

PALLIATIVE CARE FOR ALL

Integrating Palliative Care into
Disease Management Frameworks

KEY MESSAGES



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THE IRISH
HOSPICE
FOUNDATION

Palliative Care for All

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Disease Management Frameworks

Key Messages

This booklet is based on the joint IHF and HSE
report of December 2008

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Introduction and context

There is growing awareness in Ireland that palliative care has a role in the management of all life-limiting diseases in all care settings. This is reflected in both policy documents and emerging practices.

In 2001 the report of the Department of Health and Children's National Advisory Committee on Palliative Care outlined that the promotion of a palliative care approach is appropriate for all patients and that a subset of patients with non-malignant disease with complex palliative care needs or multiple medical problems would benefit from specialist palliative care (SPC).

More recently, in 2006, the Health Service Executive (HSE) stated its commitment to develop a chronic disease management patient support programme. This is in response to the changing patterns associated with life-limiting diseases and to ensure delivery of appropriate health and care services to an ageing population. The development of such a programme is in line with the work of the World Health Organisation (WHO) whose recommendations include the provision of appropriate palliative care for all patients, regardless of diagnosis.

Against this background, in 2007/08 the Irish Hospice Foundation and the HSE undertook the Extending Access Study which sought:

- to examine the palliative care needs of adults with diseases other than cancer and
- to identify how the palliative care model can be extended to such people within the Irish health care context.

The report of the Extending Access Study – “Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks” - was published in December 2008. The content of this booklet is based on the key findings of this report.

While this study had an initial focus on the palliative care needs of adults with chronic obstructive pulmonary disease (COPD), dementia and heart failure - three diseases with high morbidity and mortality – the report's findings are relevant for the introduction of palliative care for all life-limiting, non-malignant diseases.

This booklet provides an explanation of the role of palliative care for all health professionals delivering a service to people with life-limiting, non-malignant diseases in all care settings. It aims to raise awareness of the palliative care needs of people with these diseases and suggests ways in which these needs can be met.

What is palliative care?

Palliative care is described by WHO as an approach that improves the quality of life of patients and their families facing problems associated with life threatening illness through the prevention and relief of suffering. This is achieved by means of early identification, impeccable assessment and treatment of pain and other symptoms that may be physical, psychosocial and spiritual. The introduction of palliative care can be appropriate early in the course of the disease and may be applicable with other therapies that are intended to prolong life.

Bereavement support is an integral part of palliative care. It can start with anticipatory support in preparing the family for the loss of their loved one and continue through response to grief reactions. Many primary and community care professionals remain involved with the family throughout the bereavement process.

The principles of palliative care include:

- A focus on quality of life
- Maintaining good symptom control
- A holistic approach which takes into account the person's life experience and current situation
- Care that encompasses the patient and those who matter to them, including support in bereavement
- Open and sensitive communication with patients, carers and professional colleagues.

STRUCTURE OF PALLIATIVE CARE

In Ireland, palliative care services are structured in three ascending levels of specialisation as follows:

Level 1 – Palliative Care Approach. Informed by the principles of palliative care (above), the palliative care approach aims to promote both physical and psychosocial well-being. The palliative care approach is a vital and integral part of all clinical practice, in hospitals or the community, whatever the illness or its stage.

Level 2 – General Palliative Care. This intermediate level of palliative care is practised by health care professionals who have had some additional training and experience in palliative care.

Palliative care at levels 1 and 2 is routinely delivered by general practitioners, medical and nursing staff, allied health professionals, social workers and care workers in both community and hospital settings. These levels are referred to in this booklet as **non-specialist palliative care**.

Level 3 – Specialist Palliative Care. SPC services are those services whose core activity is the provision of palliative care. They are involved in the care of patients with more complex and demanding care needs. SPC services are available in primary care, acute general hospital settings and in specialist in-patient units/hospices.

Why palliative care is appropriate for people with non-malignant diseases

People with life-limiting, non-malignant diseases can experience a range of physical and psychological symptoms throughout the course of their disease. Their symptom burden has been shown to equal that of people dying with cancer. In addition, their disease trajectory can be more complex and often of much longer duration. These aspects of non-malignant disease demonstrate the need for palliative care to be incorporated as part of their routine care. They are explored in more detail below.

The life-limiting diseases that require particular consideration include:

- dementia
- heart failure
- advanced respiratory disease such as COPD, pulmonary fibrosis and cystic fibrosis
- chronic kidney disease
- scleroderma
- motor neurone disease
- cardio-vascular accident
- multiple sclerosis.

SYMPTOM BURDEN

People with **heart failure and advanced respiratory disease** can experience physical symptoms including breathlessness, pain, fatigue, nausea and insomnia. They may also have psychosocial symptoms such as depression and anxiety; experience social isolation and loss of independence and fear and uncertainty related to their disease trajectory. Many people with these diseases are also at risk of sudden death.

People with **dementia** experience a variety of symptoms which increase as their disease progresses. These range from an initial difficulty with complex tasks and forgetfulness, to their loss of the ability to carry out basic daily living skills. People with advanced dementia may experience behavioural and other changes, loss of the ability to move,

communicate or eat independently; confusion, disorientation, delirium, pain, restlessness, incontinence and recurrent infections. The final phase of dementia can be challenging and difficult to identify, which can inhibit the introduction of palliative interventions.

It is important to stress that people with life-limiting diseases frequently have other co-morbidities, the symptoms arising from which may also require a palliative response.

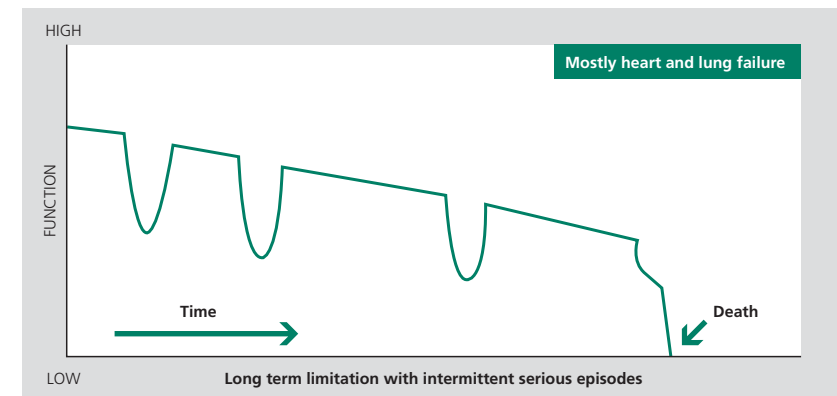
DISEASE TRAJECTORY

Understanding the different disease trajectories of life-limiting diseases can be helpful in assessing how palliative care can be integrated into routine care.

People with life-limiting diseases other than cancer often experience a gradual decline in function. This can be interspersed with acute exacerbations which may be physical and/or psychological. These episodes can be unpredictable, may be influenced by age and other co-morbidities and the frequency of exacerbations can accelerate the pace of decline. As any one of the acute physical episodes may be fatal, people with these diseases may face the prospect of death on many occasions. Exacerbations and patterns of decline may relate to increased intensity of psychological, social or spiritual symptoms as well as the more obvious physical deterioration.

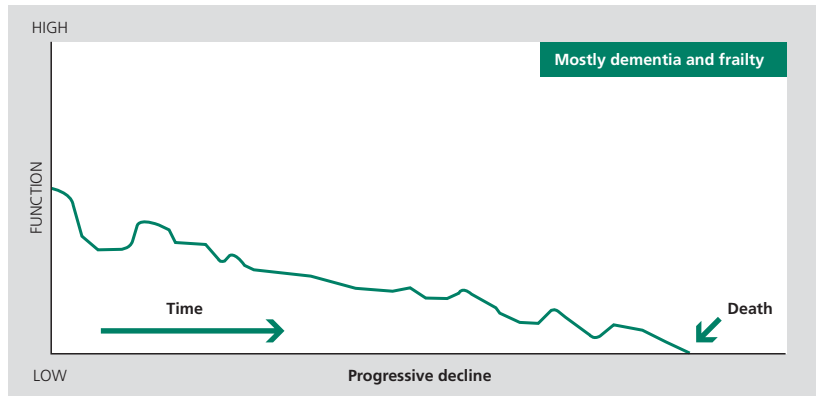
The disease trajectories typically associated with people with heart and lung failure and those with dementia are represented in diagrams 1 and 2 respectively.

DIAGRAM 1: DISEASE TRAJECTORY MOST COMMON IN HEART AND LUNG FAILURE REFLECTING PROGRESSIVE DECLINE AND ACUTE EXACERBATIONS¹



¹ Diagram 1 (Lynn) is reproduced with the permission of RAND Health

DIAGRAM 2: DISEASE TRAJECTORY MOST COMMON IN PEOPLE WITH DEMENTIA AND FRAILITY²



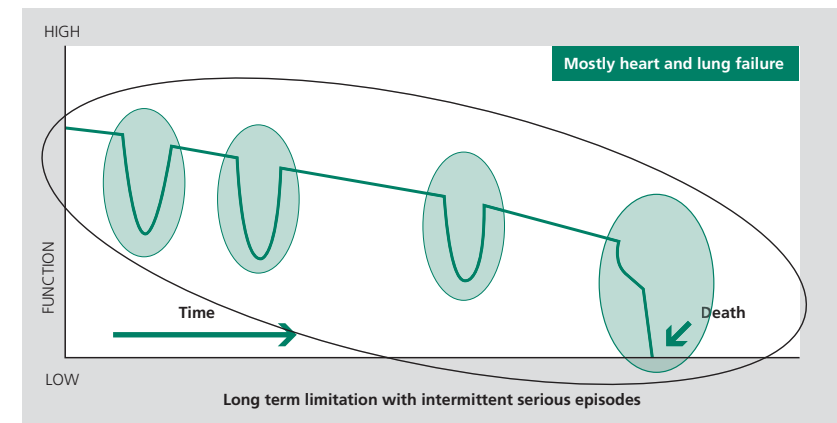
Introducing palliative care



Palliative care needs can arise at any time in the course of a person's disease and should be responded to at an appropriate level throughout their disease trajectory.

Diagram 3 below is adapted to show the potential timing of all levels of palliative care within the typical disease trajectory of people with heart and lung failure. It illustrates how palliative care may be appropriate early in the disease progression. This may be applicable in conjunction with routine treatments that actively manage the disease.

In diagram 3 the larger oval, encompassing the entire disease trajectory, indicates timing for non-specialist palliative care and the smaller, shaded, ovals indicate where referral to, or advice sought from, SPC may be appropriate.

DIAGRAM 3: TIMING OF PALLIATIVE CARE IN DISEASE TRAJECTORY MOST COMMON IN HEART AND LUNG FAILURE.³



-  Large oval indicates timing for non-specialist palliative care
-  Shaded oval indicates potential timing of specialist palliative care

² Diagram 2 (Lynn) is reproduced with the permission of RAND Health

³ Diagram 3 is adapted from Lynn et al

ROLE OF NON-SPECIALIST AND SPECIALIST PALLIATIVE CARE

Non-specialist palliative care for people with **advanced respiratory disease or heart failure** would help to:

- maintain good symptom control such as relieving pain, breathlessness and fatigue
- provide information on the nature of the disease and its likely progression
- address emotional and spiritual issues
- facilitate communication about treatment choices.

Referral to or advice from SPC should be considered for people with advanced respiratory disease and/or heart failure where extraordinary needs arise which cannot be managed by the referring team. These could include:

- management of intractable physical symptoms such as pain and dyspnoea
- treatment of anxiety and depression
- assistance with complex spiritual, emotional and psychosocial needs
- help with advance planning.

Irish research in this area has shown that where comprehensive heart failure services exist, the majority of the patient's palliative care needs can be addressed from within the heart failure team, with SPC providing support where complex and intractable symptoms persist. These findings reflect recent international guidelines on the management of heart failure. Such guidelines suggest that patients' palliative care needs are ideally met where there is a shared care approach in place between the disease specialists and palliative care teams. Emerging UK service models responding to the needs of people with heart and lung failure are demonstrating the benefit of this approach.

The UK NICE Guidelines on Dementia recommend that appropriate levels of palliative care should be available for people with **dementia** from diagnosis throughout the care pathway until death. The guidelines outline that palliative care is necessary to support the quality of life of people with dementia, to enable them to die with dignity and in the place of their choosing, while also supporting their carers in their bereavement which may both anticipate and follow death. These guidelines also emphasise the benefit of a collaborative approach to ensure person-centred patient care.

Non-specialist palliative care should be included early in the disease trajectory for people with dementia and their family carers, prompting queries relating to advance planning, spiritual and psychosocial matters, unmet physical symptoms and advice on avoiding potentially burdensome interventions at the advanced stage of the disease.

Non-specialist palliative care specifically has a role in providing advice and intervention in relation to:

- pain, symptom management, anxiety and depression
- management of issues relating to personal care including nutrition, hydration and hygiene
- increasing patients' and family members' understanding of the disease trajectory
- support relating to advance planning and future treatment decisions
- community and home care support to address increasing disability
- bereavement support throughout the disease trajectory
- prompt access to SPC as required.

Advice and assistance can be sought from SPC for people with dementia where required, for example in relation to:

- the introduction of advance directives
- clarification on ethical issues relating to treatment decisions
- where there is an acute medical event with an increase in intensity of symptoms which cannot be managed by the referring team.

CASE STUDIES

The case studies set out below suggest how existing disease-management frameworks can integrate non-specialist palliative care into routine care and encourage collaboration between the relevant disease-specialty/primary care teams and SPC professionals.

Palliative care and COPD – Case study:

Martin is 70 and lives with his wife and two daughters. He was diagnosed with COPD five years ago. He increasingly feels that his disease is severely limiting his quality of life and activity. Martin has recently been discharged from hospital - his third admission since his diagnosis - and is reluctant to go to A&E in the event of another acute episode. Fearful about the possibility of another exacerbation and his future care options, he also feels he cannot talk to his wife and family about the future without upsetting them. As a consequence he is becoming socially isolated and depressed.

HOW WOULD A PALLIATIVE APPROACH ASSIST MARTIN AND HIS FAMILY?

Martin's GP provides most of his routine healthcare. Martin also attends a respiratory clinic every few months and sees the medical team including respiratory nurse specialists. At Martin's review consultation, following his discharge, the team review his medication to ensure maximum symptom control and:

- Explore with Martin the progression of his COPD and respond fully and sensitively to any questions about possible future exacerbations.
- Help him with self-management of his symptoms and explain his adapted treatment regime.
- Discuss the benefits of and refer Martin to a pulmonary rehabilitation programme (which recently introduced a palliative care module).
- Offer the opportunity to meet Martin with his family to explore future treatment and care options and facilitate discussion on his preferences in the event of him becoming acutely ill again.
- Consider a collaborative approach by taking advice from or referring to other health professionals including SPC for appropriate assistance with complex needs such as anxiety and depression, and/or management of pain or breathlessness.
- Ensure that Martin's GP is aware of Martin's concerns and recommend follow up and possible access to appropriate community services and support where available.

Palliative care and dementia – Case study:

Mary is 78 and has been married to Tom for 56 years. Tom turned 80 earlier this year. They have four adult children, two of whom live nearby. Mary was diagnosed with dementia five years ago. She also has high blood pressure and osteoarthritis. Up to now, with the help of family, neighbours and local community services, Tom has managed to care for Mary at home. However recent deterioration in her condition has meant that Mary now requires assistance with feeding and dressing. She has become increasingly agitated and can no longer communicate in a meaningful manner. Tom feels that he can't continue to care for Mary at home any longer. While in the past she had expressed strong views about staying in her own home in the event of becoming ill, her increasing care needs require a move to a residential setting. All of the family - especially Tom - are very worried and distressed about Mary's physical and mental deterioration and feel overwhelmed about future decisions in relation to her care.

HOW WOULD A PALLIATIVE APPROACH ASSIST MARY AND HER FAMILY?

Tom and Mary's GP has looked after their healthcare needs for many years. In the past, Mary has had contact with the local Psychiatry of Old Age services and a geriatrician as well as her primary care team. The local Public Health Nurse (PHN) has been particularly active in supporting the family since Mary's diagnosis of dementia. The PHN, in consultation with the other team members involved in Mary's care, adopts a palliative approach by:

- Informing the family about the available residential and respite care options in their locality which accommodate the needs of people with dementia, as well as relevant support agencies for people with dementia and their families.
- Providing reassurance to Mary's family in relation to their decision about residential care, indicating how they can continue their care and support to Mary during her transition to residential care.
- Ensuring that the family are fully informed about the likely path the disease will take; advising them on how they can continue to respond to Mary's physical, emotional and spiritual needs, taking account of the impact of loss on all the family as the disease progresses and linking them with appropriate support services for the provision of relevant training and information.
- Indicating the assessments and treatment interventions that people with dementia can undergo.
- Discussing the management of pain, distress and agitation and any other behavioural changes.
- Exploring future options and decisions about nutrition, hydration, resuscitation and admission to acute care, and informing the family of the role of SPC in the event that Mary presents with complex symptoms.

Palliative care and heart failure – Case study:

Rita is a 66 year old widow with two adult children who do not live locally. Rita was diagnosed with heart failure three years ago. She has recently been admitted to hospital as a result of an acute exacerbation of her condition which included severe breathlessness and fatigue. This has shaken her confidence. Her medication needs are complex. Living alone and formerly very active and independent, she worries about how her disease will progress and how this will affect her life. Her perception of her increasing incapacity distresses her.

HOW WOULD A PALLIATIVE APPROACH ASSIST RITA?

In addition to the medical care she receives from her GP, Rita attends a cardiology clinic at her local hospital where she sees the medical team including a heart failure nurse specialist. The team review Rita's symptom control, and assist her with self-management strategies, ensuring that she is fully aware of her medication regime. In addition they:

- Explore with her the possible progression of her disease and how this may affect her, outlining the potential treatment options available.
- Invite her to discuss her preferences for future care plans and draw up a plan of action in the event of another exacerbation.
- Give her the opportunity to talk about her worries and fears.
- Seek to address her concerns by taking advice from or referring to other health professionals including SPC as appropriate for management of complex symptoms such as pain or breathlessness.
- With Rita's consent, encourage a more collaborative approach by involving her GP and the local primary care team in the care plan Rita has prepared, ensuring more community-based support to assist in her symptom management and optimising her independence.

Examples of service developments in Ireland

RESPIRATORY DISEASE

- A number of acute general hospitals in Ireland have included a palliative care component in their pulmonary rehabilitation programmes for people with COPD.
- The respiratory team at one teaching hospital has recently undertaken a small-scale outreach project for people with severe COPD to cater for patient preferences for home care at end of life with encouraging results.

DEMENTIA

- A number of dementia services have begun to introduce palliative interventions within their care plans and there are developing alliances between palliative care teams and services for people with dementia. This is particularly evident in the intellectual disability sector.

HEART FAILURE

- One comprehensive hospital-based heart failure service in Ireland has plans to develop a palliative component through its Advanced Nurse Practitioner's community role.

EVOLVING PRACTICE: DEVELOPING SERVICE MODELS

Action Research Projects

As part of the recommendations of the "Palliative Care for All" report, three **action research projects** are due to commence in 2009. These projects aim to establish a framework for palliative interventions within dementia, respiratory and heart failure services respectively within the Irish health care context. They each will have a service enhancement dimension and will be of two-year duration.

The action research goals are:

- to identify palliative responses in the patient pathway across primary and hospital care
- agree mechanisms for their inclusion in routine assessment and care of people with life-limiting disease
- develop educational and training material for staff and
- identify the key personnel in delivering palliative responses.

The Development page on the Irish Hospice Foundation website www.hospice-foundation.ie provides further information and updates on these projects.

THE HOSPICE FRIENDLY HOSPITALS PROGRAMME

This five-year national programme to improve end-of-life care in Irish hospitals is an initiative of the Irish Hospice Foundation. The overall aim of this programme is to put hospice principles into hospital practice. The website www.hospicefriendlyhospitals.net/ provides in-depth information on this programme.

Meeting palliative care needs – What can you do?

There are some practical measures each individual health care professional can take to help them to identify and meet the palliative care needs of their patients. Such measures include education, collaborative practices and accessing existing information and resources on palliative care for people with life-limiting diseases other than cancer. These are explored in more detail below.

EDUCATION

Both **formal and informal education and training** will help to give relevant staff the confidence and skills to respond to the palliative care needs of their patients.

- A new database of palliative care, end-of-life care and bereavement care courses has been developed by the Palliative Care Education Taskforce and QualifaX. Courses displayed on the database include formal courses, workshops, seminars, conferences and study days. This database is available on the Irish Hospice Foundation website www.hospice-foundation.ie through the Education link.
- The Education Departments attached to the eight hospices/specialist inpatient units focus their programmes on developing and delivering quality palliative care education for health care professionals and care staff. The hospice websites provide the most up-to-date information. See page 16/17 for details.
- The education sections of many professional representative organisations and professional development centres also include aspects of palliative care in their education programmes. See page 18 for details.
- The Irish Hospice Foundation runs bereavement courses for those who are engaged in supporting people who have been bereaved and those who have to fulfil a bereavement support role for clients, colleagues, employees, children or others. The Bereavement link on www.hospice-foundation.ie gives up-to-date details.
- Informal education initiatives in this area can come about through journal clubs, in-service training and seminars. These can enhance professional development and are generally organised at hospital and departmental level.

COLLABORATION

Collaboration between the relevant specialty/primary care team and SPC has been found to be beneficial in meeting the palliative care needs of people with non-malignant diseases at all stages of their illness. Collaboration happens routinely when colleagues seek advice from each other, and can also arise through initiatives such as formal and informal meetings and joint case conferences.

Many disease-specific and SPC services in acute general hospitals and in the community adopt a **shared care approach** with disease-specialist and SPC staff working together to meet the needs of their patient. This method of collaboration has been shown to be helpful in ensuring that the care the person receives is responsive and adaptable throughout their disease trajectory, particularly where there is a complexity of symptoms. This approach also enhances the skills of health care professionals involved, and can lead to mutual respect and understanding of their respective roles.

Shadowing is a collaborative approach that enables a colleague from another discipline/specialty to be accompanied by another health professional in their work. It can be a useful and practical learning opportunity, and has been shown to lead to improved partnership working and better care for patients. Examples could include SPC CNS and CNS from other specialties reviewing patients together to observe each other's work practices, or to identify appropriate interventions.

In all cases of collaborative practice the development of **local guidelines** setting out the parameters for referrals or joint/shared care are recommended.

Formal methods of collaboration are encouraged and facilitated in the UK through integrated care pathways and programmes. These seek to ensure co-ordinated care for people nearing the end of their lives. A small number of acute general hospitals and extended care units in Ireland have adapted and implemented the Liverpool Care Pathway for the Dying Patient.

Further resources and information

“PALLIATIVE CARE FOR ALL: INTEGRATING PALLIATIVE CARE INTO DISEASE MANAGEMENT FRAMEWORKS”

This publication explores the rationale for and development of palliative care for people with non-malignant diseases by considering international policy, service models, research and disease-specific guidelines. It also addresses mechanisms that can be introduced to ensure that access to SPC is based on need rather than diagnosis. In addition to the main document, the report also contains three detailed appendices on the rationale for and role of palliative care for people COPD, dementia and heart failure. It includes extensive reference sections.

It can be downloaded from:

www.hospice-foundation.ie or www.hse.ie by clicking the Publications link. A copy of this booklet is also available in PDF format from this link.

RESOURCE MATERIALS RELATED TO “PALLIATIVE CARE FOR ALL”

Information and resources on the role of palliative care for people with life-limiting diseases are being developed and gathered as part of the implementation of the recommendations of the “Palliative Care for All” report.

They will be available through the Development page of the Irish Hospice Foundation website.

Resources include copies of posters, PowerPoint presentations, and relevant publications on this topic. Updates on research, service initiatives and how to access further briefings on these developments will be available through quarterly Communiqués which will be widely circulated. See the Development page of www.hospice-foundation.ie for full details.

Hard copies of the report are available from the Irish Hospice Foundation, Morrison Chambers, 32, Nassau Street, Dublin 2 Telephone: (01) 679 3188; E-mail: info@hospice-foundation.ie

IRISH HOSPICES/SPECIALIST INPATIENT UNITS

Our Lady’s Hospice, Harold’s Cross, Dublin 6W: www.olh.ie
St. Francis Hospice, Raheny, Dublin 5: www.sfh.ie
Blackrock Hospice, Dublin: www.olh.ie/Departments/BlackrockHospice/
Milford Hospice, Limerick: www.milfordcarecentre.ie

Marymount Hospice, Cork: www.stpatricksmarymount.ie
Galway Hospice: www.galwayhospice.ie
North West Hospice Sligo: Telephone: (071) 914 3317
Donegal Hospice (Letterkenny Inpatient Unit): Telephone: (074) 917 7256

IRISH PALLIATIVE CARE ORGANISATIONS

Irish Association for Palliative Care: www.iapc.ie

The Irish Association for Palliative Care, established in 1993, is an all-Ireland body that aims to promote palliative care nationally and internationally through education, publications, representation on national bodies and opportunities for networking. It has a multi-professional membership.

Irish Hospice Foundation: www.hospice-foundation.ie

The Irish Hospice Foundation is a not-for-profit organisation that promotes the hospice philosophy and supports the development of hospice/palliative care. Its vision is that no one should have to face death or bereavement without appropriate care and support. The website provides up to date information on its work and national developments related to Bereavement, Education and Training Initiatives, Service Developments and Research.

RELEVANT IRISH PROFESSIONAL BODIES AND DISEASE-SPECIFIC SITES

Alzheimer Society of Ireland: www.alzheimer.ie

Irish Heart Foundation: www.irishheart.ie

Irish Thoracic Society: www.irishthoracicsociety.ie

Irish College of General Practitioners: www.icgp.ie/go/courses

National Council for the Professional Development of Nursing and Midwifery: www.ncnm.ie

Irish Nurses Organisation: www.ino.ie

Dementia Services Information and Development Centre: www.dementia.ie

INTERNATIONAL DISEASE-SPECIFIC SITES

Heart Failure Association of the European Society of Cardiology: www.heartfailurematters.org

British Heart Foundation: www.bhf.org.uk

European Society of Cardiology: www.escardio.org

European Respiratory Society: www.ersnet.org

Alzheimer Europe: www.alzheimer-europe.org

Dementia Services Development Centre: www.dementia.stir.ac.uk/training

OTHER USEFUL SITES:

National Gold Standards Framework: www.goldstandardsframework.nhs.uk

National Institute for Clinical Excellence: www.nice.org.uk

National Council for Palliative Care: www.ncpc.org.uk

Help the Hospices: www.helpthehospices.org.uk

Northern Ireland Hospice: www.nihospice.org

Glossary

The following definitions were used in this booklet:

Chronic Obstructive Pulmonary Disease (COPD): COPD is a progressive disease which causes damage to airways in the lungs making it continually difficult to breathe. It is associated with acute exacerbations.

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

Disease Trajectory: This is the course or progression of a disease.

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

Life-limiting disease: Any illness in which there is no reasonable hope of a cure and from which the person will die.

Non-specialist palliative care: The practice of palliative care principles by all health care professionals with a focus on quality of life, which includes good symptom control; a holistic approach that takes into account the person's life experience and current situation; care that encompasses both the dying person and those that matter to that person; and an emphasis on open and sensitive communication, which extends to patients, carers and professional colleagues. The term refers to both Level 1 palliative care approach and Level 2 general palliative care as defined in the NACPC report of 2001.

Specialist Palliative Care (SPC): SPC services are those services whose core activity is the provision of palliative care. These services are involved in the care of patients with more complex and demanding care needs. SPC services are available within primary care settings, acute general hospital settings and specialist in-patient units.

Bibliography

A full reference list is available in the “Palliative Care for All” Report and in each of its disease-specific appendices.

Report of the National Advisory Committee on Palliative Care
(Department of Health and Children 2001)

A National Chronic Disease Management Patient Support Programme for HSE
(HSE 2006)

Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks
(Irish Hospice Foundation/HSE 2008)

Extending the Gold Standard Framework to Non-Cancer Patients
(NHS 2005)

Supportive and Palliative Care in Advanced Heart Failure
(NHS Modernisation Agency 2004)

Guideline on Supporting People with Dementia and Their Carers
(National Institute for Clinical Excellence – NICE – 2007)

How Do We Involve Patients with COPD in Decisions on End of Life Care?
(Taylor et al ERS Congress 2007)

Palliative Care: The Solid Facts
(WHO 2004)

Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age
(Lynn, J. and D.M. Adamson. Rand Health, 2003).