8. 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 treatment. This care can be provided by practitioners not exclusively concerned with specialist palliative care i.e. primary care teams; hospital teams and healthcare professionals in a variety of settings (National Institute for Health Research, 2007).

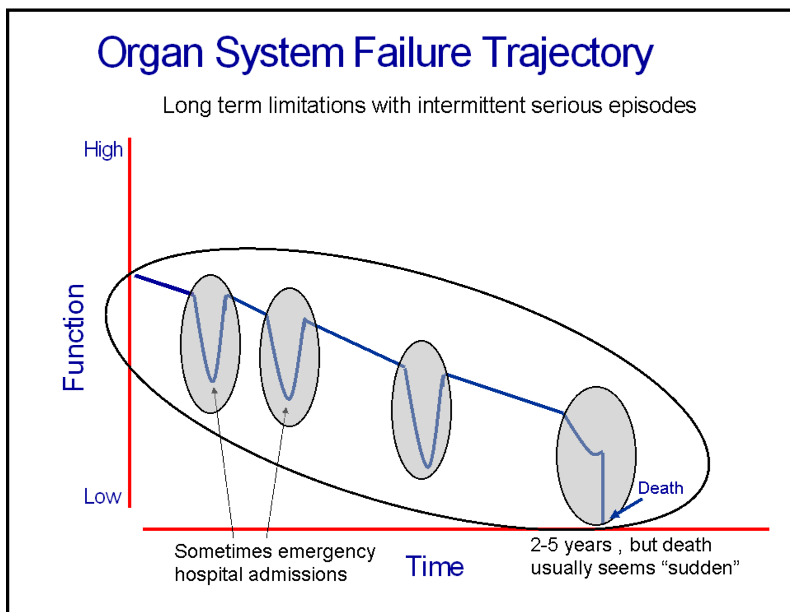
Supportive care is an ‘umbrella’ term for all services, both generalist and specialist, that may be required to support people with life-threatening illness. It is not a response to a particular disease or its stage, but is based on an assumption that people have needs for supportive care from the time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



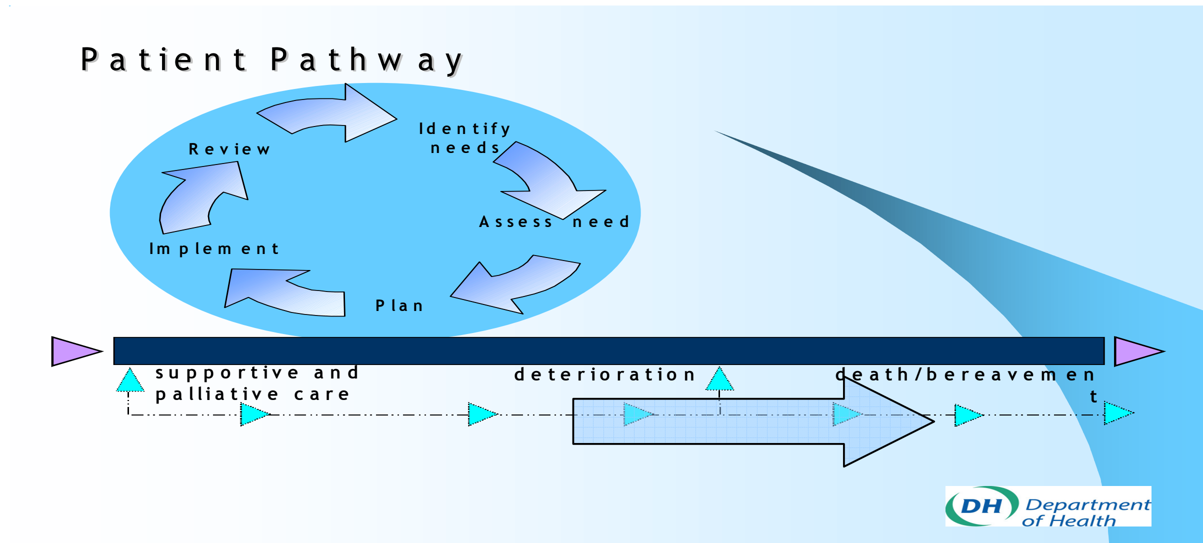
To understand the pathway of a chronic disease, such as heart or lung failure, the diagram above attempts to show a pattern of gradual decline in health and wellbeing. Whilst time is particularly difficult to quantify, the experience of living with a chronic disease will be interspersed with episodes 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 has endorsed the importance of the following key concepts:

- Early identification of palliative care patients across all disease care pathways.
- Holistic assessment.
- Coordination of care.
- Recognising that someone is at end of life and ensuring the delivery of high quality care.

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.

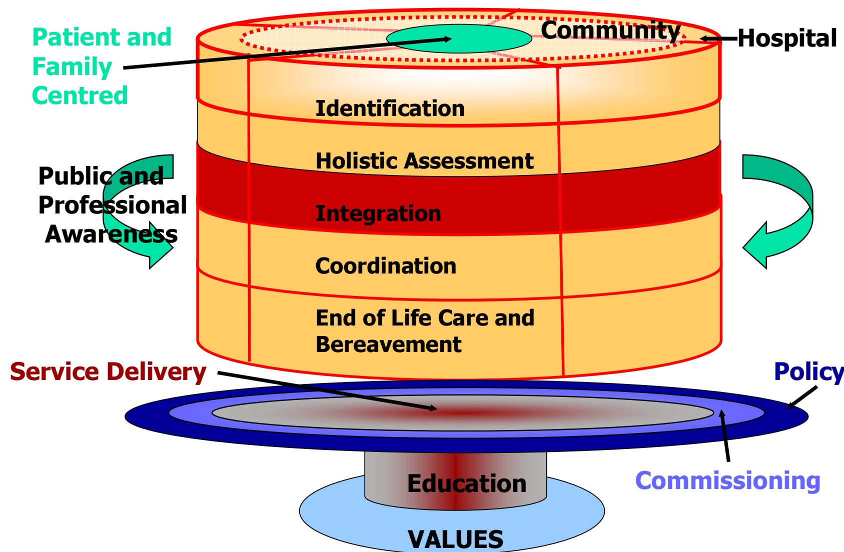
Identification of this stage of the patient's illness should be carried out in full collaboration between patient, carers, the patient's GP and secondary care consultant and their respiratory specialist nurse who is usually the ongoing key worker.

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 e.g. for COPD
    - Disease assessed to be severe e.g. FEV1 < 30% predicted
    - Recurrent hospital admissions (> 3 in 12 months for COPD exacerbations)
    - Fulfils Long Term Oxygen Therapy criteria
    - MRC breathlessness grade 4/5
    - Signs and symptoms of right heart failure
    - Combination of other factors e.g. anorexia, previous ICU/NIV/resistant organism

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.



Consultation during the development of the generic standards was sustained to further inform a regional model for palliative and end of life care diagrammatically represented (above)
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.

The following standards have been based on the generic overarching palliative care standards, but modified to take account of specific respiratory diseases.

Overarching standard 53:

Palliative Care
Health and social care professionals, in consultation with the patient, should 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) (2004) Improving Supportive and Palliative Care for Adults with Cancer
http://www.nice.org.uk/Guidance/CSGSP

National Institute for Health and Clinical Excellence (NICE) (2004) Management of chronic obstructive pulmonary disease in adults in primary and secondary care (Update due in June 2010)
http://www.nice.org.uk/Guidance/CG12

Gold Standards Prognostic Framework Programme, NHS End of Life Care programme (2006) Prognostic Indicator Paper vs 2.25
http://www.goldstandardsframework.nhs.uk

Responsibility for delivery / implementation

HSC Trusts
Primary Care (including community pharmacy)
Voluntary Palliative Care Organisations
Private nursing home and care providers

Quality Dimension
1. **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 patient, carers, the patient's GP, secondary care consultant and their specialist nurse. 2. **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. 3. **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 palliative care database	HSC Trust report	All HSC Trusts	March 2011
Percentage of patients with COPD with MRC grade 5 who have been assessed as to whether they have palliative care needs using the Gold Standards framework guidance	LTC DES (to be revised) QOF dataset	Establish baseline Performance level to be determined once baseline established	March 2012
Percentage of patients with a respiratory diagnosis on the Trust palliative care database who have had an holistic assessment appropriate to needs and a care plan developed (including carer needs)	Palliative care database Audit HSC Trust report	Establish baseline Performance level to be determined once baseline established	March 2012
Percentage of the specialist respiratory team members who have had training in appropriate palliative care competencies	HSC Trust report	70% 95%	March 2011 March 2012

Overarching standard 54:

Palliative Care
All patients, carers and families should have access to responsive, integrated services which are coordinated 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) (2004) Improving Supportive and Palliative Care for Adults with Cancer
http://www.nice.org.uk/Guidance/CSGSP

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

National Institute for Health and Clinical Excellence (NICE) (2004) Management of chronic obstructive pulmonary disease in adults in primary and secondary care (Update due in June 2010)
http://www.nice.org.uk/Guidance/CG12

Responsibility for delivery / implementation

HSC Trusts
Primary Care (including community pharmacy)
Voluntary palliative care providers
Private nursing home providers

Quality Dimension

1. **Equity, patient centred care, effectiveness, efficiency, safety**
   All patients and carers should have an agreed plan of care which 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, bereavement services.

Performance Indicator:	Data source	Anticipated Performance Level	Date to be achieved by
Percentage of patients with respiratory disease with an identified named key worker (usually specialist respiratory team member) responsible for ensuring the 24 hour plan of care is communicated to relevant professionals	Palliative care database Audit of percentage of people on register with a documented key worker	Establish baseline Performance level to be determined once baseline established	March 2011
Establish a system to ensure that updated out of hours handover forms held manually are transferred to all relevant professionals for patients who are at end of life	HSC Trust report	All HSC Trusts	March 2012
Establish a system to ensure that all patients on the Trust palliative care register / database with unresolved symptoms and complex psychosocial needs have appropriate input from specialist palliative care services for advice or management in accordance with the Regional Criteria for Specialist Palliative Care	Palliative care database HSC Trust report Audit	All HSC Trusts	March 2012

Overarching standard 55:

End of Life Care
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 maximising 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.

Advance care planning should include Do Not Attempt Resuscitation (DNAR) decision making and Preferred Place of Care in the event of deterioration to include hospitalisation, Non invasive Ventilation (NIV) and Intensive Care, where appropriate.

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

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

National Institute for Health and Clinical Excellence (NICE) (2004) Management of chronic obstructive pulmonary disease in adults in primary and secondary care (Update due in June 2010)
http://www.nice.org.uk/Guidance/CG12

Responsibility for delivery / implementation

HSC Trusts
Primary Care (including community pharmacy)
Voluntary palliative care providers
Private nursing homes

Quality Dimension			
1. Equity, effectiveness, patient centred Patients should be enabled to die in their preferred place of care, where possible Patients who meet the criteria should have their care recorded using the Care of the Dying Pathway			
Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of patients with respiratory disease who are enabled to die in their appropriate preferred place of care (identified as part of regularly reviewed assessments)	Palliative care database Audit of percentage of patients who achieve their preferred place of care	Establish baseline Performance indicator to be determined when baseline established	March 2011 March 2012
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	HSC Trust report	All HSC Trusts Performance indicator to be determined when baseline established	March 2011 March 2012
Percentage of appropriate respiratory professionals trained in advanced communication skills	HSC Trust report	Establish baseline Performance indicator to be determined when baseline established	March 2011 March 2012