assessment for specialist palliative care services should be completed in each health board area within 9 months of publication of this report.

3.3 POPULATION PROJECTIONS

Ireland, like many other developed countries, has an ageing population. Life expectancy at birth has steadily increased over the past fifty years. In Ireland, life expectancy for males at birth is now 73 years, and for females is 79 years. The number of people aged 65 years and over in Ireland is steadily increasing and will continue to rise well into this century.

Population projections indicate that between 1996 and 2031 the population aged 65 years and over is expected to more than double. This population was 413,900 in 1996 and is expected to be 839,500 in 2031, allowing for emigration (see Figure 3.1).

The largest increase will be in those aged over 80 years. This has significant implications for palliative care services, as older age groups tend to be the major users of palliative care services, and the demand for these services can be expected to rise in parallel with the rising numbers and proportion of this age cohort. Furthermore, the family carers of this group are also likely to be elderly.

Actual and Projected Population aged 65 and over, Ireland

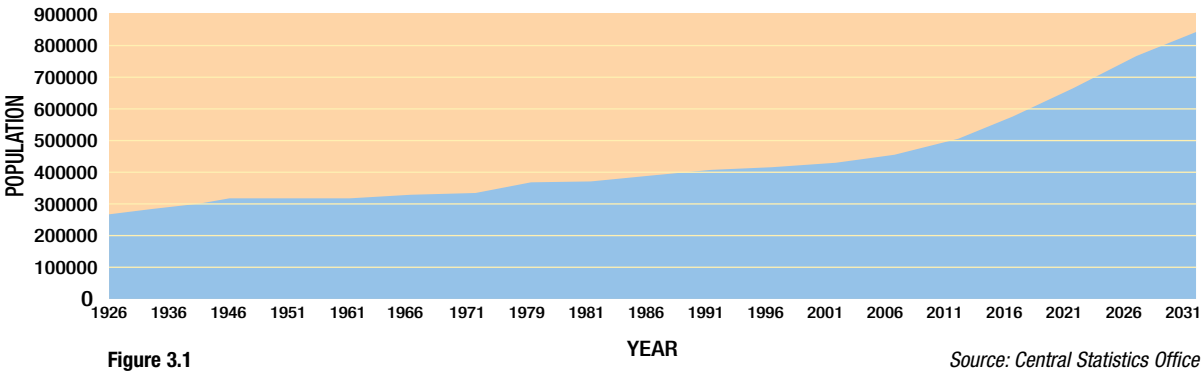


Figure 3.1 *Source: Central Statistics Office*

3.4 SPECIALIST PALLIATIVE CARE NEEDS OF CANCER PATIENTS

Over 95% of all patients currently availing of specialist palliative care services suffer from cancer.[6] The number of people dying from cancer is expected to rise in future years, due to the ageing population. Similarly, the number of patients living with cancer is also expected to rise, due to earlier diagnosis, improved treatment and longer survival.[7]

In 1997, there were 21,450 new cases of cancer reported to the National Cancer Registry in Ireland.[8] When non-melanoma skin cancer was excluded the total number fell to 13,634. The largest number of cases reported was in the 70 to 74 year age group. Patients over 65 years accounted for more than half the total number of cases. The highest age-specific incidence rate for both sexes was in the over 85 year age group.

Almost one quarter of all deaths in Ireland in 1997 were due to cancer (7,555 cancer deaths). The major cause of death from cancer was lung cancer, but breast cancer caused more deaths in women than any other cancer. Between 1969 and 1994 the total number of deaths from cancer increased by 10% in Ireland. This implies that the need for specialist palliative care services is increasing. Age-specific death rates also increased, but have levelled off in the past 10 years (see Figure 3.2).

The need for palliative care services has been estimated by Higginson,[2] based on the incidence and prevalence of different diseases, and on studies of the prevalence of symptoms in patients with these diseases.

Higginson[2] estimates that within a population of one million, there are approximately 2,800 cancer deaths per year. A significant proportion of these people would have need of specialist palliative care services. It is estimated that of these people 2,400 experience pain, 1,300 have trouble breathing, and 1,400 have symptoms of nausea or vomiting in the last year of life. There are no figures available to estimate the exact need for specialist palliative care services for these patients.

Age-Specific Death Rates - All Malignant Neoplasms Ireland - 1980-1997

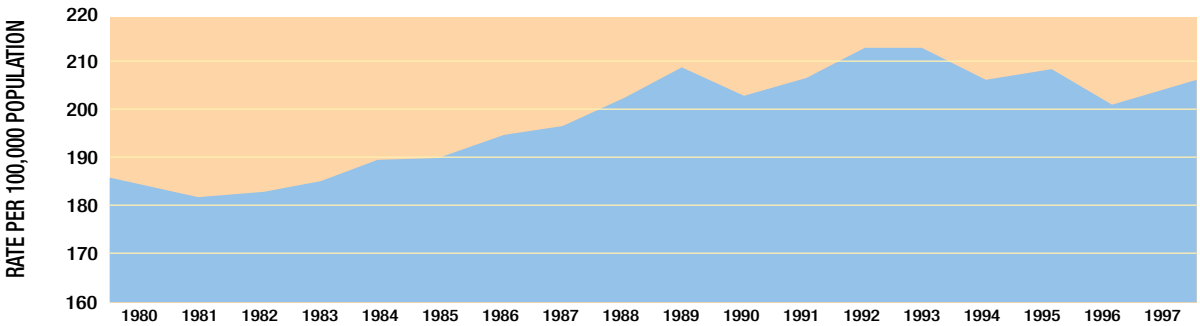


Figure 3.2 *Source: Public Health Information System V3 1999*

3.5 SPECIALIST PALLIATIVE CARE NEEDS OF NON-CANCER PATIENTS

Since their inception, some hospices and specialist palliative care units have provided care for patients with neurological conditions, particularly motor neurone disease and multiple sclerosis, and more recently for patients with HIV/AIDS.[9] However, to date, specialist palliative care has focused almost entirely on cancer

patients. Less than 4% of referrals to specialist palliative care units in the UK have non-cancer diagnoses.[6] This has led to criticisms that only a minority of patients are singled out for "de-luxe" dying.[10]

There is convincing evidence that conventional care is not meeting the needs of non-cancer patients.[9] A review of the evidence for extending palliative care to all found that patients dying from non-malignant disease need better care, and that their needs lie within the remit of specialist palliative care.[9]

Promotion of the palliative care approach is appropriate for all non-cancer patients, but a subset of patients with multiple medical problems or complex palliative care needs will benefit from specialist palliative care.[11]

The extension of palliative care beyond cancer has been advocated in the UK since at least 1980.[12] Concerns about equity have been raised in several recent reports in the UK.[12-14] Indeed, one of the underlying principles of the Health Strategy[15] in Ireland is equity of service provision based on need.

Little is known about the needs of people who die from non-malignant disease, the adequacy of existing services or the effectiveness of specialist palliative care for these patients.[16] Higginson[2] estimates that in a population of one million, there are approximately 6,900 deaths per year due to progressive non-malignant disease. Of these 4,600 suffer pain, 3,400 have trouble breathing, and 1,900 have nausea or vomiting.

The Regional Study of Care for the Dying in the UK[16] found that almost one-fifth (17%) of the non-cancer patients had symptom severity comparable to the top one third (in terms of symptom severity) of cancer patients. The results of the study suggested that non-cancer patients and their families were as much in need of the expertise of specialist palliative care services in symptom control and open communication as cancer patients.

Patients with cardiovascular and respiratory diseases made up the bulk of these non-cancer patients requiring specialist palliative care. It was estimated[16] that inclusion of this group of patients would increase the workload of specialist palliative care services by 79%. However, this may be an underestimation, and the figure may be three times as high.[16]

Extrapolating from these estimates, there would be approximately 25,000 deaths in Ireland each year from progressive, non-malignant causes, mainly circulatory and respiratory disorders. At least 5,000 of these patients would have a recognised period where they could benefit from specialist palliative care services.

The numbers of patients with multiple sclerosis, motor neurone disease and similar disorders who could benefit from specialist palliative care services are small, but the diseases have a much longer duration of symptoms than many of the cancers or other disorders.[2] This factor needs to be taken into account when planning the services.

The National Advisory Committee, having examined the available evidence and having consulted with an expert group in the UK (see Appendix Two), is of the opinion that inclusion of non-cancer patients within the scope of specialist palliative care services would at least double the need for services. This is a conservative estimate.

KEY RECOMMENDATION

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

3.6 ESTIMATES OF SPECIALIST PALLIATIVE CARE NEEDS

Specialist palliative care services are provided in three main settings: specialist palliative care units, hospitals and the community. There are no figures available on the precise requirements of services in these settings.[17] Assessing the needs for palliative care can only provide broad indications of the level of service required.

Estimating the requirements for specialist palliative care services may be achieved by examining the prevalence of disease, both cancer and non-cancer, and the prevalence of symptoms as described in the previous sections.

Another method of estimating the number of patients who may require specialist palliative care services is to examine the patterns of current utilisation of services.[18] However, these may be an underestimate of the true needs of patients with active progressive disease, particularly those with non-malignant disease, as they reflect the availability of services within a population rather than the need for services.

There is limited information available on current utilisation of palliative care services in Ireland. However, information from the UK suggests that 15-25% of patients who die from cancer receive inpatient hospice care.[17]

Calculations based on the current utilisation of inpatient services, the average inpatient duration of stay and bed occupancy in the UK, have estimated that 40 to 50 specialist palliative care beds are required for cancer patients per million population.[17] Similar calculations that include non-cancer patients give a wider range of the total bed numbers required: between 54 and 108 beds per million population.[18] Additionally, provision of general palliative care beds in community hospitals would need to be maintained. [18]

Considering the projected increase of the elderly population in future years, the inclusion of non-cancer patients in the provision of specialist palliative care services, and the principle of providing specialist palliative care at an earlier stage of disease, the National Advisory Committee, based on a detailed analysis of available research and following consultation with relevant experts, recommends that there should be at least 8 to 10 specialist palliative care beds available per 100,000 population to meet the increasing need for specialist palliative care services in Ireland.

However, this is a rapidly evolving area of care and is the subject of ongoing audit and evaluation. The Committee recognises that there may be differences in demographic structure and disease prevalence between Ireland and the UK, and also between different health board areas in Ireland.

It is recommended by the Committee that research should be undertaken at a national level to examine in more detail the prevalence and distribution of disease (both cancer and non-cancer) in Ireland. This should include examination of the distribution of disease in different age, ethnic and socio-economic groups, and should be applied to the national demographic trends. Furthermore, research should also be undertaken to examine the particular needs of non-cancer patients for specialist palliative care services.

Specific regional needs should be further informed by the recommended needs assessment study in each health board.



KEY RECOMMENDATIONS

Current available evidence suggests that there should be at least 8 to 10 specialist palliative care beds per 100,000 population. This requirement may vary within each health board, depending on the demographic and socio-economic composition of the area.

Each health board should determine the bed requirements of its own population as part of a needs assessment for specialist palliative care services.

Further research should be undertaken at national level to examine the needs of non-cancer patients for inpatient specialist palliative care.

3.7 CULTURAL NEEDS

Ethnic and cultural diversity is now a demographic reality within most western societies[19] and cannot be ignored by specialist palliative care services. Palliative care professionals should recognise and facilitate cultural difference.

Within the palliative care context, culture incorporates many aspects of the holistic approach, for example, coping with pain, diet, death and bereavement rituals.[20] All cultures and religions have particular beliefs relating to dying, death and bereavement.[19] The Irish traveller community also has different ways of looking at death and bereavement.

There are many common pitfalls in dealing with patients of different cultural background. These include making assumptions, stereotyping, and prejudging what other populations want, based on previous experience. Other problems include lack of common language, which was found to be the most difficult issue in a study of the perceptions of palliative care professionals in Australia.[19]

Education is the key to the provision of culturally appropriate care to patients and their families from all cultural backgrounds.[19]

Communication skills are invaluable, particularly non-verbal skills, when there are language barriers. Professional interpreters are the most suitable people to translate for the patient[19] and should be used in preference to family or community members. They need suitable training in palliative care, and debriefing after seeing patients.

Getting to know local leaders in the community could be helpful when dealing with patients from other cultures. Volunteers from the same cultural background would also be very beneficial.

KEY RECOMMENDATION

Specialist palliative care services should recognise and facilitate cultural diversity.

3.8 PALLIATIVE CARE FOR CHILDREN

Palliative care for children differs from palliative care for adults in that many children requiring palliative care have life-limiting conditions, as opposed to advanced terminal conditions. Children may survive many years with these conditions.

Life-limiting conditions are those for which there is no reasonable hope of cure and from which children will die.[21] Many of these conditions cause progressive deterioration, rendering the child increasingly dependent on carers.

Four broad groups have been described by the Joint Working Party of the Association for Children with Life-Threatening Conditions and their Families and The Royal College of Paediatrics and Child Health in the UK.[21] These are defined as follows:

Group 1. Life threatening conditions for which curative treatment may be feasible but can fail e.g. cancer, irreversible organ failure.

Group 2. Conditions where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal childhood activities, but where premature death is still possible e.g. cystic fibrosis, muscular dystrophy.

Group 3. Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years e.g. Batten's disease, mucopolysaccharoidosis.

Group 4. Conditions with severe neurological disability, which may cause weakness and susceptibility to health complications, and may deteriorate unpredictably, but are not usually considered progressive e.g. severe brain or spinal injury, severe cerebral palsy.

3.8.1 THE NEED FOR PALLIATIVE CARE FOR CHILDREN

The annual mortality for children aged 1-17 years with life-limiting conditions is 1 per 10,000 children.[21] Based on these figures we could expect approximately 100 children to die each year in Ireland from life-limiting conditions. Of these, 40 would die from cancer, 20 from heart disease, and 40 from other life-limiting conditions.[21]

The needs of these children differ from the needs of adults. A significant proportion will have long-term needs, and many will live with severe disability. Respite care is an important element in the care of children with life-limiting conditions. Children also have a need for continuing education.

The needs of families may be more complex. Parents and siblings may have more profound psychological and social problems, and are more likely to need access to mental health professionals, social workers and spiritual support. Their needs in bereavement may also be more complex.

3.8.2 ISSUES IN THE DELIVERY OF PALLIATIVE CARE FOR CHILDREN

The delivery of palliative care to children requires the collaboration of health professionals, social workers and education providers. Co-ordination of services for children and families is of paramount importance. The staff involved in the delivery of care should be adequately trained and experienced in the health care of children.

Issues that need to be addressed in the planning of future palliative care services for children include:

- Access to specialist palliative care services
- Home nursing care
- Access to paramedical services in the community
- Locally based respite care
- Family support
- Bereavement support
- Education and training of paediatric staff
- Educational needs of children

3.8.3 ADOLESCENTS

Children with life-limiting conditions may survive many years and often grow into their teens and beyond. These adolescents often have complex psychological and social problems. A significant proportion may also have a learning disability and their educational needs may differ from others of their age. Parents may have difficulties with complex nursing needs and with transport. Respite care is a particular problem at this age.

These adolescents do not fit well into either paediatric care or adult care. There is a gap in service provision at this age and loss of continuity of care. Special services should be established to bridge the gap between child-based and adult-based services.

3.8.4 FUTURE DEVELOPMENT OF PALLIATIVE CARE SERVICES FOR CHILDREN

An expert committee on paediatric palliative care was recently established by the Faculty of Paediatrics in Ireland. This is currently examining the future development of palliative care services for children. It is exploring the many issues documented above and will make recommendations on these issues in the near future. The committee will issue a report on palliative care services for children, and will advise the National Council for Specialist Palliative Care (see Chapter Fourteen) of its recommendations. In the meantime, the National Advisory Committee makes the following recommendations in relation to palliative care for children:

- Palliative care for children is best provided at home, except in extraordinary circumstances, with the family closely supported by the general practitioner, the public health nurse and the specialist palliative care team, where available.
- The medical and nursing care of children in hospitals should be the responsibility of paediatric-trained medical and nursing staff, with support from the specialist palliative care service.
- There should be close co-operation and liaison between paediatric and specialist palliative care services.

- Palliative care services for children, including respite care, should be provided as close to the child's home as possible.

- Each paediatric unit should review its requirements for the provision of palliative care and respite care for children in its catchment area.

KEY RECOMMENDATIONS

The medical and nursing care of children in hospitals should be the responsibilty of paediatric-trained medical and nursing staff.

There should be close co-operation and liaison between paediatric and specialist palliative care services in each health board area.

3.9 OTHER POPULATION GROUPS

In determining the need for specialist palliative care services, other population groups with particular needs should be considered. These include people with intellectual, physical and sensory disabilities. Other groups, such as prisoners and intravenous drug abusers, also need consideration when planning services.

The general health care needs of people with intellectual, physical and sensory disabilities are currently met by a range of service providers, including health board and voluntary agencies. However, when faced with a progressive incurable disease, some patients may need access to the specialist palliative care service. Particular difficulties may arise in relation to physical access to services, access to appropriate respite care and transport to and from the services.

Prisoners have their own unique needs when they require specialist care outside the prison environment. The management of prisoners in hospitals poses complex issues.[22] These include custody arrangements, confidentiality and reluctance of staff to provide unbiased care, particularly if they have been a victim of crime themselves. Risk to staff and to other patients should be taken into consideration. The British Medical Association[23] has produced guidelines on the management of prisoners in hospital.

Intravenous drug abusers have a high risk of contracting and subsequently dying from Hepatitis C and AIDS. This population group can pose a particular challenge to the specialist palliative care services, as their nursing and medical care may be more complex, particularly if they are still addicted to drugs. Their need for social and financial support may also be greater, as they are often a marginalized group within the population, and may have little family and community support.

The needs of different population groups should be addressed by each health board when assessing the need for specialist palliative care services. Links between the specialist palliative care units and key service providers for these groups should be established and used to promote a quality service for all.

KEY RECOMMENDATION

The needs of different population groups, including children, should be addressed by each health board when planning the future delivery of specialist palliative care services.



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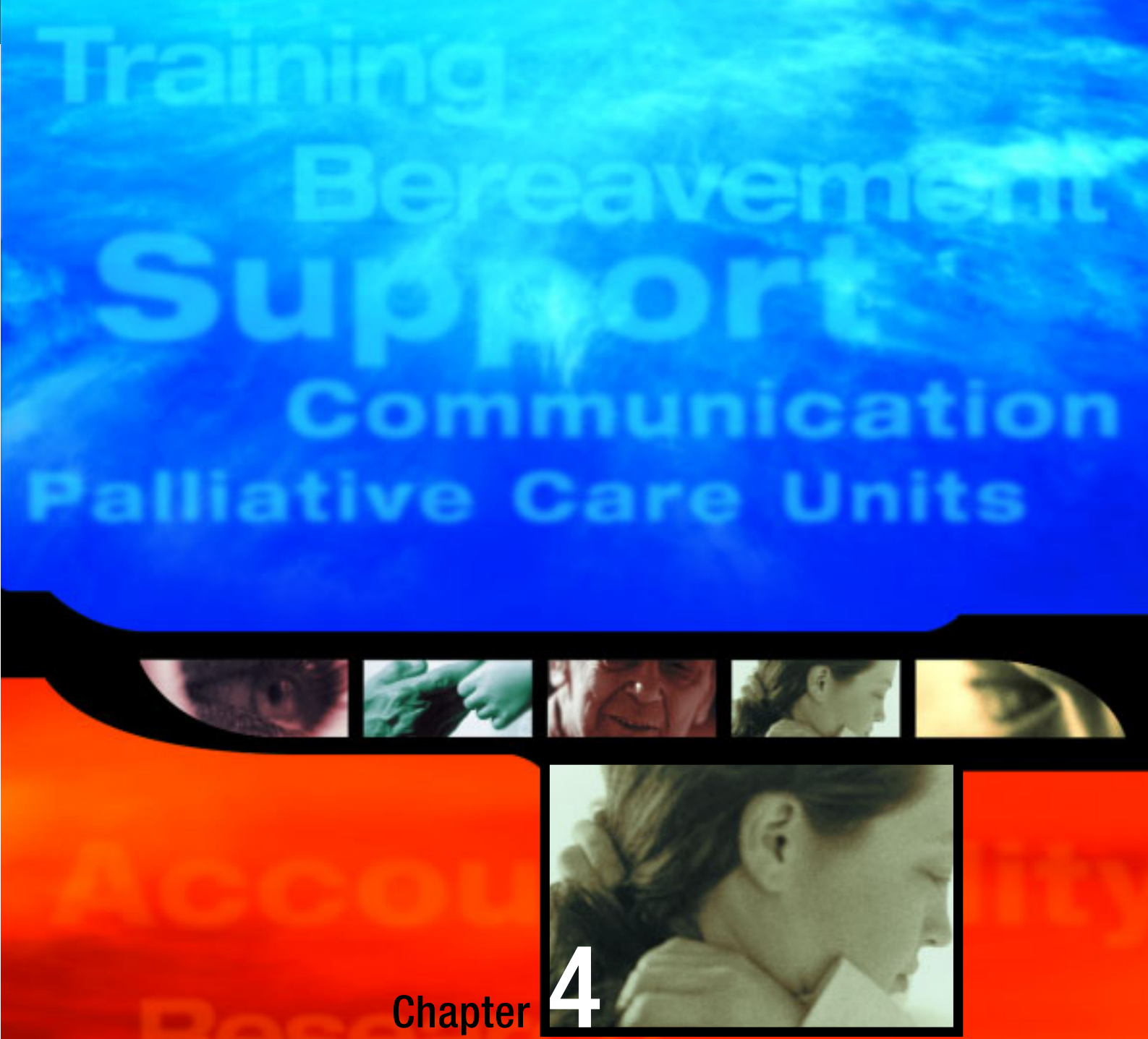
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Chapter 4

Patients and Carers Perceptions



Chapter 4

4.1 INTRODUCTION

Increasingly, the views of patients and carers are sought in the planning and evaluation of health care services.[1] Patients' and carers' needs may be best met when different perceptions are identified, shared and valued in a partnership.[2] The Health Strategy[3] stated that services should be consumer-orientated, and that evaluation of the services should take the patient's perception into account.

This chapter examines the views of patients and carers in relation to palliative care services in different care settings. It highlights areas where patients and carers expressed dissatisfaction with services. It identifies problems in the delivery of services, which need to be addressed in the future planning of palliative care services.

4.2 PROBLEMS AND PITFALLS

Seeking the views of patients and carers in relation to palliative care services has many difficulties. There is an understandable reluctance to subject those with a terminal illness, who may be weak and nearing death, to questionnaires and interviews.[4] There are also ethical concerns centred around the desire to avoid causing distress to people who have been recently bereaved.[5]

The usual strategy of most studies on palliative care has been to assemble information from relatives or professional carers of dying people. Studies support the view that accounts obtained from carers could be used as a valid source of information about important aspects of patients' experiences of terminal illness.[4]

Despite the methodological problems associated with collecting information within a palliative care environment, this type of research can provide invaluable information on consumer perspectives, which can be used to develop future, more successful models of palliative care.[6]

4.3 PREFERENCE FOR PLACE OF DEATH

There is now a growing body of evidence that home as the site of death is generally preferred,[6] although this preference may fluctuate according to the stage of the terminal illness.[7] Evidence from both population and patient surveys shows that the majority of cancer patients would prefer to die in their own home.[8]

One of the first studies to prospectively determine the needs and wishes of patients, who were dying from cancer, found that of those patients who died in hospital, half would have preferred to be at home.[9] It was also assessed that nearly two thirds of the patients in hospital for the last admission did not need 24 hour care, but could have been adequately cared for at home with the support of visits from the district nursing staff, short term use of equipment and some home care support.

Thorpe[10] described two paradoxes based on his own study and his review of the evidence. The first was that most dying people would prefer to remain at home, but most of them die in institutions. The second paradox was that most of the final year is spent at home, but most people are admitted to die. He concluded from his evidence that many people were admitted to hospital for terminal care because of inadequate support in the community.

It is important to recognise, however, that place of death may need to be determined by factors other than patient preference. Often a patient's medical condition may deteriorate to the extent that it may necessitate admission to hospital or specialist inpatient unit for intensive medical and nursing care, which could not be provided in the community. This is particularly true in the final stages of the disease process.

4.4 SATISFACTION WITH HOSPICE AND SPECIALIST PALLIATIVE CARE UNITS

A recent systematic review of the literature[6] examined the impact of specialist models of palliative care on consumer satisfaction, opinion and preference over the past 20 years. Studies in the UK consistently favoured hospice care over hospital care, particularly in relation to psychosocial aspects of care and the quality of communication. Hospice inpatients reported lower levels of pain compared to their hospital counterparts in some studies. Surveys found comparatively higher levels of satisfaction with inpatient hospice care, compared to conventional, non-specialised forms of care.

In Ireland, the results of studies on patient satisfaction with specialist palliative care services are consistent with those in the UK. A study on the quality of health service care of patients at St. James's Hospital, Dublin, during the last year of life[11] found that communication improved with specialist palliative care involvement. Reducing family distress and controlling symptoms were the areas where relatives felt the specialist palliative care service made a big difference.

As part of a needs assessment for specialist palliative care services in the Eastern Health Board area,[12] the views of patients and carers regarding satisfaction with services were sought. The view was widely shared among patients and their families that the care and treatment received in hospices was of a higher standard than that received in hospitals. Communication in hospices was also perceived as being better than in hospitals, and hospice staff were judged as having more time for both patients and their family members.

Continuity of care, with the assignment of a team of carers to each patient from the outset, was particularly valued for its effect in promoting cohesion of service provision and for increasing confidence in care. The availability of physiotherapy, occupational therapy and chiropody services were highly valued for their benefits to health and well-being.[12]

The comfort of hospice facilities, and the availability of en-suite bedrooms for patients who were most in need of privacy, were valued features of the service.[12]

4.5 SATISFACTION WITH HOSPITAL CARE

Concern about the quality of care for patients dying in general hospitals has been provoked by a number of studies.[13] Problems identified include staff avoidance of dying patients, inadequate symptom control, a focus on physical needs at the expense of psychosocial needs, and being too busy to provide adequate care.

A systematic review of the literature on consumer views on different models of specialist palliative care[6] found that the care provided by hospitals was more subject to criticism than any other type of care. It found a wide range of problems with inpatient hospital care. These included an uncaring attitude, poor symptom control, and difficulty in extracting information from doctors. Poor communication was reported as the most prominent criticism by cancer patients in one study.[14] Another complaint in this study was the lack of adequate co-ordination between primary and secondary services.

In Ireland, studies[11,12,15] also highlighted concerns about poor communication with both patients and relatives. Shortcomings included giving people bad news when they were alone, being too direct, removing hope and appearing insensitive.[11] Other concerns included insufficient information exchange, lack of privacy for conversations with the consultant, and use of medical language that the patient and carer could not understand.[15] The importance of information regarding entitlements and support services also emerged.[12]

A suitable venue at the hospital for family members to meet the doctor in private was perceived as a need that was not always available.[12] Having a private room at the time of death was considered important by relatives.[11]

Long delays were widely experienced in Accident and Emergency (A&E) departments and at hospital outpatient clinics.[11,12,15] Access to inpatient services was frequently delayed and patients often had to be routed via A&E departments in order to be assessed. Direct admission to hospital wards was widely supported to avoid undue distress and discomfort.[12]

4.6 SATISFACTION WITH CARE IN THE COMMUNITY

Studies in the UK have shown that one of the main reasons for admission of terminally ill patients to second level care is lack of support for carers.[16] One study found that support at home produced the strongest influence on place of death.[8] Another found that practical nursing support was lacking for most of the carers; there were delays in the delivery of domestic help; many carers were exhausted by the time help arrived; and most carers themselves experienced physical symptoms during the terminal illness.[17]

Other studies identified the need for more overnight help; access to respite care; and information on financial assistance, legal assistance, education, bereavement support and counselling.[6]

Studies in Ireland[12,15] also found several problem areas for carers in the community. These include emotional difficulties in coping with the terminal illness of their relative, the burden of time needed for caring, problems with night nursing, physical exhaustion and feelings of isolation.[15] They identified the need for more carer support in the community, including night nursing services, and the expansion of day care services.[12]

Carers also mentioned the lack of public health nurses over the weekend, not knowing when the public health nurse would arrive, and the perceived lack of co-ordination between the public health nurse and home care nurse.[15]

Financial costs involved in the care of a patient caused difficulties for many carers.[15] These were due to the extra costs of technical aids, drugs, services, dietary requirements and travel expenses. Housing conditions were also a problem for carers, as the patient often had difficulty in accessing the stairs, bathroom or bedroom.[15]

KEY RECOMMENDATION

In assessing the need for palliative care services, patients and their carers are prime stakeholders, and as such, their opinions and preferences should be sought and incorporated into national and regional policies.



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Section 2

Specialist Palliative Care





Chapter 5

Specialist Palliative Care Services



Chapter 5

5.1 INTRODUCTION

Specialist palliative care services are those services with palliative care as their core specialty. 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. They require a higher level of professional skills from trained staff and a high staff/patient ratio.[1]

This chapter describes the characteristics of a specialist palliative care service. It also documents the staffing requirements of such a service, and makes recommendations regarding the staffing levels required in order to provide this specialist service.

It is important to recognize that different health boards are at different stages in the development of their specialist palliative care services. The staffing levels outlined below will support a comprehensive specialist palliative care service. It is recognised that not all health boards will satisfy these criteria immediately and some may take a longer time scale than others to achieve these requirements.

5.2 PRINCIPLES

In order to achieve the best quality palliative care for patients and families, each health board should have a comprehensive specialist palliative care service in its area. This service should be available in all care settings and should support the patient wherever the patient may be: at home, in hospital, in residential care, in day centres, in outpatients, or in a specialist palliative care unit.

Specialist palliative care services have an important role in supporting other health care professionals in the delivery of palliative care services at hospital and community level. All health care professionals should be able to access advice and support from specialist palliative care service providers when required.

KEY RECOMMENDATIONS

Each health board area should have a comprehensive specialist palliative care service to meet the needs of patients and families in the area.

All health care professionals should be able to access advice and support from specialist palliative care service providers when required.

5.3 CHARACTERISTICS OF A SPECIALIST PALLIATIVE CARE SERVICE

The key characteristics of a specialist palliative care service have been described by the National Council for Hospice and Specialist Palliative Care Services in the UK[1] and are endorsed by the National Advisory Committee. They are listed as follows:

- The provision of physical, psychological, social and spiritual support, with a mix of skills, delivered through a multi-professional, collaborative team approach

- At least the lead person in each professional group within the multi-professional team should be a trained and acknowledged specialist in palliative care

- Patients and families are supported and involved in management plans
- Patients are encouraged to express their preference about where they wish to be cared for and where they wish to die
- Carers and families are supported through the illness into bereavement, and the needs of the bereaved are recognised and addressed
- There is co-operation and collaboration with primary health care professionals, hospital and home care services to support patients wherever they might be
- The contribution of volunteers is recognised and valued
- The service has either directly or indirectly a recognised academic external educational role and in-service education provision
- Standards are set for the education and training provided
- Quality assurance programmes are in place and are constantly used to review practice
- Clinical audit and research programmes exist to evaluate treatment and outcome
- Staff support arrangements exist which are appropriate to meet the needs of those working in specialist palliative care, whether full time or part time

5.4 STAFFING REQUIREMENTS OF A SPECIALIST PALLIATIVE CARE SERVICE

The National Council for Hospice and Specialist Palliative Care Services in the UK[1] has recommended that all specialist palliative care services should have available an essential minimum core of professionally trained staff with recognised post-qualification specialist training and clinical experience in palliative care services.

All specialist palliative care services should have at least one consultant in palliative medicine, with a support team of non-consultant hospital doctors (NCHDs) who should be attached to the specialist inpatient unit.

Specialist palliative care services should have nursing staff with a skill mix to meet the requirements of the service. In addition, care attendants are required to assist in the care of patients in specialist units and in the community.

Specialist services should also have the following staff available full-time, part-time or with regular sessions:

- Physiotherapist(s)
- Occupational therapist(s)
- Social worker(s)
- Staff specifically trained to meet the psychosocial needs of the patient, family and carers

- Suitably trained and experienced members of staff who will be responsible for bereavement services
- Co-ordinator of spiritual care
- Speech and language therapist
- Dietician/clinical nutritionist
- Pharmacist
- Complementary therapist(s)
- Volunteer co-ordinator
- Educational personnel
- Librarian
- Appropriate level of administrative, secretarial and general support staff

In addition, specialist palliative care services should have a close service and training link with medical/surgical specialties including medical oncology, surgical oncology and radiation oncology, and those involved in pain clinics.

The specialist palliative care service should have access to all appropriate clinical investigation facilities, including all modern imaging techniques. The specialist palliative care service should also have access to modern information technology and tele-communication systems, including facilities for video-conferencing.

The following sections give a brief description of the roles of the various staff who are involved in delivering specialist palliative care services, both in specialist inpatient units and in other settings, namely acute general hospitals and the community. The recommendations for staffing levels were determined by a consensus of the Committee, having consulted widely and having extensively reviewed the available literature.

These recommendations are the minimum requirement for specialist palliative care services. Specialist palliative care units with a smaller number of beds may need a higher ratio of staff to beds in order to provide sufficient staff to meet the care needs of patients.

5.5 MEDICAL STAFF

All specialist palliative care services should initially have at least one doctor who holds a recognised Comhairle na nOspideal approved consultant appointment in palliative medicine and who is on, or is eligible to be on, the specialist register of the Medical Council and who practices principally in this specialty. Ideally, all specialist palliative care services should have at least two such doctors.

All consultants in palliative medicine should have access to dedicated specialist beds in specialist palliative care units or in acute general hospitals.

In health board areas where there is currently no consultant in palliative medicine, a consultant should be appointed with a majority sessional commitment to the specialist palliative care unit, where one exists. The

consultant appointed to the specialist palliative care unit should also have a joint commitment to the acute general hospital in the area that has the broadest range of medical, surgical and oncological activity. In areas where there is currently no specialist palliative care unit, the majority sessional commitment should be to the acute general hospital described above.

Consultants appointed to specialist palliative care services may also have sessional commitments to other hospitals in the area. However, it is recommended that no consultant should have sessions in more than three geographic locations.

Informed by national policies and with due regard to local needs and circumstances, each health board should determine the number of consultant posts required to deliver a comprehensive and equitable service to patients in their region. In regions where there is already an existing consultant in palliative medicine in post, the sessional commitments of a second and subsequent consultant posts should be determined at regional level.

For each consultant in palliative medicine, there should be at least three non-consultant hospital doctors (NCHDs) working in the specialist palliative care unit. These NCHDs should include doctors at senior house officer (SHO) level e.g. general practice (GP) trainees and SHOs on medical rotations and also doctors at registrar level, who are on training programmes in palliative medicine.

KEY RECOMMENDATIONS

There should be at least one Whole Time Equivalent (WTE) consultant in palliative medicine per 160,000 population, with a minimum of two consultants in each health board area.

For each consultant in palliative medicine, there should be at least three non-consultant hospital doctors (NCHDs) working in the specialist palliative care unit.

5.6 SPECIALIST PALLIATIVE CARE NURSES

A dynamic team of highly trained, motivated and skilled nursing personnel is an essential component of any specialist palliative care facility. All specialist palliative care services should provide nursing staff with a skill mix to meet the requirements of the service, and all should have had at least an introductory education in palliative care principles and practice.

For the purpose of recruitment and training, it is important that the creation of specialist posts for nurses should be undertaken within the context of an appropriate career structure. Services should ensure that theoretical knowledge is balanced against practical experience in the field, to ensure high standards of quality service delivery.

All nurses in more senior posts should hold a recognised post-registration qualification, or have had equivalent experience and have achieved comparable competence.[1]

It is recognised that specialist palliative care is a new and evolving specialty, and that nursing education in this area of care is in its early stages. Therefore, as an interim measure, the National Advisory Committee recommends that services should recognise the vast experience of senior nurses who may not hold recognised post-registration qualifications, when appointing nurses to senior posts in the specialist palliative care service.

The National Advisory Committee makes the following **recommendations** with regard to the minimum staffing levels of specialist palliative care nurses required in different care settings:

5.6.1 SPECIALIST PALLIATIVE CARE NURSES IN A SPECIALIST INPATIENT UNIT:

The overall WTE specialist palliative care nurse to bed ratio should not be less than 1:1.

5.6.2 SPECIALIST PALLIATIVE CARE NURSES IN A DAY CARE CENTRE:

In each day care centre, there should be a minimum of one WTE specialist palliative care nurse to every 7 daily attendees.

5.6.3 SPECIALIST PALLIATIVE CARE NURSES IN AN ACUTE GENERAL HOSPITAL:

There should be a minimum of one WTE specialist palliative care nurse per 150 beds in each acute general hospital.

5.6.4 SPECIALIST PALLIATIVE CARE NURSE IN THE COMMUNITY:

There should be a minimum of one WTE specialist palliative care nurse in the community per 25,000 population.

The attention of the Committee has been brought to some variations in the salaries and career structures of nurses working in the area of specialist palliative care. It is recommended by the Committee that salaries and career structures should be standardised nationally across all health board areas.

5.7 PHYSIOTHERAPY

Physiotherapy has a vital role to play in the rehabilitation of palliative care patients and in the palliation of symptoms. Physiotherapists are an integral part of the inter-disciplinary team. They offer a wide range of services to patients requiring palliative care.

Physiotherapy should be provided in a range of settings. Each specialist palliative care service should have a sufficient number of chartered physiotherapists to adequately meet the palliative and rehabilitative needs of all patients under the care of the programme. This should include inpatient care, day centre patients, outpatients, and community-based patients.

In the specialist palliative care unit, physiotherapy should ideally be provided in a purpose built physiotherapy unit that is properly resourced to meet the needs of patients receiving palliative care. For patients who are too ill to attend the physiotherapy department, there should be a separate treatment area on the ward.

A specialist physiotherapy service should be available to serve the needs of palliative care patients in the community. The physiotherapists with responsibility for palliative care patients in the community should be based in the specialist palliative care unit.

Each general hospital should provide adequate staffing levels to ensure that the needs of palliative care patients are met. A designated physiotherapist should be assigned to spend a specific amount of time with palliative care patients in acute general hospitals. The physiotherapist in the acute general hospital may develop a sub-specialist interest, e.g. lymphoedema, dyspnoea, etc.

Consideration should be given to the establishment of specialist clinics led by paramedical professionals. An example would be a physiotherapy-led clinic for the management of lymphoedema or dyspnoea. The Committee recommends that there should be a pilot study to explore the feasibility of physiotherapy-led clinics for patients with progressive malignant or non-malignant disease.

KEY RECOMMENDATIONS

There should be at least one WTE physiotherapist per 10 beds in the specialist palliative care inpatient unit, with a minimum of one physiotherapist in each unit.

There should be a minimum of one WTE community physiotherapist specialising in palliative care per 125,000 population. This post should be based in the specialist palliative care unit.

5.8 OCCUPATIONAL THERAPY

Occupational therapy involves the restoration or maintenance of optimal levels of functional independence in the areas of self-care, productivity and leisure activities. An individual can benefit from occupational therapy at any stage in their illness from primary diagnosis, through attempts at curative treatment, to palliation and finally terminal care.

The occupational therapist works as part of the inter-disciplinary team in palliative care. Increasing demand for palliative care in non-malignant degenerative conditions, especially Motor Neurone Disease, has increased the need for specialist occupational therapy intervention.

All specialist palliative care units should have an occupational therapy service. The occupational therapist providing services to palliative care patients in the community should be based in the specialist palliative care unit. All acute general hospitals should have sufficient occupational therapists to meet the needs of palliative care patients.

KEY RECOMMENDATIONS

There should be at least one WTE occupational therapist per 10 beds in the specialist palliative care unit, with a minimum of one occupational therapist in each unit.

There should be a minimum of one WTE community occupational therapist specialising in palliative care per 125,000 population. This post should be based in the specialist palliative care unit.

5.9 SOCIAL WORKERS

The role of the social worker in the specialist palliative care setting includes the provision of specialist social work, support and counselling to patients and families, as appropriate, both before and after the patient's death. Medical social workers in the specialist palliative care unit address the psychological and social issues that arise when a patient and family are faced with a progressive, life-threatening condition. The social worker also consults and liases with outside agencies, such as general hospital teams, primary care providers, and voluntary agencies.

In the context of a specialist palliative care unit, the social worker should be a member of the inter-disciplinary team, attending ward rounds and offering advice and support to other team members.

Social workers trained in palliative care should also be available to patients in the community. They should be based in the specialist palliative care unit.

In acute general hospitals, it is recommended that the social worker should be part of the inter-disciplinary specialist palliative care team.

KEY RECOMMENDATIONS

There should be at least one WTE social worker employed per 10 beds in the specialist palliative care unit, with a minimum of one social worker in each unit.

There should be a minimum of one WTE community social worker specialising in palliative care per 125,000 population. This post should be based in the specialist palliative care unit.

5.10 PSYCHOLOGISTS AND PROFESSIONAL COUNSELLORS

Meeting the psychological needs of palliative care patients is an integral part of the specialist palliative care service. Counselling skills are integrated into the work practice and training of all health care professionals in the specialist palliative care service. Medical, nursing and allied professionals, including trained volunteers, offer varying degrees of emotional support and counselling to palliative care patients.

However, a significant number of palliative care patients may have complex psychological or psychiatric needs, due either to longstanding difficulties or to their advanced disease.[2] Access to professionals with expertise in this area, such as psychologists, professional counsellors or psychiatrists is essential to all specialist palliative care services.

Psychologists and professional counsellors have particular skills to offer the palliative care patient. In common with other health care professionals, they also have a role to play in bereavement counselling, particularly in the management of people at risk.

There is some concern about the lack of mandatory regulation of counsellors at present in Ireland. Voluntary bereavement counselling may be well organised and monitored in certain areas, but there are no set standards countrywide. The Department of Health and Children has recently met with the Irish Association of Counsellors and Therapists (IACT), the professional body representing counsellors, and discussed the regulation of these professionals.

KEY RECOMMENDATION

Professionals involved in the psychological aspects of specialist palliative care services should be suitably trained and experienced in this role.

5.11 SPIRITUAL CARE

Palliative care takes a holistic view of the patient and family. This includes addressing the spiritual needs of patients, particularly at the later stages of disease, when death is imminent. Fear of dying, anxiety about the after-life, denial of impending death, concerns about family and finances, or a search for meaning within personal suffering are just a few of the common psychological and spiritual issues reported by the dying.[3]

Whilst the physical, emotional and social components of holistic care are reasonably understood, the spiritual domain is far less well defined.[4] Spiritual problems may be neglected because they are regarded by doctors and nurses as secondary to the alleviation of physical problems.[5]

Patients who have religious beliefs are often greatly helped by religious support during their illness. Religious beliefs may also become more important to the relatives as death becomes inevitable.[6]

It is important to recognise the increasing diversity of religious beliefs in Ireland, and to facilitate people of all religions, and those with no religion. All patients, regardless of their belief or lack of belief, are entitled to spiritual care. In Ireland, this may be provided by personnel from various religious denominations, or by lay chaplains, who encompass the beliefs and views of all denominations.

The Committee recommends that there should be a minimum of two suitably trained chaplains available in each specialist palliative care unit to provide a 24-hour service to patients and families. The unit should have an input into the selection of these chaplains. Additionally, each patient should be able to access the spiritual advisor of their choice, depending on their beliefs.

A co-ordinator of spiritual and pastoral care should be included in all specialist palliative care services.

KEY RECOMMENDATIONS

Each specialist palliative care unit should have at least two suitably trained chaplains available to meet the spiritual needs of patients and families.

The pastoral care service should be available to patients and families 24 hours a day.

5.12 SPEECH AND LANGUAGE THERAPY

Two important measures of quality of life are the ability to communicate and to enjoy eating and drinking. When breakdown occurs in these areas the effects are devastating. Speech and language therapists are specialists in the treatment of both communication and swallowing disorders. A speech and language therapy service can greatly improve the quality of life for palliative care patients.

Speech and swallowing problems are particularly common in patients suffering from advanced neurological and malignant disease, and expert assessment is required at the earliest opportunity.

All specialist palliative care units should have ready access to the services of a speech and language therapist. The Committee recommends the establishment of formal links between the specialist palliative care unit and speech and language therapy departments in acute general hospitals in the area.

Each care setting should be adequately resourced to meet the speech and language needs of palliative care patients. This applies to the hospital and community setting.

KEY RECOMMENDATION

There should be regular speech and language therapy sessions in each specialist palliative care unit, with a minimum of one session per week.

5.13 CLINICAL NUTRITIONISTS

The services of a clinical nutritionist or dietician are important in the context of a specialist palliative care service. The advice of a clinical nutritionist on dietary matters is very valuable to patients, and is an important factor in improving quality of life. The clinical nutritionist also provides expert advice to staff with regard to supplementary nutrition for patients. However, it is important to note that nutritional therapy does not confer any survival advantage in metastatic cancer.[7]

It is recommended by the Committee that all specialist palliative care services should have access to a suitably trained clinical nutritionist or dietician. Specialist palliative care units should establish formal links with clinical nutritionists.

KEY RECOMMENDATION

There should be at least one clinical nutritionist session in each specialist palliative care unit per week.

5.14 PHARMACISTS

Pharmacists practicing both in the community and hospital setting are becoming increasingly involved in palliative care services. Pharmacists currently provide services to patients requiring palliative care in specialist palliative care units, health board facilities for older people, cancer treatment centres, nursing homes and acute general hospitals. In the community, private pharmacists play an important role in providing services to patients who are being cared for in their own homes.

It is recommended that all specialist palliative care units should have a fully trained pharmacist, who should work and function as part of the inter-disciplinary team. The pharmacist should work closely with the medical and nursing staff, offering advice and information on the most appropriate use of medications. The pharmacist would also be available to provide advice regarding medications to other health care professionals within the region.

In the acute general hospital setting, the pharmacy department should be sufficiently resourced to enable staff to become involved with the specialist palliative care team.

KEY RECOMMENDATION

There should be at least one WTE pharmacist in each specialist palliative care unit.

5.15 COMPLEMENTARY AND SUPPORTIVE THERAPISTS

Complementary and supportive therapies within the palliative care context can be described as those approaches to the patient that complement the care and treatment already offered by the inter-disciplinary team, in order to improve the quality of their experience of living with advanced disease. They offer an extra dimension to the holistic approach of palliative care. Complementary and supportive therapies include massage therapy, aromatherapy, art therapy, music therapy and meditation, among others.

While complementary and supportive therapies are valued by patients,[8] there is some concern about the lack of regulations and definitions in this area. The Committee recommends that any person providing complementary and supportive therapies should receive adequate training and be registered with the appropriate professional body.

The Department of Health and Children has recently proposed to establish a joint consultative forum to discuss the issue of statutory registration with representative bodies of the various therapeutic providers of non-conventional medicine.

In the meantime, there is currently some research being undertaken in Ireland to evaluate the role of complementary and supportive therapies. The Committee looks forward to the publication of the results of this research.

5.16 CARE ATTENDANTS

In each specialist palliative care unit, care attendants are required to assist in the care and attention of patients. These care attendants act as a support to specialist palliative care nurses in the unit. Care attendants should also be provided to support carers of palliative care patients in the community.

Care attendants should be properly selected, trained and supervised in their role.

KEY RECOMMENDATION

The care attendant to bed ratio in specialist palliative care units should not be less than 0.5:1

5.17 VOLUNTEERS

Volunteers are an integral part of the specialist palliative care service, whether they are working directly with patients and their families, or giving other essential support, such as raising money.[9] Volunteers do not take the place of staff, but work alongside them in a complementary way. They enhance the specialist palliative care service with a wide range of talent, experience and expertise. The services they provide include befriending patients and families; providing social outlets through the medium of music, art and crafts; transporting sick people to and from places of care; supporting bereaved families and friends; offering home visits and assisting at day care centres.

Volunteers should be carefully selected, trained, and supervised. There should be clarity of roles and boundaries, especially with regard to confidentiality and expenses. Volunteers should be well supported and appreciated in their role.[9]

Every specialist palliative care unit should have a volunteer co-ordinator, who should be responsible for the selection, training and placement of volunteers. He or she should also be responsible for administration and policies in relation to volunteers.

KEY RECOMMENDATION

Every specialist palliative care unit should have a volunteer co-ordinator, who should be responsible for the selection, training and placement of volunteers.

5.18 THE INTER-DISCIPLINARY SPECIALIST PALLIATIVE CARE TEAM

It is a fundamental principle of palliative care that no one individual or discipline possesses the range of skills necessary to comprehensively meet and address the varied needs of patients and their families. A good palliative care team should be composed of members of multiple disciplines, representing a variety of areas of expertise.

Teamwork may be a source of enormous mutual support in an emotionally demanding environment, but may also be a source of conflict and frustration. Issues such as role blurring and role ambiguity are often identified as potential stressors. Poor communication may result in team members feeling devalued and demoralised.

The primary focus of the specialist palliative care team should be the care and welfare of the individual patient and family. All other personal, professional and departmental agendas should be subordinated for the good of the patient. Unresolved and persistent conflict within teams undoubtedly results in poor team performance.

The National Advisory Committee **recommends** that the following principles of teamwork should be upheld:

- Palliative care patients and their families should receive input from a highly trained and adequately resourced team who share a commitment to excellence.

- Each member of the team should be capable, competent and confident in their own professional role and should ensure that they attend to their personal and professional development.

- Each team member should recognise the limits of their own expertise and should actively encourage and facilitate the appropriate and timely involvement of other health care professionals at hospital and community level.

- Teams should establish formal channels of communication so as to ensure that all team members have an opportunity to contribute to the decision making process and are informed of developments at the earliest opportunity.

5.19 RESOURCES AND SUPPORT FOR STAFF

The staff of the specialist palliative care service require adequate and suitable accomodation that is equipped and furnished to a high standard in order to enable them to discharge their duties effectively, safely and professionally. They also require an appropriate level of administrative and secretarial support.

All staff should have ready access to necessary aids, appliances and technologies. Specialist palliative care providers in the community should be provided with an efficient means of communication, such as mobile phones.

Specialist palliative care services should ensure that all members of staff are provided with the necessary opportunity and resources to pursue continuing education and training in the interest of their own professional and personal development, and in the interest of patient care and excellence.

There should be easy access to the services of the occupational health department, including counselling services if required. The Committee recommends that formal links between the specialist palliative care service and the occupational health department in the area should be established.

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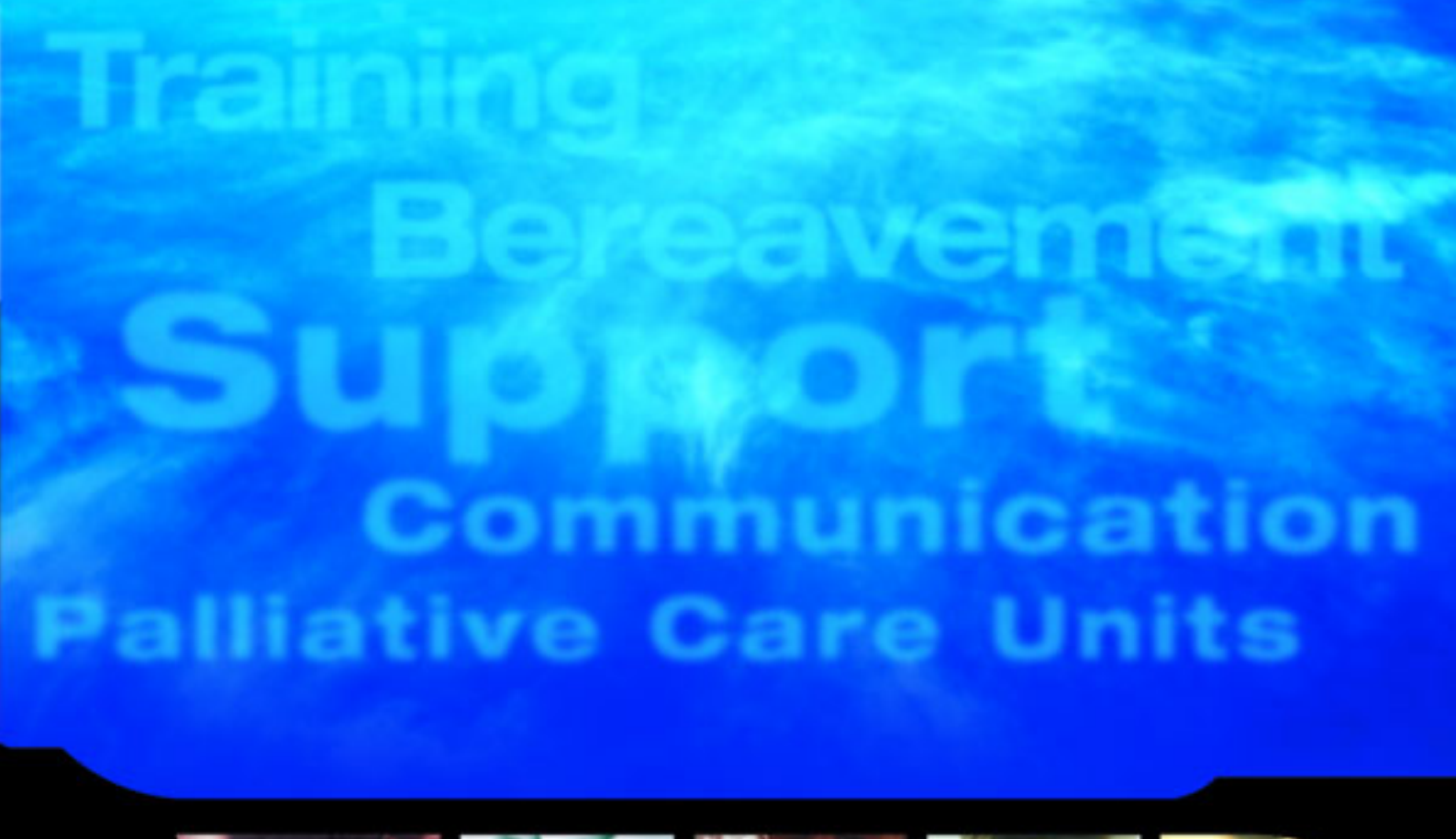
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Chapter 6

Specialist Palliative Care Units



Chapter 6

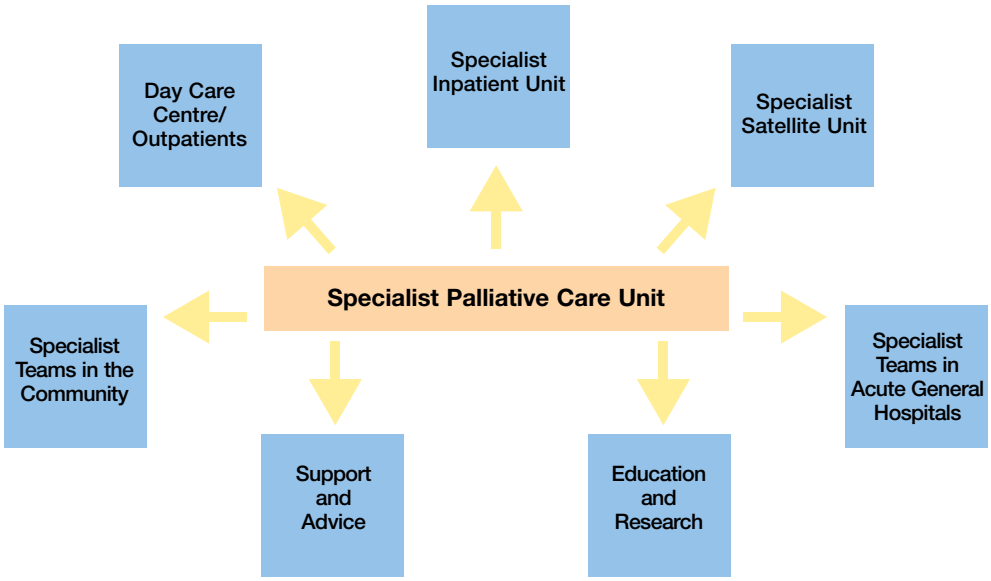
6.1 INTRODUCTION

Traditionally, palliative care inpatient units or "hospices" were seen as homes for the dying. More recently, there has been a great improvement in the physical environment and general ambience of these units. The range and level of services available in these units has increased considerably.

This chapter describes the ideal specialist palliative care inpatient unit, and how it should be the leader and co-ordinator of all specialist palliative care services in the region. It also introduces the concept of satellite specialist palliative care units, which would provide specialist palliative care services in areas with a wide geographical spread.

6.2 PRINCIPLES

The specialist palliative care inpatient unit should be the core essential element of the specialist palliative care service in each health board area. It should be the "hub" of the service, around which all components of the specialist service revolve.



Specialist palliative care services in all other settings, including the community and hospital settings, should be based in or have formal links with the specialist palliative care unit.

The specialist unit should act as a resource for other health professionals in the area, by providing support and advice when needed. The specialist unit should also provide facilities for research and education in palliative care.

KEY RECOMMENDATIONS

The specialist palliative care inpatient unit should be the core essential element of the specialist palliative care service.

Specialist palliative care services in all other settings, including general hospitals and the community, should be based in or have formal links with the specialist palliative care unit.

6.3 SPECIALIST PALLIATIVE CARE INPATIENT UNIT

A specialist palliative care inpatient unit is usually an independent free-standing unit, with its own inpatient facilities and full complement of staff. In some circumstances, a specialist palliative care inpatient unit may be located within an acute general hospital, sharing resources with the hospital, but with its own specialist staff, and its own designated beds for palliative care patients.

The specialist palliative care inpatient unit should provide a consultant-led service. It should provide a wide range of specialist services to patients and families, addressing their medical, nursing, psychosocial and spiritual needs. It should have medical, nursing and paramedical staff specially trained in palliative care, and a high nurse to patient ratio. A range of paramedical services should be provided for patients and their families or carers, as described in Chapter Five.

The National Advisory Committee recommends that there should be at least one specialist palliative care inpatient unit in each health board area. All specialist palliative care units should be of sufficient size to enable them to meet the specialist palliative care needs of the population. There are currently five consultant-led specialist palliative care units in the country.

Specialist palliative care units should, where possible, be based close to the acute general hospital with the broadest range of specialist services, including radiotherapy and oncology, in the area. This would enable services to work more efficiently together, sharing expertise and resources, and allow easy access to facilities, such as clinical investigations.

Patients should be admitted to these units to avail of the specialist skills of the inter-disciplinary team. Reasons for admission would ordinarily include complex symptom management, psychosocial problems, and intensive rehabilitation. Patients requiring general palliative care, respite or terminal care would be more appropriately admitted to local community hospitals.

Assessment of patients prior to admission is recommended to determine the appropriate level of care for the patient. Comprehensive assessment by the consultant in palliative medicine, in consultation with the general practitioner, would enable patients to be admitted to the setting most suitable to their needs.

A number of beds should be kept available in specialist units for urgent admissions. This would allow easier access to specialist beds for patients in the community. It has been shown that the availability of specialist palliative care beds has paradoxically permitted more confident perseverance at home.[1]

KEY RECOMMENDATIONS

There should be at least one specialist palliative care inpatient unit in each health board area.

6.4 SATELLITE SPECIALIST PALLIATIVE CARE INPATIENT UNIT

The National Advisory Committee has recommended that there should be a specialist palliative care unit in each health board area, capable of supporting the services across the region.

However, it is recognised that patients living a considerable distance from the lead specialist inpatient unit may have difficulty in accessing inpatient care. Consequently, the Committee also recommends that in regions where there is a wide geographical spread, the health board in that area should give consideration to the feasibility of establishing a single satellite inpatient unit.

Ideally, any satellite inpatient unit should be based in a major centre of population, and sited close to an acute general hospital, where possible. All beds allocated to the satellite unit should be taken from the total quota of beds estimated for that health board. In order to be viable, the satellite unit should ideally have not less than 10 specialist palliative care beds.

The satellite specialist palliative care inpatient unit should provide specialist services to patients, families and health professionals in the area. These should include the wide range of services recommended for the lead specialist palliative care unit. Staffing of these units should be in accordance with the recommendations laid down in Chapter Five. The specialist palliative care team serving the community, i.e. for the particular catchment area covered by the satellite specialist palliative care inpatient unit, should be based in the satellite unit.

Satellite inpatient units would function as an extension of the lead specialist palliative care unit for the region and would maintain strong links with the lead unit, particularly with regard to education, training and professional support. It is not intended that satellite units would replicate the educational and research aspects of the lead specialist palliative care unit.

Furthermore, it is recommended that there should be no more than one satellite specialist palliative care inpatient unit in any health board area.

KEY RECOMMENDATIONS

In areas with a wide geographical spread, it may be necessary to develop a satellite specialist palliative care inpatient unit to meet the needs of patients and families in the area.

Satellite inpatient units would function as an extension of the lead specialist palliative care unit for the region.

There should be no more than one satellite specialist palliative care inpatient unit in any health board area.

6.5 SATELLITE SPECIALIST PALLIATIVE CARE COMMUNITY BASE

Many health board areas with a wide geographical spread may not have the population density to support a satellite inpatient unit. Consequently, the provision of services to patients in the community may present logistical difficulties for specialist palliative care staff.

In some health board areas it may be necessary to establish a number of satellite bases, from where specialist

palliative care staff would provide services in the community. The decision to establish satellite bases in health board areas should be taken at regional level.

Such satellite bases would function as an extension of the lead specialist palliative care unit for the region and would have close clinical, educational and administrative links with the lead unit.

KEY RECOMMENDATIONS

In some health board areas it may be necessary to establish a number of satellite bases, from where specialist palliative care staff would provide services in the local community, i.e. for the catchment area covered by the satellite base.

The decision to establish satellite bases in health board areas should be taken at regional level.

Satellite bases would function as an extension of the lead specialist palliative care unit for the region and would have close clinical, educational and administrative links with the lead unit.

6.6 SPECIALIST PALLIATIVE DAY CARE CENTRE

One of the goals of specialist palliative care is to provide care for patients in the most appropriate setting. As patients and relatives often express a choice for care at home, there has been a shift in focus to community-based services. The evolution of day care can be seen in relation to the overall development of services in the community.[2]

The broad aims of palliative day care are maintaining or improving quality of life, the provision of holistic care by a multi-professional team, the opportunity for rehabilitation, continuity of care through collaboration, and helping patients to remain at home for as long as they wish.

Day care centres attached to specialist palliative care units provide access to all specialist palliative care services. Patients may be admitted to day care programmes for medical treatment or for rehabilitation. The range of day care activities provided includes nursing procedures, personal care, physiotherapy, occupational therapy, complementary therapies, relaxation, music and art therapy.

Volunteers are often actively involved in the provision of day care services, providing a carefully planned programme of events, including entertainment and outings. They also play an important role in providing transport to the day care centres.

There are currently five specialist palliative day care centres in Ireland. The number of days on which each day care service is operational varies from unit to unit. Transport is usually provided to and from the day care unit for all patients.

The National Advisory Committee recommends that all specialist palliative care inpatient units should provide day care facilities for patients and families. Appropriate transport should be provided to and from the day care centre.

KEY RECOMMENDATIONS

All specialist palliative care units should provide day care facilities for patients and carers.

Appropriate transport should be provided for patients to and from the centre.

6.7 PHYSICAL STRUCTURE AND ENVIRONMENT

The structure and environment of a specialist palliative care inpatient unit should be appropriate to the needs of patients and staff, and should also be sensitive to the needs of families and friends. Planning should always take the need for privacy into consideration.

The National Advisory Committee recommends that an Expert Group on Design Guides for Specialist Palliative Care Settings should be established, in parallel with the formulation of a national policy, and the commissioning of a needs assessment study by health boards. This Expert Group would propose design guidance documentation, which would inform all parties to the facilities procurement process and ensure a national consistency of standards for all specialist palliative care centres.

The Committee recommends that this Expert Group should be established immediately, and have completed its report within twelve months of publication of this report.

KEY RECOMMENDATIONS

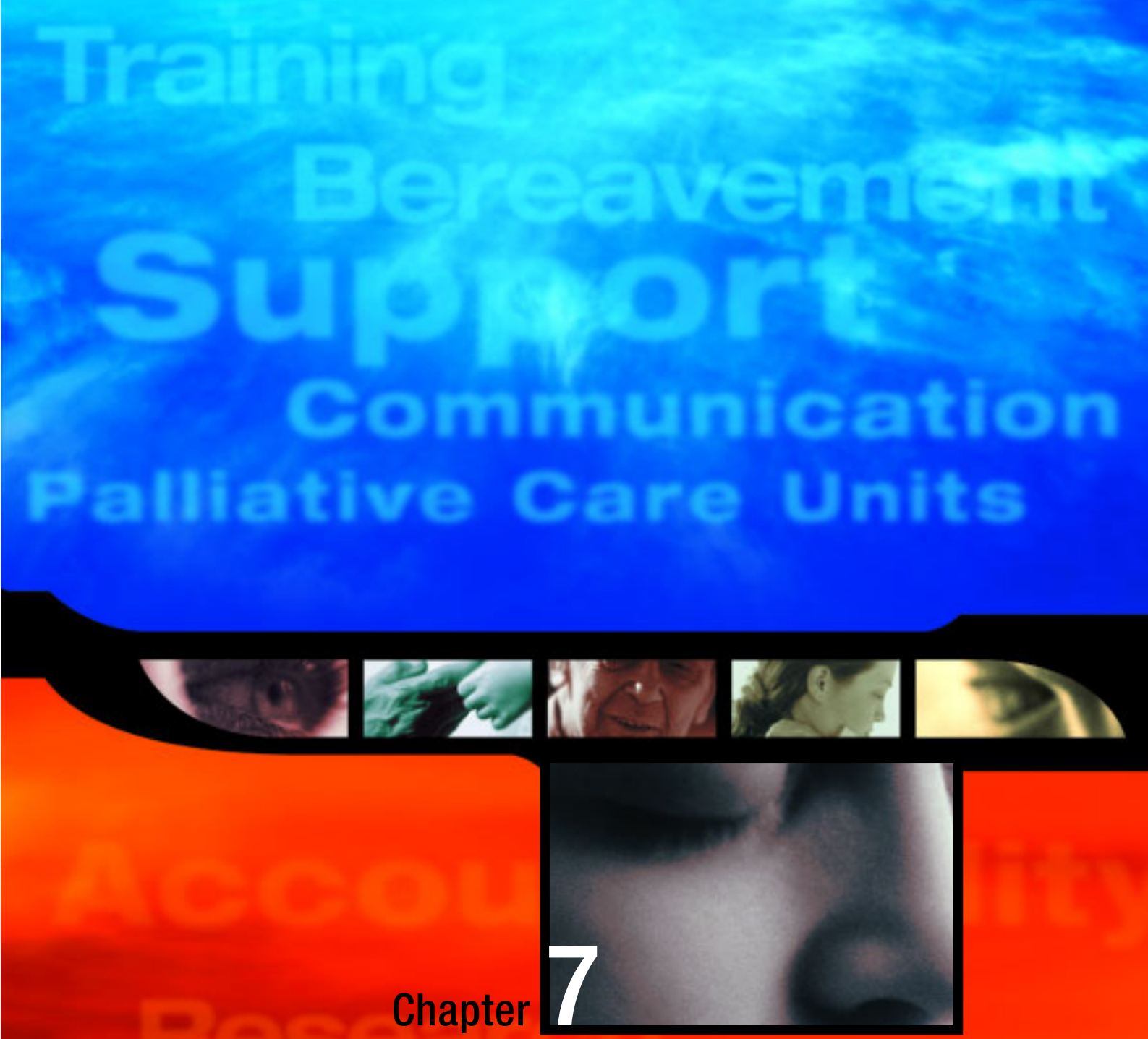
Specialist palliative care facilities should be sensitive to the needs of patients, families and staff. The environment should offer privacy to patients and their families when required.

An Expert Group on Design Guides for Specialist Palliative Care Settings should be established to inform all relevant parties, and to ensure a national consistency of standards for all specialist palliative care centres.

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Chapter 7

Specialist Palliative Care in Acute General Hospitals



Chapter 7

7.1 INTRODUCTION

Although most of the last year of life is spent at home, approximately 90% of patients dying from cancer are admitted to a hospital or hospice in their last year.[1] Hospital In-Patient Enquiry (HIPE) data from the Economic and Social Research Institute indicates that there were over 26,000 admissions to public hospitals in Ireland with a primary diagnosis of cancer in 1998.

It has been reported that 66% of all Irish deaths take place in hospitals or institutions.[2] Many more people die in hospital than in a designated palliative care unit. This makes the need for, and the benefits of specialist palliative care in a general hospital all the more important.[2]

This chapter describes the recommended specialist palliative care service in acute general hospitals. It describes a comprehensive hospital based specialist palliative care team, and how the team should function within the hospital. It recommends the development of integrated outpatients, which would allow the specialist team to become involved in patient care at an early stage.

Several problems have been identified in the delivery of services to palliative care patients in acute general hospitals. These are documented, and recommendations are made on how to improve the quality of care in hospitals.

7.2 PRINCIPLES

The Cancer Strategy[3] stated that the structured development of specialist palliative care services in acute hospitals would offer appropriate specialist input at a critical time for patients and their families.

In keeping with the principle that palliative care should be integrated into patient care at an early stage in the disease process, all acute general hospitals should have a specialist palliative care service. This service should meet the palliative care needs of the large number of patients with progressive disease who are admitted to hospital every year. The specialist palliative care service should focus on maximising quality of life for the patient, and offer advice to other health care professionals in the hospital. It should provide the support needed to help patients return home when appropriate, and provide a link to specialist palliative care teams working in the community.

7.3 SPECIALIST PALLIATIVE CARE TEAMS IN ACUTE GENERAL HOSPITALS

The concept of a “roving” hospice team working within the acute hospital sector emerged in New York in the mid 1970’s.[4] More recently, the Irish Hospice Foundation played a significant role in the development of palliative care teams in acute general hospitals in Ireland. It provided the initial funding for a number of palliative care nurses in several hospitals.

Hospital palliative care teams have evolved into specialist inter-disciplinary consulting teams, who offer advice and support to professional health care providers regarding the management of patients with progressive disease. Studies have shown that the introduction of a specialist palliative care team into general hospitals has resulted in improvements in the overall care of patients with terminal illness.[5,6]

The specialist palliative care team in the acute general hospital should consist of at least a consultant in palliative medicine, a specialist palliative care nurse, a social worker, and a secretary. While the consultant might be employed on a sessional basis, the specialist palliative care team would be based in the hospital and would function as an extension of the lead specialist palliative care unit for the region.

Patients should be referred to the specialist palliative care team for advice on symptom control, psychosocial support and problems relating to quality of life. The function of the specialist palliative care team is to act as a role model, sharing its knowledge and skills with hospital teams, and not to de-skill members of the ward team by taking over care.[4]

The specialist palliative care team should act as a resource for other services in the hospital, and offer education and training in palliative medicine to undergraduates, non-consultant hospital doctors, nursing staff and other disciplines, as required.

KEY RECOMMENDATION

The specialist palliative care team in an acute general hospital should consist of at least a consultant in palliative medicine, a specialist palliative care nurse, a social worker, and a secretary.

7.4 SPECIALIST PALLIATIVE CARE SERVICES IN ACUTE GENERAL HOSPITALS

Specialist palliative care services in acute general hospitals are at an early stage of development in Ireland. A number of hospitals have medically led specialist palliative care teams, while others are developing links with local palliative care units and home care services.

There are a number of consultant specialists with joint appointments between inpatient specialist palliative care units and acute general hospitals. More recently, there has been a consultant appointment that is regionally based, covering hospital and community services.

Currently, there are no designated beds in acute general hospitals for the specialist palliative care service. Patients remain on their own wards, under the care of their referring consultant.

The National Advisory Committee recommends that a specialist palliative care service should be available in all acute general hospitals. This service should be provided by a specialist palliative care team, which should be led by a consultant in palliative medicine. The consultant should be appointed for a defined minimum number of sessions per week.

KEY RECOMMENDATIONS

All acute general hospitals should have a consultant-led specialist palliative care service, offering advice and support to health care professionals in the hospital.

The specialist palliative care team should work alongside other hospital teams, complementing their work, rather than taking over care of the patient.

In smaller general hospitals, where it may not be feasible to employ a full-time specialist palliative care team, the specialist palliative care team serving the community should provide a service to patients requiring palliative care in the hospital.

Specialist palliative care services should also be accessible in other hospitals, such as psychiatric hospitals, orthopaedic hospitals, or maternity hospitals, where there may be patients with progressive disease who would benefit from specialist palliative care advice. It is envisaged that the consultant in palliative medicine would be available on a consultancy basis, and involve the specialist team as appropriate.

7.5 SPECIALIST PALLIATIVE CARE UNITS IN ACUTE GENERAL HOSPITALS

In some health board areas, a particular hospital may designate a ward or unit to function as the specialist satellite palliative care unit for the region for patients requiring specialist palliative care. This should be determined at regional level, depending on the needs of the area, and should be in keeping with the regional development plan for specialist palliative care.

These specialist units would have dedicated beds for palliative care patients, which would be taken from the total quota estimated for the health board area. The units would be led by a consultant in palliative medicine, supported by a full inter-disciplinary team.

7.6 INTEGRATED OUTPATIENT SERVICES

It is recognised that specialist palliative care services should be integrated with treatment services at an early stage of a patient's illness. One way of promoting this concept is to establish joint outpatient clinics, where patients would attend their consultant surgeon or physician and the specialist palliative care team at the same session. Other services would also be available where appropriate, e.g. radiotherapy, oncology, pain control, stoma therapy, breast care, etc.

This approach to service provision would promote the integration of services by facilitating the timely exchange of information between different service providers, and allow the patient access to a range of services at the one visit.

KEY RECOMMENDATION

Joint outpatient clinics should be established in acute general hospitals, allowing the specialist palliative care team to become involved in patient care at an early stage in the disease process.

Patients receiving palliative care may need to attend outpatient departments at regular intervals during the course of their illness. Waiting times for an appointment for outpatient services have been identified as a major problem for people requiring palliative care.[7,8] This issue is of particular importance for those with a short prognosis, who would be unable to wait several weeks for appointments. Arrangements should be made to "fast-track" outpatient appointments for patients receiving palliative care.

Patients receiving palliative care should not have to wait in outpatient departments for lengthy periods of time. Ideally, they should be given a specific outpatient appointment time and be seen as close to this time as possible.

KEY RECOMMENDATION

Arrangements should be made to "fast-track" outpatient appointments for patients receiving palliative care.

7.7 ACCESS TO HOSPITAL BEDS

Access to hospital beds can sometimes pose problems for patients, especially those with a short prognosis, for whom a long wait would be entirely inappropriate. Patients may require planned admission for surgical procedures, such as the insertion of a feeding tube. The concept of "fast-tracking" patients who are in the care of specialist palliative care services should be introduced.

In situations where a patient might require the services of several disciplines within the hospital, there should be one point of entry to the services, and subsequent referrals should be speedily organised.

Hospital admission policies should be sensitive to the needs of patients with advanced disease. Direct admission to a hospital bed should be facilitated for patients receiving specialist palliative care, particularly those with advanced disease. There should be minimum delay in waiting times for a hospital bed.

KEY RECOMMENDATION

There should be one point of entry to hospital services for palliative care patients, and subsequent referrals should be speedily organised.

7.8 ATTENDANCE AT A&E DEPARTMENTS

It may sometimes be necessary for a patient to be assessed in the Accident and Emergency (A&E) department of a hospital prior to admission to the most appropriate service. Studies have been critical of the long delays for palliative care patients in A&E departments.[2] Arrangements should be made by the referring doctor with the receiving hospital prior to transfer of the patient. There should subsequently be rapid assessment of the patient's condition in A&E with subsequent "fast-tracking" of the patient to the appropriate service.

Developments in information technology should be used to allow rapid access to medical records. This would facilitate the rapid assessment of patients by admitting teams.

KEY RECOMMENDATION

In A&E, the patient's condition should be rapidly assessed, and the patient should be referred to the appropriate team without delay.

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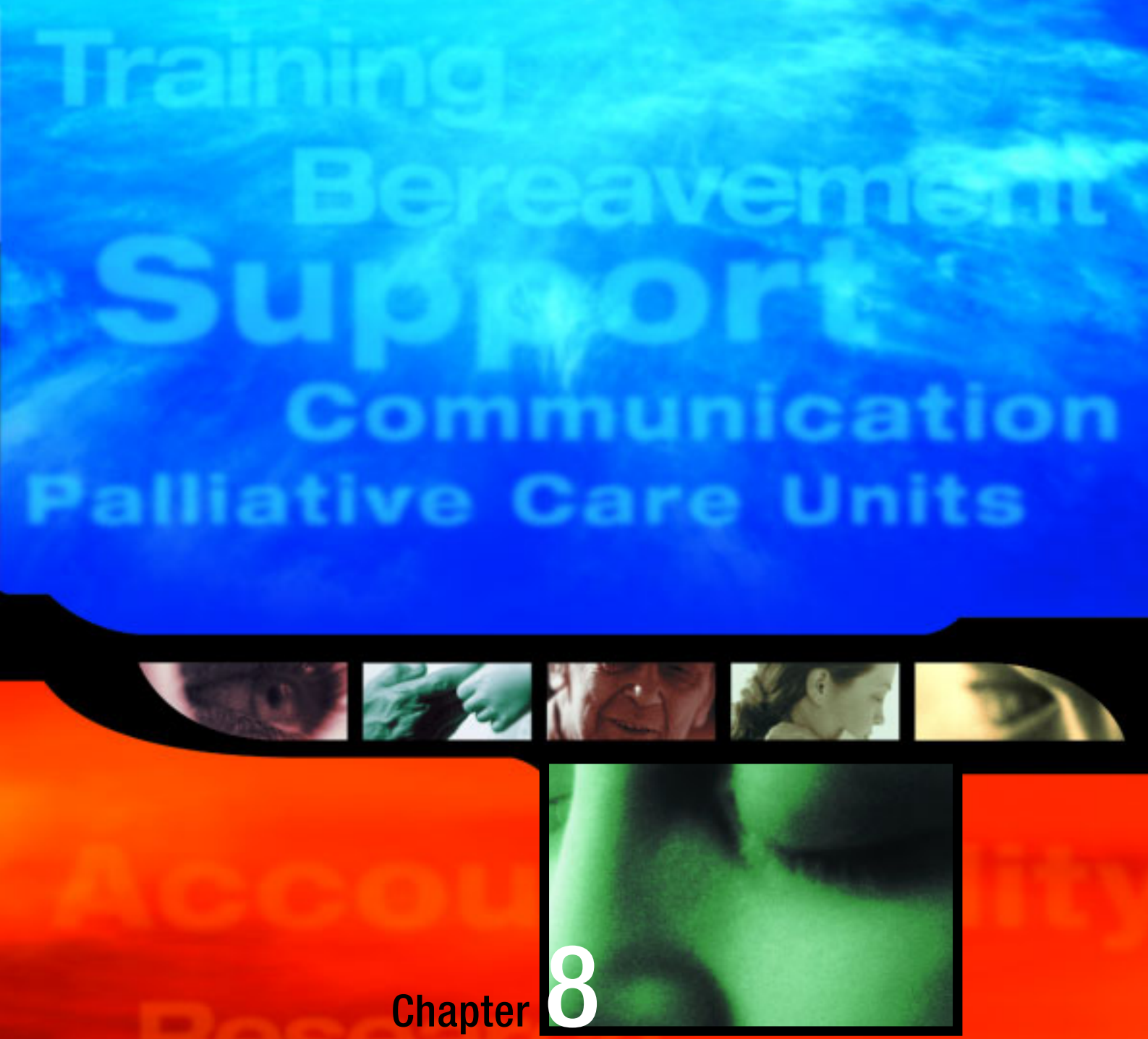
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Chapter 8

Palliative Care in the Community



Chapter 8

8.1 INTRODUCTION

The 1994 Health Strategy[1] put a strong emphasis on the further development of community services for palliative care, based on the principles of health and social gain. It encouraged the provision of integrated care, with a move towards the provision of care in the community, as an alternative to long-term institutionalised care.

The 1996 Cancer Strategy[2] acknowledged that most palliative care is likely to be delivered in the primary care setting. Studies have indicated that over 90% of people with terminal illness spend most of their final year of life at home.[3,4] Studies have also found that most people would prefer to die at home[5,6] but less than a quarter of people actually achieve this.[5]

There are many factors that prevent patients from receiving adequate care in the community and which result in the admission of patients to hospitals, nursing homes or specialist palliative care units. The main reason has been identified as lack of support for carers in the community.[3,5,7]

This chapter describes the delivery of palliative care to patients in the community. It documents the roles of the main health care providers, and makes recommendations with regard to the future delivery of specialist palliative care services in the community. The chapter also examines some of the barriers to efficient care in the community, and offers some solutions to these problems.

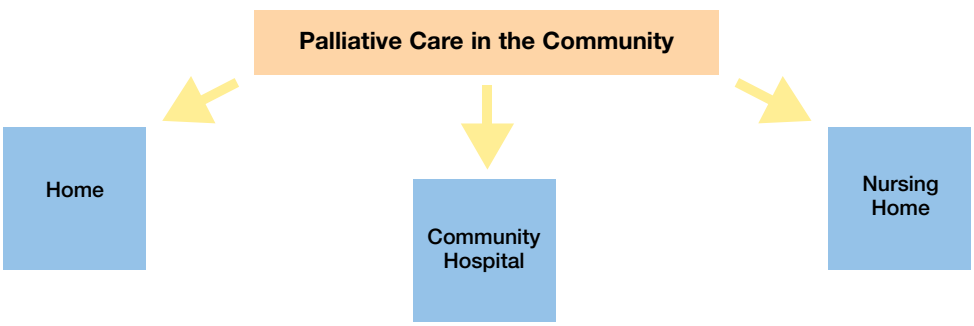
8.2 PRINCIPLES

One of the main principles of the Cancer Strategy[2] is to provide palliative care services to patients in a setting of their choice. The development of community-based palliative care services is vital in the future development of palliative care services in order to best meet the needs and personal preferences of patients with cancer or progressive life-threatening disease of other aetiologies.

Specialist palliative care services should be available to all palliative care patients living in the community - be it at home, in a nursing home, or in a community hospital. There should be a specialist palliative care team working in the community in all health board areas. Adequate support should be available in the community for patients and families to enable patients to remain at home, if that is their wish.

8.3 PALLIATIVE CARE IN THE COMMUNITY

The majority of care in the community is provided by the general practitioner and public health nurse,[3,8] but increasingly the specialist palliative care nurse has become involved in the care of patients with advanced disease. Other disciplines are also involved in the care of patients in the community to varying degrees. These include the physiotherapist, the occupational therapist, the speech and language therapist and social workers.



8.3.1 THE GENERAL PRACTITIONER

The general practitioner has overall responsibility for the medical care of patients in the community. In caring for patients in the community, the general practitioner liaises closely with other community-based health care professionals, and also with hospitals and nursing homes.

KEY POINT

The general practitioner has overall responsibility for the medical care of patients in the community.

Not all patients with advanced disease require the services of the specialist palliative care team. For many patients in the community, the general practitioner is adequately trained to care for their needs, without referral to specialist palliative care services. However, there is a group of patients with complex psychosocial issues or difficult symptom control who will clearly need specialist palliative care.[9]

The general practitioner should involve the services of the specialist palliative care team when required. Clinical responsibility for the patient, however, remains with the general practitioner. While the specialist palliative care team might make suggestions regarding medication and other aspects of patient care, the decision to implement these decisions is at the discretion of the general practitioner.

The general practitioner has a responsibility to ensure good continuity of care to patients in the community.[10] In the event of a general practitioner being covered by a locum or deputising service, it is essential that there is full exchange of information regarding any patient who is receiving palliative care, particularly in the later stages of disease, to ensure continuity of care.

Continuing medical education in the palliative care field is important for general practitioners who provide ongoing care for their patients in the community. Some general practitioners may decide to study for a diploma in palliative care, and act as a resource for other general practitioners in the area, and for local community hospitals. This should be facilitated by the relevant health board.

8.3.2 THE PUBLIC HEALTH NURSE

The public health nurse plays an important and integral role in the delivery of palliative care to patients in the community. Public health nurses carry out a diverse range of nursing services, responding to the needs of individuals, families and the community. Nursing care is provided in the community on the basis of need, as assessed by the public health nurse, taking into account the type and level of illness, the social supports available to the patient, and the carer's ability to cope.

The public health nurse is responsible for a particular geographical area. She has ready access to the homes and families in her area, and has an important role in building links with other professionals and services in the community.

KEY POINT

The public health nurse provides nursing care to patients in the community on the basis of need.

As well as providing nursing care, the public health nurse advises patients and their families about other services in the community or financial assistance available, and how to access these. The public health nurse is a key person in accessing aids and appliances in the community.

The public health nursing service is provided five days a week. At weekends and public holidays, a rostered public health nurse provides a limited service to patients who require nursing care on a daily basis. This usually involves pre-planned calls to particular patients in the area.

Referrals to the public health nurse may come from the general practitioner, general or community hospitals, other community-based health care professionals, family members or the patients themselves.

In the case of patients requiring palliative care, the public health nurse may work in collaboration with the specialist palliative care nurse, and may also receive support from the specialist palliative care team, if there is one in the area. This support may be in the form of information and advice regarding particular problems. There is also support from the specialist palliative care unit in the form of education and training in palliative care.

Continuous education in the area of palliative care is very important for all public health nurses. This educational input should be facilitated and adequately funded by the relevant health board.

8.3.3 THE SPECIALIST PALLIATIVE CARE TEAM

The evolution of specialist palliative care in Ireland has resulted in the development of a specialist palliative care team in the community. The first multi-disciplinary team was established by the Sisters of Charity at Our Lady's Hospice, Dublin in 1985.[11]

This team was traditionally known as the "home care team" and funding for these services was largely raised locally by charities and support groups. The Irish Cancer Society has played a significant role in funding and developing palliative care nursing services, including night-nursing services, for patients with terminal cancer in the community.

The specialist palliative care team in the community should be an inter-disciplinary consultant-led team, consisting of nursing staff and at least a physiotherapist, an occupational therapist and a social worker. All team members should be trained in specialist palliative care.

The specialist palliative care team should be based in the specialist palliative care unit in the area. It should bring the skills and resources of the unit to the patient in his or her setting in the community. In some areas, the specialist palliative care team may be based in satellite palliative care units as discussed in Chapter Six.

The specialist palliative care team should work in support of and in collaboration with established community health care professionals. The aim of the service is to support patients who choose to be cared for, and sometimes die in their own homes, in a local community hospital, or in a nursing home.

Specialist palliative care teams in the community may receive referrals from general practitioners and hospital consultants. When a referral is made by a hospital consultant the specialist palliative care team should liaise with the patient's own general practitioner. Early referral to the specialist palliative care team in the community is strongly recommended, as good palliative care should be available in the earlier stages of illness, both for the patient and his or her family.



KEY RECOMMENDATIONS

The specialist palliative care team in the community should be an inter-disciplinary consultant-led team.

The specialist palliative care team should be based in, and led by, the specialist palliative care unit in the area.

Currently, there are over 120 nurses working in support of palliative care in the community. The majority of these nurses are trained as specialist palliative care nurses. The composition of the palliative care team varies throughout the country. Few teams have the optimal level of staffing recommended for a specialist palliative care team, most teams consisting of palliative care nurses only.

8.3.4 THE SPECIALIST PALLIATIVE CARE NURSE

The specialist palliative care nurse plays a key role in the specialist palliative care team. This role is to provide information, advice and support to patients and families, and extends to bereavement support of families or individuals following the death of a patient, where appropriate.

The specialist palliative care nurse acts as a resource for other community service providers, and a liaison between the community services and the specialist palliative care unit. The specialist palliative care nurse supports and advises primary care health professionals in the community. The advisory role of the specialist palliative care nurse is particularly important in relation to symptom control.

KEY POINT

The specialist palliative care nurse provides information, advice and support to patients, families and health care professionals in the community. This extends to support in bereavement.

The specialist palliative care nurse may provide educational updates for other health care professionals in the community. General public information talks are also frequently requested and provided.

Families of patients who suffer from cancer may also receive additional support from the Irish Cancer Society in the form of nursing care at night. Currently the Irish Cancer Society will fund payment for five nights of nursing care to patients dying from cancer. The night nursing needs of patients dying from non-malignant disease will require examination, particularly when palliative care services are extended to include the care of patients with non-malignant disease.

8.4 PALLIATIVE CARE IN COMMUNITY HOSPITALS

Support beds for palliative care patients are provided in a number of community hospitals around the country. Patients may be admitted to these beds following discharge from acute general hospitals for further nursing care. They may also be admitted from the community for symptom control. Community hospitals also provide respite for patients and carers, when patients are being cared for at home.

The medical care of patients in community hospitals is provided by general practitioners. In some community hospitals a patient's own general practitioner may provide this care; in other community hospitals a designated general practitioner or practice may be employed on a sessional basis to look after the medical needs of all patients in the hospital.

The specialist palliative care team working in the community may be involved in the patient's care when appropriate. The team offers support and advice to the doctors and nurses in the community hospital.

In areas where there is no specialist palliative care team, improvements in tele-communications should be made to facilitate contact between the community hospital and the specialist palliative care unit. The development of a video-link would be invaluable in accessing advice and expertise, particularly in rural areas, where transport to a specialist palliative care unit would be difficult.

The National Advisory Committee recommends that community hospitals should have designated beds for palliative care patients who require an intermediate level of inpatient care. Facilities in local community hospitals should be upgraded, with provision made for privacy for patients and their families, when required.

Formal links should be established between community hospitals and the specialist palliative care teams in the area. Staff members of community hospitals should be enabled to undertake some formal training in palliative care, such as a diploma in palliative care. This should be funded by the relevant health authority. Specialist palliative care units should recognise the training needs of staff in community hospitals, and offer support when required.

KEY RECOMMENDATION

Community hospitals should have designated beds for palliative care patients who require an intermediate level of inpatient care.

8.5 PALLIATIVE CARE IN NURSING HOMES

Patients are sometimes admitted to nursing homes when their nursing care needs can no longer be adequately provided for at home. Patients may also be admitted to nursing homes as an interim measure following discharge from hospital or from specialist palliative care units. Some patients may be admitted on a short-term basis for respite care.

Generally, the patient's own general practitioner provides medical care to patients in the nursing home. A proportion of patients in the nursing home setting may require palliative care. General palliative care is provided by the nursing staff in the nursing home, with the support of the general practitioner. Some nurses may have additional training in palliative care, such as a diploma in palliative care.

The specialist palliative care service may be involved in the patient's care when appropriate. This may be in the form of consultation with the staff of the specialist palliative care unit, or may involve visits to the nursing home by the specialist palliative care team in the community.

8.6 CO-ORDINATION OF SERVICES IN THE COMMUNITY

The quality of care delivered in the community is dependent both on the effectiveness of each individual service and the co-ordination between them. Lack of co-ordination between the services disrupts continuity of care, leads to unnecessary admissions or prolonged stay in hospitals, and may have a negative impact on the quality of life of patients and their families. Unco-ordinated services may result in the duplication of services to some patients and lack of services to others.[12]

An inter-disciplinary team approach in the community is important in order to provide a seamless and efficient service to patients and their families. Health care professionals in the community should share a common set of goals and objectives.

Ideally, an individual care plan should be drawn up for each patient being cared for in the community, and all primary care providers should work from this care plan. This care plan should be regularly reviewed, in consultation with other service providers, in order to respond to a patient's changing needs.

The role of the specialist palliative care nurse frequently overlaps with that of the public health nurse. The concept of "shared care" should be promoted to avoid duplication of services, and ensure that patients are not overcrowded in their own home. Communication between health professionals in the community is further discussed in Chapter Eleven.

KEY RECOMMENDATION

The concept of "shared care" for patients receiving palliative care in the community should be promoted.

8.7 SUPPORT FOR THE PATIENT AND FAMILY AT HOME

Many patients express a preference to be cared for at home, assuming that their health needs allow this, and that they have adequate family and community support. Social and demographic changes in recent years have resulted in a smaller pool of available carers at home, and more demands on those who are available. Homes and families are smaller, many women are working outside the home, and there is more migration of family members.[13]

Although care has improved greatly over recent years, deficits still exist - namely, lack of early domestic support, lack of financial advice, lack of information about resources outside the health service, and lack of practical support.[7]

Studies found that the difficulties of relatives were more often a cause for hospital admission than those of the patients.[14] Others found that support at home produced the strongest influence on place of death, with nursing and social services support, access to specialist equipment, and receipt of an attendance allowance all showing statistically significant effects.[5]

Further obstacles to care in the community include access to community-based services, and access to equipment or medicines in the community, which may be necessary for the adequate care of a patient at home. There are a number of supports for patients and carers that could be introduced to make care at home an easier option, thereby reducing unnecessary hospital admissions.[4] These are discussed below.

8.7.1 ACCESS TO SPECIALIST PALLIATIVE CARE ADVICE

Access to specialist palliative care advice outside office hours is important to health care professionals in the community.[10,15,16] Arrangements should be made for health care professionals to have access at all times to specialist advice.[16]

The National Advisory Committee recommends that specialist palliative care nurses should provide a seven-day service to patients in the community. The service should be expanded from the current level of service provision at weekends and on public holidays.

In areas where a specialist palliative care nurse may not be available in the community at all times, a telephone advisory service should be provided by the specialist palliative care unit to provide 24-hour access to specialist advice.

KEY RECOMMENDATION

Specialist palliative care nurses should provide a seven-day service to patients in the community.

8.7.2 ACCESS TO PARAMEDICAL SERVICES IN THE COMMUNITY

Patients who choose to stay at home rely on community-based services. In the community, physiotherapists and occupational therapists play a role in many aspects of home care, such as assisting mobility, pain relief, and making recommendations on adaptations to the home if required. Social workers offer advice and support on psychosocial issues to patients in the community. Paramedical services are often inadequate to meet the needs of patients in the community, providing a very limited service, with very long waiting lists.

The National Advisory Committee recommends that each specialist palliative care unit should develop its own physiotherapy, occupational therapy and social work departments, which would also meet the needs of patients in the community. The physiotherapist, occupational therapist and social worker involved with palliative care patients in the community should be based in the specialist palliative care unit. This would ensure continuity of care for patients when they move from one care setting to another, and enable easier access to these services.

KEY RECOMMENDATION

Each specialist palliative care unit should develop its own physiotherapy, occupational therapy and social work departments, which would also meet the needs of palliative care patients in the community.

8.7.3 AIDS AND APPLIANCES IN THE COMMUNITY

The availability of aids and appliances in the community is currently limited. This is particularly relevant to palliative care patients, whose life expectancy may be limited to days or weeks, and for whom a delay in accessing aids and appliances would be inappropriate.

The National Advisory Committee recommends that each health board should have a sufficient bank of equipment to meet the needs of palliative care patients in the community. This equipment should be easily

accessible to palliative care patients. There should be an identified key holder to the community stores to enable access to equipment at weekends.

In addition, all specialist palliative care units should have their own small bank of aids and appliances to facilitate rapid access to equipment. These aids and appliances could be rotated, as they may not be required for long periods of time in any particular household. The units should also keep a number of syringe drivers, which could be made available to general practitioners when required.

A defined, agreed budget should be provided in each health board area for the provision of aids and appliances to palliative care patients. This budget should include maintenance, collection and delivery of equipment. The budget should be reviewed on an annual basis.

KEY RECOMMENDATION

Each health board should have a sufficient bank of equipment to meet the needs of palliative care patients in the community.

8.7.4 ACCESS TO MEDICINES IN THE COMMUNITY

Community pharmacists and primary care health professionals have identified several issues regarding the availability of medicines in the community. Pharmacists have identified problems in communication between the specialist palliative care unit or hospital and primary care health professionals, including pharmacists.

There should be prior notice of discharge to the local pharmacist to ensure that adequate supplies of medications are available locally. This would involve some communication between the hospital and community pharmacist prior to discharge. This is particularly important at weekends.

Occasionally, there may be some difficulty in accessing infrequently used drugs in the community. A small supply of infrequently used medications should be available to local pharmacists when needed by patients requiring palliative care. These could be stocked by the local hospital, the specialist palliative care unit or a designated pharmacy. Local arrangements should be formalised to ensure that patients receiving palliative care have access to all necessary medications as and when required.

Patients requiring palliative care often need strong analgesics for relief of pain. It is the responsibility of general practitioners to prescribe such medications for patients. The general practitioner, in collaboration with the specialist palliative care nurse, should try to anticipate a patient's need for analgesia and other drugs in advance, and plan accordingly. When the need for these drugs is anticipated, it may be appropriate to leave a supply in the patient's home for emergency use by community nursing staff.[16]

KEY RECOMMENDATION

Local arrangements between pharmacists in specialist palliative care units, hospitals and in the community should be formalised to ensure that patients receiving palliative care have access to all necessary medications as and when required.

8.7.5 CARE ATTENDANTS

Physical and emotional exhaustion of the principal carer is an important issue.[10] Much carer breakdown is preventable by better planning and provision of support services. Development of carer services would help to alleviate stress for many families and carers.

The provision of help for carers, such as trained care attendants or companions, could postpone or even prevent admission to inpatient facilities, if such was the preference of the patient and family. These care attendants could provide extra help for the family in caring for the patient, for example with washing, dressing and feeding, and could also provide some respite for carers.

Night-sitters would be invaluable in relieving carers of their responsibility for the night and allowing some respite.[13] High dependency care at night could be provided by care attendants or by trained registered nurses, depending on the complexity of care required.[16] Patients' needs should be matched with the skill level required.

The role of care attendants should be clearly defined and stated to avoid confusion and potential difficulties for both the family and health care professionals. Care attendants should be properly screened, selected and trained for their involvement with palliative care patients.

KEY RECOMMENDATION

Care attendants should be available to support families of palliative care patients in the community.

8.7.6 RESPITE CARE

Access to respite care is very important to patients and families. Respite facilities provide an opportunity to re-assess symptoms, and provide an opportunity for rehabilitation for the patient.[16] Respite has the additional benefit of providing a change of environment, which is stimulating for the patient. Respite care enables more patients to be cared for in their own home, by providing carers with a much needed rest.

Respite care may be accessed by attendance at a day care centre, admission to a specialist palliative care inpatient unit or admission to a community hospital. Local respite care is particularly important, as it allows patients to be close to their families and friends. The National Advisory Committee recommends that adequate respite care be available locally to all patients with advanced progressive disease.

KEY RECOMMENDATION

All palliative care patients should have adequate access to respite care in a setting of their choice.

8.7.7 TRANSPORT

Transport to and from hospital for outpatient appointments or to day care centres is frequently a problem for patients in the community. Arrangements should be made for the transport of patients receiving palliative care to different care settings, when required. Funding should be provided by the health board to assist patients with transport to and from specialist palliative care services.

Transport to other health board areas for services that are not available in the patient's own health board, can be a major problem. Protocols for transport between different health board areas should be developed, and arrangements made to refund patients for any expenses incurred.

KEY RECOMMENDATION

Arrangements should be made for the transport of patients receiving palliative care to different care settings, when required.

8.7.8 HOME ADAPTATIONS

Managing a patient at home requires more than an assessment of the patient's symptoms; it also requires an assessment of the patient's home. This may require the visit of an occupational therapist to advise on the need for suitable aids and, if necessary, modifications to the home.[16]

Palliative care patients should have their homes assessed by an occupational therapist, if appropriate, and should be advised of any adaptations that may be required to make the accommodation more suitable to their needs. Applications for housing grants should be processed as a priority.

KEY RECOMMENDATION

There should be a "fast-track" system in place to enable patients with advanced disease to access grants for housing alterations.

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Chapter 9

Bereavement Support



Chapter 9

9.1 INTRODUCTION

The principles of a palliative care philosophy take a holistic view of health care in the lead up to, and aftermath of a person's death. The emphasis placed on family centred care means that continuing support after a patient's death is an integral component of palliative care.[1] In the context of palliative care, the family is defined as any person who is significant to the patient.

The Irish Hospice Foundation played a significant role in the development of bereavement support services in Ireland. It currently provides a bereavement support service in a number of specialist palliative care units, and also provides national education and training programmes in bereavement support. It also supports the work of HEBER, which is the Association for Hospice and Allied Bereavement Groups in Ireland.

This chapter describes the levels of support that may be needed by individuals and families before and after a patient's death. It also describes the main providers of bereavement support. It documents the aims of bereavement support and makes recommendations regarding its delivery.

9.2 PRINCIPLES

Bereavement support is an essential part of palliative care and should be incorporated into all specialist palliative care programmes. Bereavement support should begin early in the disease process, long before the death of the patient.

Bereavement support should be available in all settings where specialist palliative care is offered. This includes specialist palliative care units, general hospitals, community hospitals and within the home care setting.

9.3 BEREAVEMENT SUPPORT

The aim of bereavement support is to rehabilitate individuals and families before and after the death of a loved one. Not every family member or friend of a deceased person needs bereavement counselling.[2] The majority of bereaved people are able to manage with the help of family and friends. However, a substantial minority may be at risk of long-term disruption of their physical and psychological well-being and social functioning.[3]

Prevention of complex bereavement problems is an important component of bereavement support. This can be achieved by anticipating severe grief reactions, and preparing the family for the loss of their loved one. This may include facing unresolved issues, and encouraging the family to say goodbye. Privacy at the time of death is also important in the grief process.

Bereavement services should be particularly attentive to the needs of children and adolescents, whose way of understanding, expressing and coping with grief may be quite different to that of adults. Bereavement services should also recognise and facilitate cultural differences.

KEY RECOMMENDATIONS

Bereavement support should be an essential part of all specialist palliative care programmes and should be available in all settings where specialist palliative care is offered.

Bereavement support should begin early in the disease process, long before the death of the patient.

9.4 LEVELS OF BEREAVEMENT SUPPORT

The Irish Hospice Foundation, in its submission to the National Advisory Committee, described three levels of support, based on its long experience in bereavement support, consultation with colleagues involved in similar work, and through research in this area. These levels are applicable to the minority of people who may require bereavement support.

The **first level** is general bereavement support. This can be provided by well-trained staff and supervised volunteers. It is not counselling, although trained bereavement support volunteers will draw on appropriate counselling skills. It may be particularly valuable to those who lack social support or feel isolated from potential sources of support. This level would adequately meet the needs of the vast majority of those who require bereavement support.

The **second level** is bereavement counselling, which should be provided by suitably qualified staff attached to a specialist palliative care service or in the community. This counselling would be appropriate for those whose loss is more complicated, perhaps by the presence of additional stressors in their lives or inadequate coping mechanisms.

The **third level** involves more intensive psychotherapy, requiring referral to specialist health professionals. This may occur in situations where a loss triggers an underlying layer of dysfunctional behaviour or a more pervasive emotional crisis.

Implicit in these three levels of support is the use of risk assessment, which can be used to guide discussions with individuals or families about the level of bereavement care that might be most suitable for them. Assessment of need for bereavement support should be routine in specialist palliative care services. Mechanisms to help professionals anticipate severe grief reactions should be developed. Counselling should be targeted at those in high-risk categories.[4]

9.5 PROVIDERS OF BEREAVEMENT SUPPORT

Bereavement services should be organised to meet a range of needs. The range of services provided by specialist palliative care services includes group work, one to one counselling, telephone contact, social activities, mutual support groups and written information about bereavement and grief. Non-structured bereavement support is also provided by all specialist palliative care staff.

Appropriately trained staff such as social workers, psychologists and professional counsellors may each play a role in bereavement support in different settings, and at different levels. Specialist palliative care nurses also play a role in bereavement support, both in specialist inpatient units and in the community.

Volunteers may be trained to provide general bereavement support to family and carers. Volunteers provide emotional support, information about grief, and help with managing all the life changes triggered by loss.

An appropriate member of staff should be nominated as bereavement service co-ordinator. This person should also be responsible for the selection, training, supervision and assignment of all volunteers involved in bereavement support.

KEY RECOMMENDATIONS

Bereavement support should be provided by appropriately trained personnel from the available pool of staff in each service.

Assessment of need for bereavement support should be routine in all specialist palliative care services.

A system for the accreditation and regulation of bereavement counsellors should be introduced to ensure the delivery of the best quality of bereavement support.

Provision should be made for the education and training of all staff involved in bereavement support.



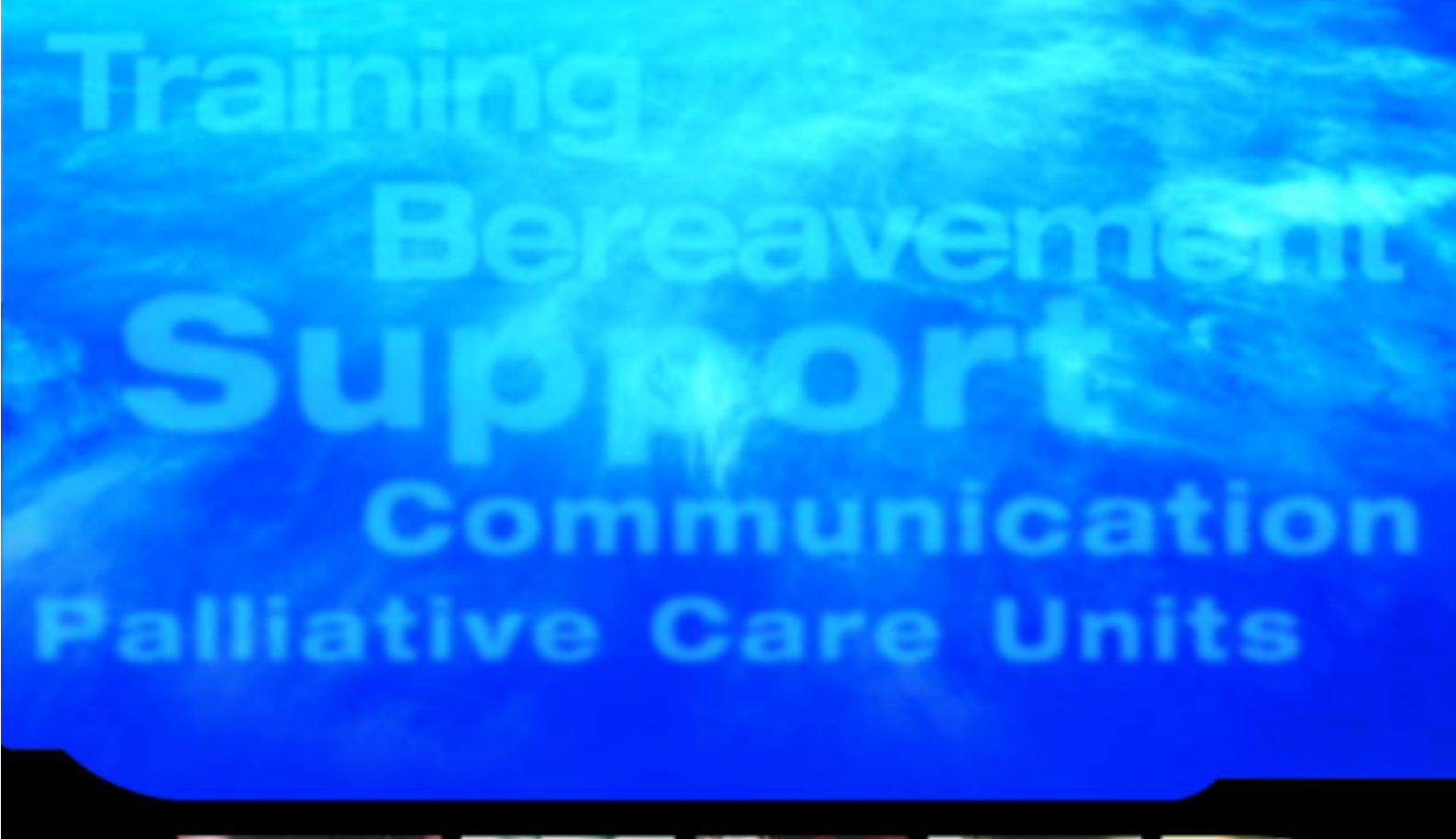
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Chapter 10

Education, Training and Research



Chapter 10

10.1 INTRODUCTION

Education is a core component of specialist palliative care. The importance of disseminating the principles of palliative care is central to the philosophy of empowering not only other health care professionals but also the patient, family and carers. Similarly, the application of research findings encourages the growth and development of a specialty and is a critical element in defining a specialist palliative care service.

A strategy for developing education and research in palliative care in Ireland is vital to enable the specialty to develop to its full potential. In broad terms this requires the current stakeholders, namely specialist palliative care services, universities, professional bodies and charities to work together towards supporting the provision of continuing educational and research opportunities for those who work in this area.

There should also be a commitment from both statutory and voluntary bodies to support education and research in palliative care in all disciplines.

This chapter briefly documents the current situation regarding education and research in palliative care in Ireland. It describes the recent changes in nursing education and training in Ireland. Finally, it makes recommendations with regard to the future direction of education and research in the specialist palliative care services.

10.2 EDUCATION AND TRAINING

Palliative care is quite different from any other area of health care practice. The needs of patients and families receiving palliative care are often diverse. In delivering palliative care, these needs are often best addressed by multi-professional teams rather than by single practitioners. These different professional groups will have areas of common interest, but require different levels of specialist knowledge.

The establishment of a number of academic departments of palliative medicine is essential to the overall development of the specialty. These should offer inter-disciplinary educational opportunities to all health care providers involved in the delivery of palliative care. The National Advisory Committee recommends that academic departments of palliative medicine should be established in each medical faculty to develop and support education and research in all disciplines.

The culture of continuing professional education and development should be promoted in all areas of palliative care. Continuing education should be the joint responsibility of both staff and employers.

Specialist palliative care libraries should be further developed, with up-to-date information technology, to access information on palliative care. Funding should be made available to develop an educational website in palliative care that could be a resource for all.

KEY RECOMMENDATION

Academic departments of palliative medicine should be established in each medical faculty, with the development of inter-disciplinary courses for all professionals involved in the delivery of palliative care.

10.2.1 MEDICAL EDUCATION

Medical undergraduates receive limited formal teaching in palliative medicine from consultants who hold lecturer appointments. They may also have the opportunity to visit their local palliative care unit. The number of hours devoted to palliative medicine during the student's time at university is very small and is inadequate. A core curriculum for medical undergraduates should be developed and should be introduced throughout medical undergraduate training.

With regard to post-graduate education, general practice (GP) trainees generally have some teaching on palliative care from general practice (GP) trainers. More recently, a distance-learning module has been successfully introduced by the Irish College of General Practitioners (ICGP). The National Advisory Committee recommends the continued development of the ICGP palliative care programme.

Non-consultant hospital doctors (NCHDs) may have occasional lunchtime lectures and, depending on location, may interface with a hospital-based specialist palliative care team. Further training in palliative care should be developed for NCHDs in all specialties, with a particular emphasis on communication skills.

Specialist registrars in palliative medicine have a defined curriculum and training programme with supervision from a consultant trainer. The Committee recommends the creation of new lecturer posts at specialist registrar level to allow specialist registrars increased opportunities for education and research.

10.2.2 NURSING EDUCATION

The appointment of a nurse tutor to Our Lady's Hospice, Dublin, in 1987 was the first formal recognition of the importance of palliative care education for nurses. A purpose built education unit was developed, supported by the Irish Hospice Foundation, facilitating formal palliative care education. Palliative nursing is now formally recognised as an accredited specialty.

Irish nursing is currently undergoing a significant change from the perspective of education. This change will transfer learning from schools of nursing to third level university programmes. There is now a third level course in palliative nursing, the Higher Diploma in Nursing Studies (palliative nursing) offered by University College Dublin, in partnership with Our Lady's Hospice. On completion, students may proceed to further studies to obtain a Bachelor Degree or a Master Degree. A similar programme was introduced by University College Cork in 1999.

The Report of the Commission on Nursing[1] recommended two levels of specialist nurse and highlighted a perceived level of academic attainment to underpin this:

- Clinical Nurse Specialist - education to Diploma/Bachelor level with at least five years clinical experience in the area of the specialty

- Advanced Nurse Practitioner - education to Masters level and holding at least ten years experience

It is recognised that specialist palliative nursing is a new and evolving specialty, and that nursing education in this area of care is in its early stages. Therefore, as an interim measure, the National Advisory Committee recommends that services should recognise the practical experience of senior nurses who do not hold recognised post-registration qualifications, when appointing nurses to senior posts in the specialist palliative care service.

The Committee recommends that each specialist palliative care unit should be encouraged to set up a nursing practice development unit to develop, implement, and monitor nursing practice in the unit. A clinical practice development co-ordinator should be employed in each specialist palliative care unit to develop a nursing practice development unit and quality assurance programmes, and to co-ordinate student placements.

The Committee recommends that specific palliative care university courses should be developed in collaboration with service providers, which should meet the needs of nurses wishing to acquire different levels of academic education. Nurses in specialist palliative care posts should be enabled to develop their professional expertise.

10.2.3 PARAMEDICAL EDUCATION

An inter-disciplinary team approach is central to the provision of palliative care services. Existing training opportunities for paramedical professionals who work in palliative care are very limited. Placement of undergraduate students from different disciplines in specialist palliative care settings would be of benefit. This has already been piloted in the Social Work Department of Our Lady's Hospice, Dublin.

The National Advisory Committee recommends that additional places for paramedical training should be provided as an urgent measure to meet the requirements of specialist palliative care services.

The development of university based courses, such as an inter-disciplinary diploma in palliative care, would also improve access to educational opportunities for paramedical staff.

10.2.4 CARE ATTENDANTS

Specific recognised courses in core caring skills should be offered to care attendants working in specialist palliative care units, community hospitals, nursing homes and those working with patients in the home environment.

10.2.5 INFORMAL CARERS

Care is often provided at home by informal carers, such as a relative, partner or friend. There are no formal educational opportunities for carers to help them cope with this demanding role. The palliative care professional involved with the patient should have a role in educating carers about the relevant issues involved in their area of expertise.

10.3 RESEARCH IN PALLIATIVE CARE

There is currently little in the way of structured palliative care research taking place in Ireland. The basis for much palliative care practice is anecdote and history rather than scientific method and evidence based research. New structures should be put in place to encourage and facilitate greater participation in palliative care research with a view to improving the quality of care offered to patients and their families.

All health care professionals working in palliative care should have the opportunity to engage in research in order to develop evidence based practice, leading to improved quality of care for patients and their families. Research should be included in all nursing and medical curricula.

Each specialist palliative care service should designate one person, usually a senior clinician, to have overall responsibility for research and development. Each service should determine its own research priorities and where possible, should link with existing institutes to access specialist expertise.

A number of research centres, linked to academic departments of palliative medicine, should be established. These should have access to all the specialties (e.g. epidemiologists, statisticians) necessary to carry out quality research.

Close co-operation between different palliative care research groups is important. The pooling of resources would make it possible to overcome small sample sizes. Research findings would be more valid if the study reflected different geographical influences. A comprehensive network of research groups would also provide support and advice for each other, and provide an opportunity to co-operate in multi-centre trials.

The Committee recommends that palliative care representatives should be included in the proposed Health Research Board National Research Forum.

KEY RECOMMENDATIONS

All health care professionals working in palliative care should have the opportunity to engage in research.

A number of research centres, linked to academic departments of palliative medicine, should be established.

10.3.1 QUALITATIVE RESEARCH

The use of qualitative methods is gaining increased acceptance within the field of health research.[2] Qualitative research makes use of interviews and focus groups to elucidate the views of patients, carers and service providers. It is a method that is useful in health needs assessment, policy development, and in the evaluation of services, particularly in the local context.

Qualitative research is undoubtedly the best research method for researching many aspects of palliative care.[3] It can provide invaluable information on consumer perspectives of the quality of communication, access to care, problem areas and valued aspects of care. It can be used to develop future, more successful models of palliative care.[4]

10.3.2 FUNDING AND RESOURCES FOR RESEARCH

The Irish Hospice Foundation is committed to supporting research in palliative care and bereavement. It plans to establish a national resource centre, which will include a centre for bereavement education, training and research. The Irish Cancer Society has plans to fund nursing research from 2001, which will include research in palliative care.

In general, palliative care does not attract a large amount of funding for research, particularly from the pharmaceutical industry. The National Advisory Committee recommends that there should be a major public funding allocation to promote palliative care research in Ireland.

Adequate resourcing of research groups, with provision of the necessary infrastructure, is essential. Internet access, the availability of e-mail, and access to specific journals and library facilities are essential components in helping to foster the growth of a research network. As research in palliative care develops in Ireland, the results should be disseminated to reach as wide an audience as possible.

KEY RECOMMENDATION

There should be a major public funding allocation to promote palliative care research in Ireland, and to put in place the necessary infrastructure to allow this to happen.

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Section 3

Quality in Palliative Care





Chapter 11

Communication



Chapter 11

11.1 INTRODUCTION

Failure by health service staff to communicate effectively has been identified in many studies as a major impediment to the quality of care. This failure to communicate occurs at several levels in different care settings - communication with patients and their families, communication within hospital services, communication within community services, and communication between hospital and community health care professionals.

This chapter examines communication in these different settings, and makes recommendations on how improvements in communication could enhance the quality of care for patients and families.

11.2 COMMUNICATION WITH PATIENTS AND FAMILIES

Several studies in the UK[1-5] have found dissatisfaction with communication between health care professionals and patients, especially in hospitals. Irish studies[6-8] found that respondents were particularly critical of the circumstances and manner in which bad news was given. Specific complaints related to the way in which patients were given bad news - telling people when they were alone, being too direct, removing hope and appearing insensitive.[6]

Insufficient information exchange, lack of time and lack of privacy were also reported as problems.[7] Respondents were clear about their need for accurate, consistent and comprehensive information about the implications of their diagnosis.[8]

The absence of hospital-based training in communication skills and bereavement care was particularly evident in a study of medical training in palliative care.[9]

The right of patients to information regarding their disease and prognosis should be recognised by health care professionals in all care settings. Patients should also be given an opportunity to express their wishes regarding how and where they would like to receive care, and these wishes should be taken into account whenever possible.

The National Advisory Committee recommends that all staff involved in the care of patients with progressive illness and their families should receive specific training in communication skills. This is particularly important in the area of breaking bad news.

Structures should be put in place to support this recommendation. Suitable space and facilities to allow privacy during conversations between doctors and patients and their families should also be provided.

KEY RECOMMENDATION

There should be specific training in communication skills for all staff involved in the care of patients with progressive illness.

11.3 COMMUNICATION WITHIN HOSPITALS

Communication between health care professionals within the hospital environment has been highlighted as in need of improvement.[8] The time available for communication between providers is often limited. Time constraints were identified as a major barrier to full information exchange between service providers.[7]

Consultation and case conferences should be an important part of the inter-disciplinary team approach in hospitals. Time for such communication should be taken into account by management when allocating staff and resources to hospital services.

11.4 COMMUNICATION BETWEEN HOSPITAL AND COMMUNITY HEALTH CARE PROVIDERS

Discharge problems may occur as a result of a delay in communication and information exchange between hospital staff and general practitioners.[7] These problems may have consequences for the care that general practitioners are able to deliver, influence the adequacy of referral to other community care services and may have a negative impact on the quality of life of patients requiring palliative care.

The Committee recommends that the general practitioner, public health nurse and specialist palliative care team (when appropriate) should be contacted directly by hospital staff in advance of a patient's discharge to discuss changes in medication and to clarify any other issues relating to patient care, such as identifying aids or appliances that may be required. Early notification of discharge is essential, in order that health care professionals in the community and the family can prepare adequately for the patient's return home.

On discharge from hospital, palliative care patients should be provided with a clear discharge summary, along with a detailed prescription for any medication or supplies necessary. The degree to which patients and their relatives are aware of their diagnosis is vital information for primary health care professionals.

In future, when there is a specialist palliative care service in each acute general hospital, the specialist palliative care nurse should be a key person to liase with community health care professionals.

KEY RECOMMENDATION

The general practitioner, public health nurse and specialist palliative care team, when appropriate, should be contacted directly in advance of a patient's discharge from hospital.

11.5 COMMUNICATION BETWEEN COMMUNITY HEALTH CARE PROVIDERS

Effective communication underpins good collaborative working.[10] Primary health care professionals should have an open line of communication with each other, and with other services, in order to respond to the changing needs of patients. Regular team meetings, where problems are discussed and potential solutions explored, should lead to improvement in patient care.[11] Regular communication by phone, fax or e-mail is also recommended. Pagers and mobile phones should be available to facilitate communication between primary health care providers.

Within general practice, all partners and trainees should be aware of the proposed management and medication plan for each palliative care patient. Any change in a patient's condition should be communicated directly to the general practitioner on-call, including locum services.

KEY RECOMMENDATION

Primary care health professionals should have an open line of communication with each other, which should involve regular team meetings when possible, and regular communication by phone, fax or e-mail.

11.6 INFORMATION FOR PATIENTS AND FAMILIES

Lack of information about services available has been cited in many reports as being a serious obstacle to adequate care in the community.[7,8,12,13] This includes information about entitlements to financial benefits and sources of help outside the health care services. Patients and families may benefit from advice on access to benefits such as disability allowance, mobility allowance and housing grants.[14]

Health care providers should be proactive in the provision of information to patients and families. They should advise them about their entitlements to health services, General Medical Services (GMS) cards, aids and appliances, housing grants, and financial support. Families may also need information after the patient has died, for example help with funeral expenses or how to obtain a death certificate.

In order to provide this information to patients and their families, health care providers should be fully informed themselves regarding the services available, and the entitlements and eligibility of patients for these services.

Printed information leaflets should be available to palliative care patients and their families in all care settings. These should provide up-to-date information on services and allowances available and how to access them. These leaflets should also be distributed to all relevant health care professionals.

KEY RECOMMENDATION

Health care providers should be proactive in the provision of information regarding services, allowances and entitlements to patients and families.

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Chapter 12

Standards in Palliative Care



Chapter 12

12.1 INTRODUCTION

The quest for quality, though by no means new, has gained particular prominence in the health service in the past decade.[1] Increasing emphasis is being placed on the importance of evaluating services to ensure that their use is based on evidence of their efficacy, cost-effectiveness and acceptability, rather than on anecdote. It is now recognised that a systematic approach to evaluating and improving quality of care should be central to any service.[1]

Concern for quality is central to the palliative care approach and to specialist palliative care services. It is therefore natural for specialist palliative care services to be involved in quality improvement, which is loosely defined as any systematic approach to the improvement and evaluation of service quality.[1]

This chapter outlines how quality in palliative care can be measured, and how services can be evaluated to ensure that patients receive the best quality possible in service delivery. Dimensions of quality and how they relate to palliative care are briefly outlined.

12.2 PRINCIPLES

Every specialist palliative care service should have an explicit commitment to quality improvement. A culture of delivering the best possible quality should be promoted in all disciplines and be assumed by all staff.

In order to achieve this, there is a need to ensure that quality assurance programmes are in place and are constantly used to review practice, and that clinical audit and research programmes exist to evaluate treatment and outcome.

The development of standardised data sets at national level, and the use of appropriate performance indicators and outcome measures is essential to the evaluation of quality in specialist palliative care services.

12.3 DIMENSIONS OF QUALITY IN PALLIATIVE CARE

Equity refers to equal access to services for equal need. This should be irrespective of socio-economic group, ethnicity, age, sex or diagnosis. The National Advisory Committee recommends that the provision of services and equipment to palliative care patients should not depend on ability to pay.

Under legislation, eligibility for a medical card (under the General Medical Services Scheme) is determined by the Chief Executive Officers (CEO) of the health boards, having regard to relevant criteria, most notably the financial circumstances and medical needs of the individual concerned. This approach reflects the accepted philosophy that available resources are best targeted to those most in need.

In making decisions on any particular application for a medical card, the health board CEO may, within the legislative framework, exercise his or her discretion to ensure the best possible outcome, having regard to the relevant factors. The Committee recommends that the CEOs should have such regard to patients receiving palliative care.

KEY RECOMMENDATION

The provision of services and equipment to palliative care patients should be based on need, and not on the ability to pay.

Access to services is currently limited by where a patient lives, as specialist services are not available in all geographical locations. Access to services also encompasses the concept of timeliness, that is, the availability of services when needed. Long waiting lists are entirely inappropriate for patients requiring palliative care services.

KEY RECOMMENDATION

Specialist palliative care services should be available to all patients wherever and whenever they require them.

Acceptability refers to the way in which patients and carers view the quality of the treatment and care they receive. Specialist palliative care services should be provided in a suitable environment, which should include appropriate facilities for visiting relatives, including children.

Effectiveness is the extent to which health care objectives are achieved. All services should be based on the best available evidence of effectiveness.

Appropriateness refers to the relevance of services, in relation to the needs of patients, and also to the needs of the population. The development of services should be linked to the requirements of the population served, as determined by a needs assessment.

12.4 MEASUREMENT OF QUALITY IN PALLIATIVE CARE

Currently, in Ireland, there is a lack of data with which to measure quality in specialist palliative care programmes. Services are often asked to provide information about their activity, such as the number of patients and families cared for, or the number of team visits to patients at home. However, this information does not indicate whether a patient has benefited from care.

The National Advisory Committee recommends that standards should be set in all dimensions of service provision in relation to the structure, process and outcome of care. These should also encompass aspects of training and development of services. Standards should be explicit and measurable, and linked to the audit cycle, to allow for evaluation of the service.

Systems should be developed to evaluate the quality of specialist palliative care services. These should include methods of monitoring and auditing the services provided, setting outcome standards and developing methods to measure activity in a standardised way throughout the country.

KEY RECOMMENDATIONS

Every specialist palliative care service should have an explicit commitment to quality improvement.

Quality standards should be set in all specialist palliative care settings, in consultation with key service providers and consumers.

Systems should be put in place in all specialist palliative care services to measure the quality of the services provided.

12.4.1 MINIMUM DATA SETS

Some quantitative data may be available from different sources in Ireland. This, however, reflects the activity of services rather than the quality of services delivered. The data provided is on an ad-hoc basis, and is not standardised.

Standardised activity data from all specialist palliative care services throughout the country should be available as a baseline for the measurement of service activity and utilisation.

A Minimum Data Set (MDS) should be developed at national level, along the lines of the MDS developed in the UK.[2] This should include demographic (e.g. age, sex, ethnic group), administrative (e.g. source of referral) and diagnostic information on all patients of the specialist palliative care services. The MDS should be used by all palliative care services and in all settings.

The MDS would introduce a common currency for the measurement of patient activity, and would enhance continuity of care by ensuring that all providers use the same information base.

KEY RECOMMENDATION

A Minimum Data Set should be developed in Ireland, in order to provide standardised information on all patients of the specialist palliative care services.

12.4.2 PERFORMANCE INDICATORS

Performance indicators provide an estimate of how well a service is achieving its objectives. In order to be able to assess whether specialist palliative care services are providing care that satisfies patient and family needs, a set of indicators should be developed to give an accurate picture of performance.[3]

The Australian Association for Hospice and Palliative Care has developed a set of performance indicators, with recommended measurement tools in palliative care.[4] Examples include the following:

- Length of time between referral to a palliative care service and death
- Proportion of people who die from cancer and receive palliative care
- Proportion of palliative care services that provide 24-hour access
- Proportion of services with an identifiable palliative care budget
- Identification of people at risk during bereavement

The Committee recommends that suitable performance indicators should be identified at national level for use in specialist palliative care services throughout the country.

12.4.3 OUTCOME MEASURES IN PALLIATIVE CARE

Increasingly, there is a shift towards trying to provide some information on the outcomes of care, to find out how much the care actually affects the patient and family.

An outcome has been defined as any end result that is attributable to health services intervention.[5] In the context of palliative care, outcomes cannot be measured using mortality or disability, but require measurement of aspects that are important to patients with progressive disease and their families. Outcome measures should include social and psychological functioning, and should reflect:[5]

- The patient's quality of life
- The quality of dying
- The needs of the family
- The bereavement outcome

There is no single Quality of Life instrument that will serve as the definitive outcome measure for all aspects of palliative care.[6] A specialty-specific approach that considers the specific requirements of the terminally ill is required.[7]

The Support Team Assessment Schedule (STAS) is a validated tool geared towards evaluation of symptoms, and patient and family requirements.[8] STAS is widely used in the UK and has been translated into over 10 languages for use worldwide.

More recently, the Palliative Care Outcome Scale (POS) has been developed. Results of a validation study have shown that the POS has acceptable validity and reliability.[9]

It has been recommended that rather than developing new outcome measures, which may be very time consuming and can take many years, it is usually better to use the most appropriate existing measure.[5] These should be agreed at national level.

KEY RECOMMENDATION

Suitable performance indicators and outcome measures should be identified and utilised in specialist palliative care services in order to evaluate and maintain quality standards.

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Section 4

Organisation





Chapter 13

Funding and Accountability



Chapter 13

13.1 INTRODUCTION

The level of financial support available from individual health boards for palliative care services varies from one health board area to another. This has arisen mainly due to the absence of a policy on palliative care services at national level.

The future development of specialist palliative care services requires a commitment to the ongoing provision of an adequate level of public funding, with a corresponding commitment to quality and accountability on behalf of service providers.

This chapter makes recommendations on how the future funding of palliative care services should be organised. It pays particular attention to the interface between health boards and voluntary organisations, and describes the service agreement that forms the basis for partnership arrangements between these parties. It emphasises the accountability of service providers in respect of money obtained from the health board or through fundraising events.

KEY POINT

The future development of specialist palliative care services requires a commitment to the ongoing provision of an adequate level of public funding, with a corresponding commitment to quality and accountability from service providers.

13.2 FUNDING

An adequate level of public funding is necessary to meet the requirements of a specialist palliative care service. Statutory funding should be made available on a phased basis to meet the core running costs of all specialist palliative care services, in all care settings.

The distribution of this funding should be through service plans adopted by each health board, and through service agreements between the board and voluntary service providers in the region.

All proposals for specialist palliative care services, including capital developments, in service plans and service agreements should be prepared within the context of national policy, regional plans, agreed priorities and local needs. These requirements bring into clear focus the need to strengthen and develop partnership structures between the statutory and voluntary sectors.

KEY RECOMMENDATIONS

Adequate and equitable statutory funding should be made available on a phased basis to meet the core running costs of all specialist palliative care services.

The distribution of funding should be through service plans adopted by each health board, and through service agreements between the health board and voluntary service providers in the region.

13.3 ACCOUNTABILITY

One of the key principles of the 1994 Health Strategy[1] was accountability. It stated that decision makers must take financial and legal responsibility for achieving agreed objectives. The statutory responsibility for the provision of all health care services rests with the Chief Executive Officer (CEO) of each local health board.

The service planning process within the health board provides a structure by which the health care system can secure measurable health gain, by striking a balance between the need to achieve social returns on investments in healthcare and the requirement to be publicly accountable for use of the funds provided. The service plan produced by each health board gives a very detailed breakdown of the services to be provided over the following twelve months.

The Health Strategy[1] stated that in the future, voluntary agencies should receive funding from the health authorities, to whom they should be accountable for the public funds that they receive. Voluntary agencies should recognise themselves as accountable, not only to their own board or executive, but also to the wider public.

KEY RECOMMENDATION

Structures for the planning, delivery and evaluation of health services should support a high degree of accountability and transparency at all levels.

13.4 PALLIATIVE CARE BUDGET

The National Advisory Committee recommends that there should be a separate protected budget for specialist palliative care services at health board level. This budget should be under the administrative control of a senior officer of the health board.

This budget should be distributed among all service providers, including voluntary agencies, in accordance with the regional palliative care policies, service plans and service agreements. The budget should fund specialist palliative care services in all care settings. All money received from the palliative care budget should be spent specifically on specialist palliative care services.

The funding of specialist palliative care services should be determined at health board level. All day-to-day expenditure should be met by the health board specialist palliative care budget. Voluntary agencies should work with statutory bodies in sourcing funding for new initiatives in palliative care on a partnership basis.

Decisions about individual major capital developments in the palliative care sector should be taken by the relevant health board in discussion, where appropriate, with the relevant service provider. Decisions should be approved by the Department of Health and Children. Such developments should conform to the priorities identified in the board's development plan for specialist palliative care services in the region.

KEY RECOMMENDATIONS

There should be a separate protected budget for specialist palliative care services at health board level.

All day-to-day expenditure should be met by the health board specialist palliative care budget.

13.5 THE INTERFACE BETWEEN VOLUNTARY AND STATUTORY AGENCIES

Voluntary organisations, in the context of health care services, refer to the non-statutory organisations that play a significant role in the funding and delivery of health care services in Ireland. "Voluntary organisations" may range from large general hospitals or specialist palliative care units, which may be funded primarily by statutory bodies, to small local organisations, which are mainly involved in fundraising initiatives to meet local needs.

The 1996 Cancer Strategy[2] acknowledged the important role of the voluntary sector in the provision of palliative care services, particularly the Irish Hospice Foundation, the Irish Cancer Society and the many independent hospice support groups throughout the country.

At present there are no guidelines or standards of practice governing the way in which health boards work together with voluntary agencies in planning and providing palliative care services. Hence there are large variations in practice between different health board areas, and even between the arrangements with different voluntary agencies falling within the same health board area.

The ad-hoc nature of such arrangements has resulted in many, if not all, of the existing service providers having an over-dependence on fundraising. This applies to meeting day-to-day running expenses of services, as well as the sourcing of funding for the future development of services.

There is now greater acceptance among health boards and voluntary agencies regarding the need to develop closer working relationships. This would be particularly important in reaching mutual agreement on how local priorities are to be decided and delivered. The voluntary service providers, while retaining their autonomy, should form part of an integrated framework for health care provision in the region.

The National Advisory Committee recommends that partnerships between the health boards and individual voluntary agencies should be formalised by way of service agreements.

KEY RECOMMENDATION

Health boards should work in partnership with the voluntary service providers in their areas.

13.6 SERVICE AGREEMENTS

Service agreements should form the basis of future working relationships between the health boards and all voluntary specialist palliative care service providers. The use of service agreements should provide a means to establish safeguards and reassurances for both parties.

The process should respect the independent identity and operational autonomy of individual voluntary service providers. However, the process should also respect the statutory, regulatory and public accountability responsibilities of the health boards, the Department of Health and Children, and the Minister for Health and Children.

Service agreements with the health authorities should link funding by the authorities with an agreed level and range of services to be provided by the voluntary agency. The service agreement should define in broad terms the services to be provided.

Voluntary service providers should have appropriate accounting and audit procedures in place in respect of money paid to them by health boards, or other statutory bodies. They should meet with the health boards and make financial returns to the board on a quarterly basis.

Voluntary service providers should have independence in budget-programming issues, pay, non-pay and other income, provided the service continues at the agreed base levels and within its agreed allocation, and that staff numbers are within approved levels.

Multi-annual budgets should form part of the agreement where this is possible.

KEY RECOMMENDATIONS

Service agreements should form the basis of future working relationships between the health boards and all voluntary specialist palliative care service providers.

The process should respect the independent identity and operational autonomy of individual voluntary service providers, and also respect the statutory, regulatory and public accountability responsibilities of the statutory bodies.

13.7 FUNDRAISING

Charitable and voluntary fundraising groups exist in a wide variety of forms, from individuals through to formal entities with many employees. Operational issues that need to be addressed in relation to fundraising include:

- The unregulated nature of local and regional fundraising
- Lack of disclosure by some groups in relation to funds raised, expenditure, and reserves
- The clear, unambiguous, identification of the purpose of the fundraising

Fundraising groups should identify key objectives and strategies in relation to their activities. They should also define the geographical area and boundary of their fundraising activities. Usually this will correspond to the area or parishes where services are delivered.

Money collected as charitable donations should be spent on the purpose described, at the earliest opportunity. In relation to money obtained for specialist palliative care services through fundraising, any projects funded from this source should be in accordance with the overall palliative care development plan for the region.

Fundraising groups should be fully accountable, not only to their own board or executive, but also to the wider public. They should accurately account for all income earned and all costs incurred by activities under the group's control.

KEY RECOMMENDATIONS

Fundraising groups should identify key objectives and strategies in relation to their activities, and should be fully accountable for all money raised.

Any projects funded should be in accordance with the overall palliative care development plan for the region.

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Chapter 14

Planning and Development



Chapter 14

14.1 INTRODUCTION

The WHO, in its Report on Cancer Pain Relief and Palliative Care,[1] stated that one of the major obstacles to the implementation of palliative care appears to be the absence of national policies on cancer pain relief and other aspects of palliative care. It recommended that a national policy should outline a step-by-step plan for the implementation of a palliative care programme.

In Ireland, several reports and studies[2-4] in the past decade have recommended the development of a national policy on future development of specialist palliative care services. These followed reports on cancer and palliative care from the UK,[5-7] which informed the development of specialist palliative care services.

This chapter outlines how a framework for the planning of specialist palliative care services should be established. It describes the structure of a National Council for Specialist Palliative Care, its composition, and its terms of reference. It also describes the structure, composition and terms of reference of Regional Committees for Palliative Care at health board level.

14.2 FRAMEWORK FOR DEVELOPMENT

The National Advisory Committee recommends that the Minister for Health and Children should publish, as a matter of priority, a comprehensive national policy for the development of palliative care services in Ireland, taking account of the recommendations of this report.

The Committee also recommends that the Minister should establish a National Council for Specialist Palliative Care, with a view to advising the Minister on national policy. The National Council should also advise on ways of encouraging greater partnership between statutory and voluntary agencies in the provision of palliative care services; how best to meet the needs of all those who require palliative care; and the appropriate future development of services.

The Committee also recommends the establishment of Regional Committees at health board level, which should apply national policy, as determined by the Department of Health and Children, with particular regard to local needs and resources.

The legislative requirements under which the health boards operate are acknowledged. Account will need to be taken of the statutory basis of the Eastern Regional Health Authority, particularly as it relates to the area of service agreements.

Following consultation with relevant service providers, agencies and committee members, and having regard to recent reports on the development of palliative care services, nationally and internationally, the National Advisory Committee recommends the following structures for the future planning and development of palliative care services in Ireland.

14.3 NATIONAL COUNCIL FOR SPECIALIST PALLIATIVE CARE

The Minister for Health and Children should establish a National Council for Specialist Palliative Care to offer advice on the ongoing development and implementation of national policy on palliative care services in Ireland, having regard to this Committee's report. The National Council should be broadly based and have representatives from the appropriate statutory and voluntary agencies. Its membership should be appointed by the Minister for Health and Children.

The National Council should address issues such as funding, structures, standards, education, training and research, and the scope of specialist palliative care services. It should identify key areas for future service development in palliative care.

The National Council should act as a unifying link across all levels of palliative care services and should ensure co-ordination of services at national level. It should encourage greater partnership between statutory and voluntary agencies in providing palliative care services.

The National Council should oversee the development of an equitable and high quality palliative care service across all health boards areas. It should ensure standardisation of policies and practices nationally and regionally. It should promote a seamless service for all who require palliative care, and seek to ensure that services are adequately resourced and equipped for the delivery of the highest possible level of care.

The National Advisory Committee recommends that there should be formal links between the National Council for Specialist Palliative Care and the National Cancer Forum. At present, the National Cancer Forum has a representative from the specialist palliative care services. The Committee recommends that this arrangement should continue, and that appropriate plans should be made to ensure that adequate linkages are in place between the two bodies.

KEY RECOMMENDATIONS

The Minister should establish a **National Council for Specialist Palliative Care** to offer advice on the ongoing development and implementation of a national policy on palliative care services in Ireland.

The National Council should be broadly based and have representatives from the appropriate statutory and voluntary agencies.

There should be formal links between the National Council for Specialist Palliative Care and the National Cancer Forum.

14.4 REGIONAL COMMITTEES FOR PALLIATIVE CARE

The National Advisory Committee recommends that each health board should establish two regional committees for palliative care. This Committee is of the view that the structure of regional committees developed in relation to services for people with an intellectual disability[8] should also be developed for palliative care. These are a Regional Consultative Committee and a Regional Development Committee.

14.4.1 REGIONAL CONSULTATIVE COMMITTEE FOR PALLIATIVE CARE

A Regional Consultative Committee for Palliative Care should be established by the Chief Executive Officer (CEO) in each health board region. The Regional Consultative Committee should be an advisory committee, which should provide a broadly based forum for the exchange of information and ideas on all matters pertaining to palliative care, both specialist and non-specialist, in the region.

The terms of reference of the Regional Consultative Committee should be as follows:

- Advising the Regional Development Committee on any matters relating to the provision of palliative care services in the region, including new developments.
- Advising on strategies to maximise co-operation between patients, families, statutory authorities and service providers, both voluntary and statutory.
- Participating in the evaluation of services in the region.
- Agreeing mechanisms and actively pursuing effective advocacy in relation to standards and resources for persons who may benefit from palliative care in the region.

The Regional Consultative Committee should consist of:

- Senior officers of the health board
- Representatives of specialist palliative care service providers, voluntary and statutory
- A representative from oncology services
- A representative from acute hospital services
- A general practitioner representative
- A public health nurse representative
- A representative of community hospitals
- Two consumer representatives
- Other persons that the CEO may deem appropriate

The CEO should be responsible for appointing members to the Regional Consultative Committee for an agreed period of time.

The Chairperson of this Committee should be appointed by the CEO and be a member of the Regional Development Committee. The appointment should be for an agreed period of time.

Secretarial support to the Committee should be provided by health boards. The Committee should meet not less than three times each year.

In the interest of the effective functioning of the Regional Consultative Committee, membership should not exceed 15 members. In some health board areas, it may be less than this.

14.4.2 REGIONAL DEVELOPMENT COMMITTEE FOR SPECIALIST PALLIATIVE CARE

A Regional Development Committee for Specialist Palliative Care should be established by the CEO in each health board region. The Regional Development Committee should report to the CEO.

The terms of reference of the Regional Development Committee should be as follows:

- Recommending to the CEO the allocation of all statutory resources (capital and revenue) provided annually or multi-annually for new and developing services within the policy guidelines issued by the Department of Health and Children, having regard to the recommendations of the National Council and the Regional Consultative Committee.
- Preparing an agreed development plan for the region, based on a health board needs assessment, which should ensure the delivery of a comprehensive service of the highest quality.
- Monitoring the implementation of the regional development plan.
- Establishing such sub-committees as may be required from time to time.
- Providing an annual report on Palliative Care Services to the CEO.
- Encouraging and participating as appropriate in the evaluation of service delivery in accordance with the agreed mission statement.

The Regional Development Committee should consist of:

- A maximum of three senior representatives from statutory agencies providing specialist palliative care services
- A maximum of four senior representatives from amongst the voluntary organisations providing specialist palliative care services, and having a service agreement with the health board
- A maximum of three senior officers from the health board

The CEO should be responsible for appointing members to the Regional Development Committee from the nominations received from the organisations referred to above.

One of the senior officers of the health board should be the person in the health board who has overall responsibility for specialist palliative care services. This person should be the Chairperson of the Committee.

The Committee should meet not less than four times each year. Secretarial support for the Committee should be provided by the health boards.

KEY RECOMMENDATION

Each health board should establish two regional committees for palliative care. These are:

1. A **Regional Consultative Committee**, which should provide a broadly based forum for the exchange of information and ideas on all matters pertaining to palliative care.
2. A **Regional Development Committee**, which would advise the CEO on the implementation of the National Policy.

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Section 5

Implementation





Chapter 15

Priorities, Timeframes and Costs



Chapter 15

15.1 INTRODUCTION

In this chapter the estimated cost of the recommendations made in the report by the National Advisory Committee are detailed. Every effort has been made to ensure that the estimates are accurate. However, given demographic and geographic differences, which impact on regional service requirements, the estimates should be viewed as indicative.

15.2 PRIORITIES

As has been recognised earlier in the report, palliative medicine is a new and developing specialty. This report describes the ideal service and acts as a blueprint for its development. However, as a first step, a national policy should be formulated.

The report recommends that health boards should undertake a needs assessment to define the palliative care needs within their catchment area, while a further recommendation provides for the establishment of a regional structure to consider and advise health board Chief Executive Officers on the implementation of national policy.

In accordance with the above, it is recommended that priorities should be based on national policy and should be decided by health boards at regional level, based on the need for services, as defined by the needs assessment and also taking account of advice provided by the regional committees.

The National Advisory Committee would like to draw particular attention to the key recommendation that each health board should have a specialist palliative care unit, and believes this is essential to the development of palliative care services.

15.3 IMPLEMENTATION TIMEFRAME

The Committee recommends that the implementation of the report's recommendations should occur within a five year period.

15.4 CAPITAL

The need and scale of capital developments to support the plan for specialist palliative care services will be determined by an interpretation of national policy, the previously mentioned needs assessment by each health board, and the report of the Expert Group on Design Guides for Specialist Palliative Care Settings.

The National Advisory Committee, based on a detailed analysis of available research and following consultation with relevant experts, recommends that there should be at least 8 to 10 specialist palliative care beds available per 100,000 population to meet the increasing need for specialist palliative care services in Ireland. However, it is acknowledged that this is a rapidly evolving area of care and is the subject of ongoing audit and evaluation and, as recommended, requires further research to be undertaken at national level to examine the prevalence and distribution of disease, the result of which may require some re-alignment of the ratio of specialist palliative care beds to population.

Specific regional needs should be further informed by the recommended needs assessment study in each health board area.

In view of the strong tradition of the role of the voluntary sector in this area of care, and in the context of the proposed regional structures, it may be possible to develop capital projects as a partnership exercise between voluntary agencies and health boards.

15.5 ESTIMATES OF COSTS

In the following pages, details of the estimated cost of the recommendations of this report are provided. These have been divided into pay and non-pay revenue elements, and are also shown in tabular format at the end of the chapter. Where relevant, the upper range of the recommended norm of 10 specialist palliative care beds per 100,000 population has been used. In some instances there are rounding differences in Euro amounts.

15.6 PAY COSTS

15.6.1 MEDICAL STAFF

a) It is recommended that there should be at least one whole time equivalent (WTE) consultant in palliative medicine per 160,000 population, with a minimum of two consultants in each health board area (see 5.5).

Estimate: £3.45m/€4.38m

b) It is also recommended that for each consultant in palliative medicine there should be at least three NCHDs (see 5.5).

Estimate: £4.5m/€5.71m

15.6.2 SPECIALIST PALLIATIVE CARE NURSES

A number of recommendations are made on the staffing level of specialist palliative care nurses working in different care settings (see 5.6).

a) Specialist Palliative Care Nurse in a Specialist Inpatient Unit: It is recommended there should be a ratio of not less than one WTE specialist palliative care nurse to each bed.

Estimate: £16.7m/€21.2m

b) Specialist Palliative Care Nurse in the Community: It is recommended there should be at least one WTE specialist palliative care nurse per 25,000 population.

Estimate: £6.67m/€8.47m

c) Specialist Palliative Care Nurse in an Acute General Hospital Team: It is recommended that there should be at least one hospital-based specialist palliative care nurse per 150 beds.

Estimate: £2.85m/€3.62m

d) Specialist Palliative Care Nurse in a Day Care Centre: It is recommended that in each day care centre there should be at least one specialist palliative care nurse per 7 daily attendees.

Estimate: £1.66m/€2.11m

15.6.3 PHYSIOTHERAPY

a) It is recommended that there should be at least one WTE physiotherapist per 10 beds in the specialist palliative care inpatient unit, with a minimum of one physiotherapist in each unit (see 5.7).

Estimate: £1.3m/€1.65m

b) It is recommended there should be at least one WTE community physiotherapist specialising in palliative care per 125,000 population, to be based in the specialist palliative care unit (see 5.7).

Estimate: £1.04m/€1.32m

15.6.4 OCCUPATIONAL THERAPY

a) It is recommended that there should be at least one WTE occupational therapist per 10 beds in the specialist palliative care unit, with a minimum of one in each unit (see 5.8).

Estimate: £1.3m/€1.65m

b) It is recommended that there should be at least one WTE community occupational therapist specialising in palliative care per 125,000 population, to be based in the specialist palliative care unit (see 5.8).

Estimate: £1.04m/€1.32m

15.6.5 SOCIAL WORKERS

a) It is recommended that there should be at least one WTE social worker employed per 10 beds in the specialist palliative care unit, with a minimum of one in each unit (see 5.9).

Estimate: £1.33m/€1.69m

b) It is recommended that there should be at least one WTE community social worker specialising in palliative care per 125,000 population, to be based in the specialist palliative care unit (see 5.9).

Estimate: £1.07m/€1.36m

c) It is recommended that there should be at least one WTE specialist palliative care social worker in acute general hospitals that have a specialist palliative care team (see 7.3).

Estimate: £1.15m/€1.46m

15.6.6 SPIRITUAL CARE

It is recommended that each specialist palliative care unit should have at least two suitably trained chaplains available to meet the spiritual needs of patients and families, and this service should be available 24 hours a day (see 5.11).

Estimate: £0.61m/€0.77m

15.6.7 SPEECH AND LANGUAGE THERAPY

It is recommended that there should be regular speech and language therapy sessions in each specialist palliative care unit, with a minimum of one session per week (see 5.12).

Estimate: £0.13m/€0.17m

15.6.8 CLINICAL NUTRITIONISTS

It is recommended that there should be at least one clinical nutritionist session in each specialist palliative care unit per week (see 5.13).

Estimate: £0.13m/€0.17m

15.6.9 PHARMACISTS

It is recommended that there should be at least one WTE pharmacist in each specialist palliative care unit (see 5.14).

Estimate: £0.4m/€0.51m

15.6.10 CARE ATTENDANTS

a) It is recommended that there should be not less than 0.5 WTE care attendants to each bed in a specialist palliative care unit (see 5.16).

Estimate: £4m/€5.08m

b) It is recommended that care attendants, including night sitters, should be available to support families of palliative care patients in the community (see 8.7.5).

Estimate: £1.58m/€2.01m

15.6.11 VOLUNTEERS

It is recommended that every specialist palliative care unit should have a volunteer co-ordinator (see 5.17).

Estimate: £0.34m/€0.43m

15.6.12 ADMINISTRATIVE STAFF

It is recommended that specialist palliative care services should have an appropriate level of administrative staff (see 5.4 and 7.3).

Estimate: £1.95m/€2.47m

15.6.13 LIBRARIAN AND EDUCATIONAL PERSONNEL

It is recommended that specialist palliative care services should have a librarian and educational personnel (see 5.4).

Estimate: £0.65m/€0.83m

15.6.14 GENERAL SUPPORT SERVICES STAFF

It is recommended that specialist palliative care services should have an appropriate level of general support services staff (see 5.4).

Estimate: £3.18m/€4.04m

15.7 NON-PAY COSTS

A number of recommendations relating to non-pay costs have been made in the report, as follows:

15.7.1 WIDER COMMUNITY

It is recommended that the concept of palliative care should be promoted in the wider community (see 2.6).

15.7.2 NEEDS ASSESSMENT

It is recommended that a needs assessment for specialist palliative care services should be completed by each health board area within 9 months of the publication of this report (see 3.2).

15.7.3 EQUIPMENT

It is recommended that each health board should have a sufficient bank of equipment to meet the needs of palliative care patients in the community. It is also recommended that all specialist palliative care units should have their own small bank of aids and appliances to facilitate rapid access to equipment (see 8.7.3).

15.7.4 INFORMATION

It is recommended that health care providers should be proactive in the provision of information regarding services, allowances and entitlements to patients and families (see 11.6).

Non-pay costs also refer to such items as medications, dressings and travel costs.

It has been estimated that non-pay costs would total £7.2m/€9.15m.

It is estimated that the total revenue costs, both pay and non-pay is £64.23m/€81.57m. It is estimated that £20m/€25.39m is provided for current revenue expenditure for the provision of palliative care services. A net additional revenue expenditure of £44.23/€56.18m is required to meet the recommendations of this report.



TABLES SHOWING ESTIMATED REVENUE COSTS
(In some instances there are rounding differences in Euro amounts)

A. PAY COSTS

Table A.1 Specialist Palliative Care Units

Post	Estimated cost £	Estimated cost €
Consultants	3.45m	4.38m
Medical officers	4.50m	5.71m
Specialist palliative care nurses	16.70m	21.20m
Social workers	1.33m	1.69m
Occupational therapists	1.30m	1.65m
Physiotherapists	1.30m	1.65m
Pharmacists	0.40m	0.51m
Speech and language therapists	0.13m	0.17m
Clinical nutritionists	0.13m	0.17m
Care attendants	4.00m	5.08m
General support services	3.18m	4.04m
Chaplains	0.61m	0.77m
Administration	1.24m	1.57m
Volunteer co-ordinator	0.34m	0.43m
Librarian and educational staff	0.65m	0.83m
Total	**39.26m**	**49.85m**

Table A.2 Specialist Palliative Care Day Care Centres

Post	Estimated cost £	Estimated cost €
Specialist palliative care nurses	1.66m	2.11m
Total	**1.66m**	**2.11m**

Table A.3 Specialist Palliative Care Staff in the Community

Post	Estimated cost £	Estimated cost €
Specialist palliative care nurses	6.67m	8.47m
Care attendants	1.58m	2.01m
Social workers	1.07m	1.36m
Occupational therapists	1.04m	1.32m
Physiotherapists	1.04m	1.32m
Total	**11.4m**	**14.48m**

Table A.4 Specialist Palliative Care Teams in Acute General Hospitals

Post	Estimated cost £	Estimated cost €
Specialist palliative care nurses	2.85m	3.62m
Social workers	1.15m	1.46m
Adminstration	0.71m	0.90m
Total	**4.71m**	**5.98m**

B. NON-PAY COSTS

Details	Estimated cost £	Estimated cost €
Non-pay including medication, dressings, aids and appliances, travel	7.00m	8.89m
Needs assessment	0.10m	0.13m
Promotion and information packs	0.10m	0.13m
Total	**7.20m**	**9.15m**

SUMMARY OF REVENUE ESTIMATES

Total estimated revenue cost of recommendations		Current revenue expenditure		Net estimate of additional revenue required	
£	€	£	€	£	€
64.23m	**81.57m**	**20.00m**	**25.39m**	**44.23m**	**56.18m**


Training
Bereavement
Support
Communication
Palliative Care Units
Research
Education
Planning
Standards

Appendices

APPENDIX ONE

SUBMISSIONS RECEIVED FOR CONSIDERATION BY THE NATIONAL ADVISORY COMMITTEE ON PALLIATIVE CARE

Una Boland, Director of Clinical Pastoral Education, Southern Health Board

Claire Callan, Hospitaller Order of St John of God, Dunleer, Co Louth

Kieran Coughlan, Foxrock, Dublin

Mary Dempsey, South Tipperary Hospice Movement, Co Tipperary

Dr Eleanor Faul, Dundalk

Eithne Frost and Dr Orla Hardiman, Irish Motor Neurone Disease Association, Dublin

Claire Goddard and Dr Howard Kunin, Irish Hospice Foundation, Dublin

Alice Gormley, Occupational Therapist, Cavan/Monaghan Community Services, Cavan

Dr Liam Grogan, Consultant Oncologist, and Dr Regina McQuillan, Consultant in Palliative Medicine, Beaumont Hospital, Dublin

Teresa Hanevy, Speech and Language Therapist, Southern Health Board

Florence Hogan, A Nurse for Daniel, Shankill, Co Dublin

Dr Tony Holohan, Department of Public Health, Midland Health Board

Mary Keane, Hospitaller Order of St John of God, Stillorgan, Co Dublin

Brother Lawrence Kearns OH, Suzanne House, Tallaght, Dublin

Gerardine Lynch, Education Centre, St Patrick's Hospital/Marymount Hospice, Cork

Matthew Lynch, The Pharmaceutical Society of Ireland, Dublin

Helen MacMahon and Bridie Mullen, Specialist Nurses in Palliative Care, Co Donegal

Dr Mary McAteer, School of Physiotherapy, University College Dublin

Dr James McDaid, TD, Minister for Tourism, Sport and Recreation, Dublin

Sr Helena McGilly, Matron, Our Lady's Hospice, Dublin

Noreen McGloin, Northwest Hospice Ltd, Sligo

Nursing Department, St Patrick's Hospital/Marymount Hospice, Cork

Nursing Staff, St Joseph's Community Hospital, Castletownbere, Co Cork

Nancy O'Flynn, The Irish Pharmaceutical Union, Dublin

Michael O'Halloran, Irish Senior Citizens Parliament, Dublin

Dr Rory O'Hanlon, TD, Leas-Cheann Comhairle, Dublin

Dr Aisling O'Leary, School of Pharmacy, University of Dublin

Eileen O'Leary and Dr Regina McQuillan, Irish Association for Palliative Care, Dublin

Siobhán O'Mahony, Physiotherapy Department, St Patrick's Hospital/Marymount Hospice, Cork

Dr. Anne O'Meara, Consultant Paediatric Oncologist, Our Lady's Hospital for Sick Children, Dublin (on behalf of the Faculty of Paediatrics)

Noreen O'Shea, Physiotherapy Department, St James's Hospital, Dublin

Fiona Pegum, Physiotherapist, Our Lady's Hospice, Dublin

Carol Phelan, Bereavement Counsellor, North Western Health Board

Celine Phelan, Hospitaller Order of Saint John of God, Shankill, Co Dublin

Fiona Purcell, The Cystic Fibrosis Association of Ireland, Dublin

Mary Reilly, North Louth Hospice and Home Care Foundation, Dundalk, Co Louth

Jim Rhatigan, Social Worker, Milford Care Centre, Limerick

Deirdre Rowe and Margaret Cullen, Association of Occupational Therapists of Ireland, Dublin

Eileen Scott and Gabrielle Corbett, Social Workers, Our Lady's Hospice, Dublin

Dr Aine Sullivan, Cavan

Gerard Sweeney, Irish Kidney Association, Dublin

APPENDIX TWO

MEETING AT ST. CHRISTOPHER'S HOSPICE, LONDON.

Prof. David Field	Deputy Director, Centre for Cancer and Palliative Care Studies, Institute of Cancer Research, Royal Marsden Hospital.
Prof. Irene Higginson	Professor of Palliative Care and Policy, Guy's, King's and St. Thomas' School of Medicine and St.Christopher's Hospice.
Barbara Monroe	Acting Chief Executive and Director of Patient and Family Services, St. Christopher's Hospice.
Dr. Sheila Payne	Director of Research, Health Research Unit, University of Southampton.
Frances Sheldon	Macmillan Lecturer in Psychosocial Palliative Care, University of Southampton.

APPENDIX THREE

GUIDELINES FOR A PALLIATIVE CARE NEEDS ASSESSMENT

The three key components of a health needs assessment[1] include:

- The gathering and interpretation of epidemiological and demographic data
- The estimation of the views of the major stakeholders, including service providers, service users and purchasers/planners
- The collection and collation of comparative data relating to outputs, outcomes and costs

1. POPULATION DATA

An analysis of epidemiological and demographic data forms the first key dimension of any assessment of health need.

1.1 EPIDEMIOLOGICAL DATA

In the palliative care context, this will include estimating the incidence and prevalence of conditions such as cancer and other progressive non-malignant diseases, taking into account local and regional variations. Information sources that can be used include the National Cancer Registry, the Hospital In-Patient Enquiry (HIPE), the Public Health Information System and Central Statistics Office data. Although neither incidence nor prevalence necessarily equates with need, a knowledge of both of these rates is an essential starting point for a needs assessment to describe the burden of disease in the region.[2]

1.2 DEMOGRAPHIC DATA

Current incidence and mortality rates for cancer and other progressive diseases can be applied to future population figures, predicted by using population projections, to estimate the expected number of cases of and deaths from a specific disease in the future. This can be useful in predicting future service needs.

2. STAKEHOLDER PERSPECTIVES

The perspectives of key stakeholders regarding present services and how they could be improved is a key component of any health needs assessment. For palliative care services the key stakeholders include service users (patients and carers), service providers and service planners. Both qualitative and quantitative techniques may be used including:

(a) interviewing patients and their family members individually or in focus groups

(b) sending questionnaires to service providers or planners

3. COMPARATIVE DATA

This part of the process is concerned with the outputs, outcomes and costs of services.

3.1 OUTPUTS

Firstly, the palliative care services that are currently provided in a health board region should be documented. For inpatient units, indicators of utilisation such as admission rates, discharge rates, bed occupancy, average length of stay, throughput, turn-over intervals and death-to-admission rates can also be described. Service utilisation figures can also be collected and collated for day care (e.g. number of patients seen per annum, average number of visits per week) and home care services (e.g. number of patients seen by service, average number of home visits per patient). Data should also be collected regarding waiting times to avail of the various services. This information can be obtained by collaborating with service providers.

3.2 OUTCOMES

For the palliative care services, outcome measures can include place of death, patient satisfaction with services and satisfaction of family members with the process of dying and with bereavement services.

3.3 COSTS

The funding of palliative care services is often provided by both statutory and non-statutory agencies. The cost of providing these services can be examined using a simple cost analysis. Sources of funding can also be examined, where this information is available.

Information regarding the cost of providing palliative care services can be obtained from the annual reports of existing palliative care services and by contacting the administrators of the various services.

REFERENCES

1. Clark D, Malson H. Key issues in palliative care needs assessment. Progress in Palliative Care 1995; 3: 53-5.

2. Williams R, Wright J. Epidemiological issues in health needs assessment. BMJ 1998; 316: 1379-82.



DEPARTMENT OF HEALTH AND CHILDREN

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