SECTION 7: STANDARDS FOR SUPPORTIVE AND PALLIATIVE CARE

Improving care during the last phase of life means ensuring that people get the appropriate care, at the right time, in the right place, in a way that they can rely on. This often requires a shift in focus from prevention, treatment and cure to alleviating symptoms, making thoughtful decisions, supporting families and providing ongoing care in the appropriate setting. These standards will apply to a number of service frameworks under development and for this reason they are described as generic standards. Their inclusion within a number of service frameworks is of great significance to ensure the equitable delivery of supportive, palliative and end of life care for all people.

Supportive and palliative care is the care given to patients and their families whose disease is not responsive to curative or life sustaining treatment. This care can be provided by practitioners not exclusively concerned with specialist palliative care ie primary care teams; hospital teams and healthcare professionals in a variety of settings (National Institute for Health Research, 2007).

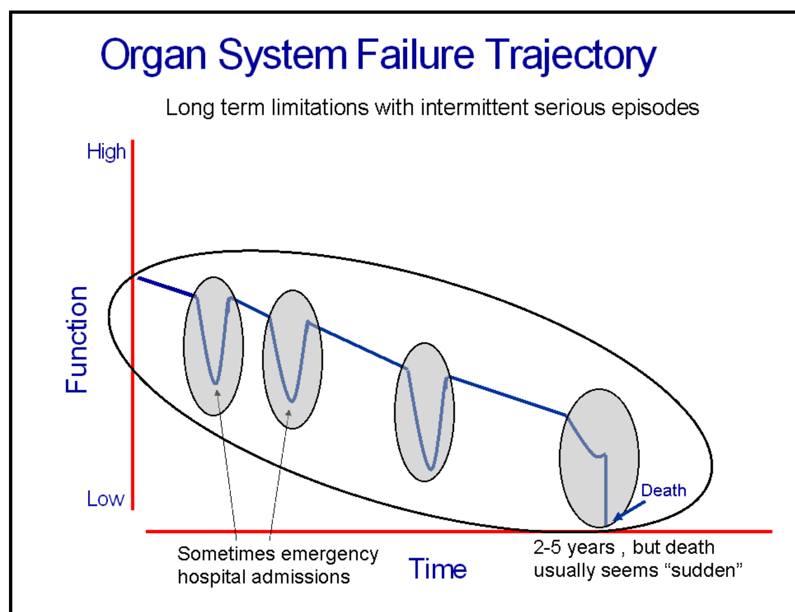
Supportive care is an ‘umbrella’ term for all services, both generalist and specialist, that may be required to support people with life-threatening illness. It is not a response to a particular disease or its stage, but is based on an assumption that people have needs for supportive care from the time that the possibility of a life-threatening condition is raised. (National Council for Palliative Care, 2002).

Palliative care is the active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments. (WHO, 2002)

End of life care helps all those with advanced, progressive, incurable conditions to live as well as possible until they die. It enables the supportive and palliative care needs of both the patient and the family to be identified and met throughout the last phase of life and into bereavement. It includes physical care, management

of pain and other symptoms and provision of psychological, social, spiritual and practical support. (National Council for Palliative Care, Focus on commissioning, Feb 2007)

Recognising the breadth of health and social care providers, patient and carers included within this definition provides both challenge and opportunity in the development of standards which can be measured to demonstrate improvement in the experience of the living and the dying.



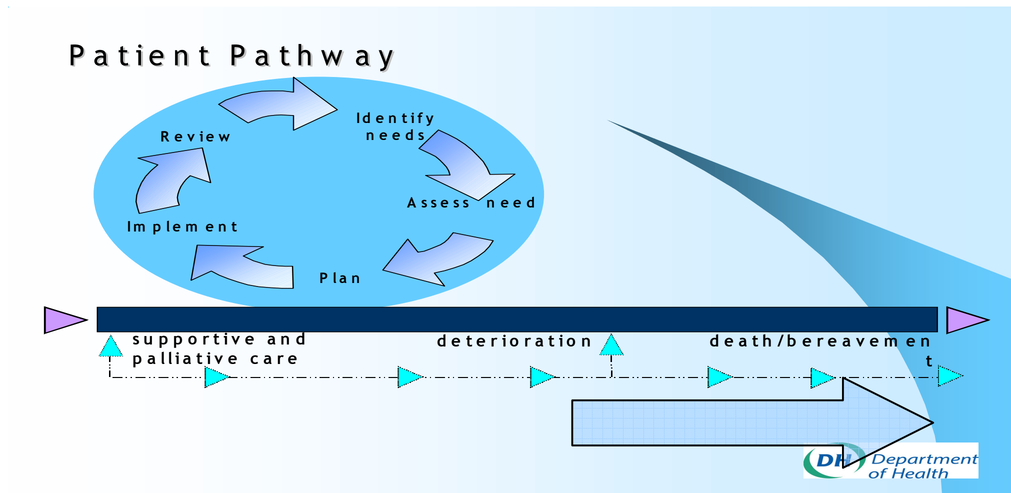
To understand the pathway of a chronic disease, such as heart or lung failure or increasingly cancer, the diagram above attempts to show a pattern of gradual decline in health and wellbeing. Whilst time is particularly difficult to quantify, the experience of living with a chronic disease will be interspersed with episodes of sudden exacerbation, which may be physical and/or psychological in nature.

The large circle emphasizes the early identification of palliative care and inclusion of non-specialist palliative problem solving from early on in the disease trajectory, including issues such as pain management, spiritual, psychological or financial matters.

The small shaded circle in each of the diagrams indicates where particular consideration of the need to refer to, or discharge from,

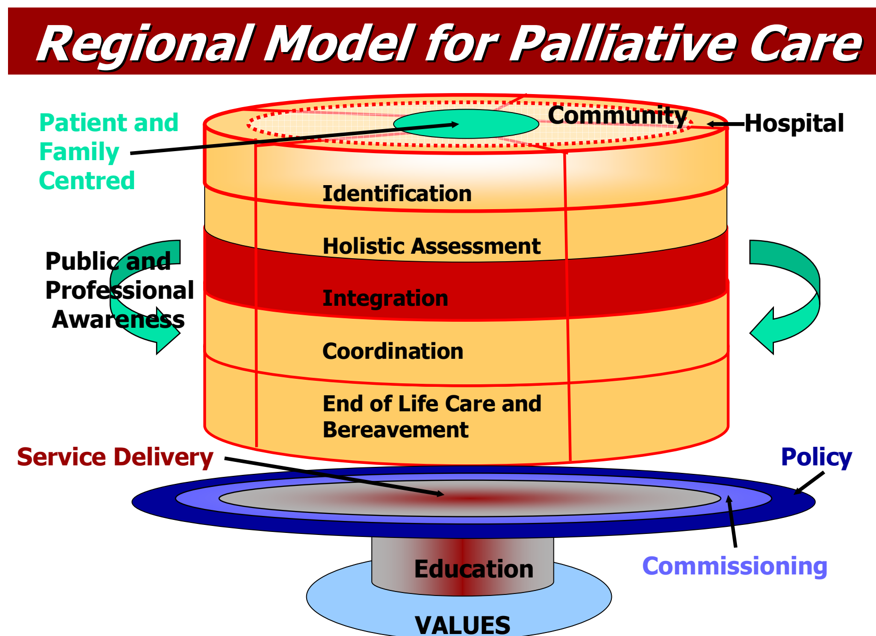
Specialist Palliative Care may rise. The needs identified may be physical, emotional and or / spiritual needs which are particularly complex and cannot be met in totality by the referring team. Referral may result in a one off consultation with an appropriate member of the specialist palliative care team or a period of more intense support.

Figure 1: Continuum of Care (DOH, 2005)



Consultation during the development of these generic standards was sustained to further inform a regional model for palliative and end of life care diagrammatically represented (below)
The guiding principles of the model are patient and family centred care, enhanced community provision and supported by specialist and hospital provision.
Applicable to all conditions, the model consists of six main components:

1. Identification
2. Holistic assessment
3. Integration of Services
4. Coordination of Care
5. End of Life and Bereavement Care
6. Professional and Public Awareness



The model is underpinned by the core values of equity, respect, empowerment and choice. These principles, embedded within robust education, support the quality of service delivery and influence policy and commissioning.

Underpinning outcome of quality for patients with palliative care need is the need for all professionals to have a competent knowledge base and the ability to ensure effective and empathic face to face communication.

Deterioration of a patient's condition should be identified according to the 3 triggers of the Gold Standard Framework prognostic indicator guide for adults with advanced disease.

Three triggers for assessment to decide if the patient may have Supportive/Palliative care needs – to identify these patients there are a number of trigger questions

- **The surprise question**, "Would you be surprised if this patient were to die in the next 6-12 months?" – an intuitive question integrating co- morbidity, social and other factors
- **Choice/Need** – the patient with advanced disease makes a choice for comfort care only, not 'curative' treatment, or is in special need of supportive/ palliative care
- **Clinical indicators** – Specific indicators of advanced disease for each of the three main end of life patient groups – cancer,

organ failure, elderly frail/ dementia. These are an attempt to estimate when patients have advanced disease or are in the last year or so of life. These act as a rough guide to those in primary care and secondary services that a patient may be in need of supportive and palliative care. Hospitals may like to suggest in discharge letters that such patients are included in the GPs Supportive and Palliative Care Register, if considered appropriate.

Heart Disease – CHF(Coronary Heart Disease collaborative,2004)
• At least two of the indicators below:- • CHF NYHA stage III or IV – shortness of breath at rest or on minimal exertion • Patient thought to be in the last year of life by the care team – the “surprise question” • Repeated hospital admissions with symptoms of heart failure • Difficult physical or psychological symptoms despite optimal tolerated therapy

Stroke
• Persistent vegetative or minimal conscious state/dense paralysis/incontinence • Medical complications • Lack of improvement within 3 months of onset • Cognitive impairment/Post-stroke dementia

Renal Disease
• Patient with stage 5 kidney disease who are not seeking or are discontinuing dialysis or renal transplant (from choice or because they are too frail or too many co-morbid conditions) • Patient with stage 4 or 5 chronic kidney disease whose condition is deteriorating and for whom the surprise question is applicable. • Clinical indicators: • CKD stage 5 (eGFR <15 ml/min) • Symptomatic renal failure (anorexia, nausea, pruritus, reduced functional status, intractable fluid overload)

Identification of this stage of the patient's illness should be carried out in full collaboration between patient, carers, the patient's GP and secondary care consultant and their specialist nurse who is usually the ongoing key worker.

Partnerships in Caring (2000) recognised the need for a key worker to be identified to ensure the appropriate sign posting, provision of information and organisation of individualised care in response to need. A lack of description of the elements of this role has lead to an ad hoc approach to the significance and responsibility attached to it. The inclusion of this role is significant across all disease frameworks and potential future service models, to ensure the continuity of care and maximise the quality of patient experience.

It is anticipated that the fulfilment of these standards will shape a service model for supportive, palliative and end of life care across all conditions.

Overarching standard 43:
Health and social care professionals, in consultation with the patient, will identify, assess and communicate the unique supportive, palliative and end of life care needs of that person, their caregiver/s and family.

Rationale:
Early identification of the supportive, palliative and end of life care needs of patients, their care-givers and family, through an holistic assessment, maximises quality of life for all in terms of physical, emotional, social, financial, and spiritual health and wellbeing.

Patients and carers highly value face-to-face communication with skilled health and social care professionals who are able to 'engage with patients on an emotional level, to listen, to assess how much information a patient wants to know, and to convey information with clarity and empathy'

Evidence:-
National Institute for Health and Clinical Excellence (NICE) Improving Supportive and Palliative Care for Adults with Cancer (2004)
http://www.nice.org.uk/Guidance/CSGSP

Supportive and Palliative Care for Advanced Heart Failure, Coronary Heart Disease Collaborative, NHS Modernisation Agency (2004)
http://www.library.nhs.uk/cardiovascular/ViewResource.aspx?resID=78319

National Institute for Health and Clinical Excellence (NICE) Chronic Heart Failure; Management of Chronic Heart Failure in Adults in Primary and Secondary Care (2003) http://www.nice.org.uk/Guidance/CG5

National Institute for Health and Clinical Excellence (NICE) Chronic Obstructive Pulmonary Disease; Management of Chronic Obstructive Pulmonary Disease in Adults in Primary and Secondary Care (2004)
http://www.nice.org.uk/Guidance/CG12

Regional Cancer Framework: A Cancer Control Programme for Northern Ireland DHSSPSNI (2006)
http://www.dhsspsni.gov.uk/eeu_cancer_control_programme_eqia.pdf

Responsibility for delivery / implementation

HSC Trusts
Primary care team, inclusive of social care.
Voluntary Palliative Care Organisations
Private nursing home and care providers

Quality Dimension

Patient Centred, Equity, Effectiveness
Patients and clients should be empowered to identify areas of supportive and palliative care need throughout the progression of their illness. Deterioration of a patient's condition should be identified according to the 3 triggers of the Gold Standard Framework prognostic indicator guide for adults with advanced disease and in collaboration between the patient, carers, the patient's GP, secondary care consultant and their specialist nurse.

Equity, timeliness, safety
All patients identified as requiring supportive and palliative care should have their needs recorded. This should be available to the patient and all health and social care professionals involved in the holistic assessment of needs

Effectiveness
All health and social care professionals should be able to identify the appropriate level of palliative care required for the individual patient

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
Establish a Trust palliative care register/database	Trust report	All Trusts	March 2010
Percentage of patients, with end stage cardiovascular disease, identified as requiring palliative care and who have been placed on the palliative care register/database	Trust palliative care register /database once developed	Establish baseline Performance levels to be determined once baseline established	March 2011

Percentage of patients with a cardiovascular diagnosis on the palliative care register who have had a holistic assessment appropriate to needs and a care plan developed	Trust palliative care register /database once developed	Establish baseline Performance level to be determined once baseline established	March 2011
Percentage of staff (professional and non professional) with appropriate generalist and / or specialist palliative care training to prescribed level of competency (as per NICaN S&PC Education)	Trust training records of all cardiovascular team members CPD records	Establish baseline Performance level to be determined once baseline established	March 2011
Percentage of cardiovascular team members who have had training in appropriate palliative care competencies	Trust Report	30% 70% 90%	March 2010 March 2011 March 2012

Overarching standard 44:
All patients, carers and families should have access to responsive, integrated services which are co-ordinated by an identified team member according to an agreed plan of care, based on their needs.

Rationale:
The coordinated delivery of an agreed plan of care, in collaboration with the patient, will ensure the appropriate engagement of members of the multi professional team, at generalist and /or specialist level, across all care settings and inclusive of caregivers and families.

Evidence:
National Institute for Health and Clinical Excellence (NICE) Improving Supportive and Palliative Care for Adults with Cancer (2004)
http://www.nice.org.uk/Guidance/CSGSP

Definitions of levels of palliative care, National Council for Palliative Care
http://www.ncpc.org.uk

Supportive and Palliative care for advanced heart failure, Coronary Heart Disease Collaborative, NHS Modernisation Agency (2004)
http://www.library.nhs.uk/cardiovascular/ViewResource.aspx?resID=78319

National Institute for Health and Clinical Excellence (NICE) Chronic Heart Failure; Management of Chronic Heart Failure in Adults in Primary and Secondary Care (2003) http://www.nice.org.uk/Guidance/CG5

National Institute for Health and Clinical Excellence (NICE) Chronic Obstructive Pulmonary Disease; Management of Chronic Obstructive Pulmonary Disease in Adults in Primary and Secondary Care (2004)
http://www.nice.org.uk/Guidance/CG12

Responsibility for delivery / implementation

HSC Trusts
Primary Care teams
Voluntary palliative care providers
Private nursing home providers

Quality Dimension			
Equity, patient centred care, effectiveness, efficiency, safety All patients and carers should have an agreed plan of care that ensures timely and effective communication of information, reflecting their individual care needs including intended outcomes of care. Patients and carers have access to a range of services including 24-hour nursing (with rapid response), AHP input, night sitting, day sitting, social care, care packages, pharmacy, hospice-at-home, intermediate care/respite /daycare, dedicated in-patient beds, specialist advice, psychological, emotional and spiritual support and bereavement services.			
Performance Indicator:	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of patients with cardiovascular disease with an identified / named key worker responsible for ensuring the 24 hour plan of care is communicated to relevant professionals	Trust palliative care register /database Audit of percentage of people on register with documented key worker	Establish baseline Performance level to be determined once baseline established	March 2010
Establish a system to ensure that updated out of hours handover forms held manually are transferred to all relevant professionals for patients who are actively receiving palliative care	Trust report	All Trusts	March 2011

Establish a system to ensure that all patients on the Trust palliative care register/database with unresolved symptoms and complex psychosocial needs have been referred to specialist palliative care services for advice or management in accordance with the Regional Criteria for Specialist Palliative Care	Trust palliative care register/database Trust report Audit	All Trusts	March 2011

Overarching standard 45:
All people with advanced progressive conditions, their caregivers and families, will be informed about the choices available to them, by an identified team member, and have their dignity protected through the management of symptoms and provision of comfort in end of life care.

Rationale
"End of life care" has the potential to enhance care for the dying person and their family, culminating in a well coordinated, responsive and identified approach to their unique needs at this time.

When professionals overcome their desire to protect patients from potentially distressing information and discuss end of life issues honestly, with sensitivity to patient and carer, the outcome maximises the health and well being of the patient, carers and family.

Advanced care planning should include Do Not Attempt Resuscitation (DNAR) decision making and Preferred Place of Care in the event of deterioration to include hospitalisation, and intensive care, where appropriate.

Evidence:
National Institute for Health and Clinical Excellence (NICE), 2004, Improving Supportive and Palliative Care for Adults with Cancer
http://www.nice.org.uk/Guidance/CSGSP

Regional Cancer Framework: A Cancer Control Programme for Northern Ireland DHSSPSNI (2006)
http://www.dhsspsni.gov.uk/eeu_cancer_control_programme_eqia.pdf

Supportive and Palliative care for advanced heart failure, Coronary Heart Disease collaborative, NHS Modernisation Agency (2004) -
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http://www.nice.org.uk/Guidance/CG12

Responsibility for delivery / implementation			
HSC Trusts Primary Care teams Voluntary palliative care providers Private nursing home providers			
Quality Dimension			
Equity, effectiveness, patient centred Patients should be enabled to die in their preferred place of care, where possible Patients who meet the criteria should be placed on the Care of the Dying Pathway			
Performance Indicator:	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of patients with cardiovascular disease who are enabled to die in their appropriate preferred place of care (identified as part of regular reviewed assessments)	Trust palliative care register /database Audit of percentage of patients who achieve their preferred place of care	Establish baseline Performance level to be determined once baseline established	March 2010
Establish a common approach to care for people in the last days of life e.g. Care of the Dying Pathway in hospital and community	Trust report	All Trusts Performance level to be determined once baseline established	March 2010 March 2011

Percentage of appropriate professionals trained in advanced communication skills (particularly Breaking Bad News)	Trust report Trust Training Records	Establish baseline Performance level to be determined once baseline established	March 2010