

SECTION 9 - PALLIATIVE & END OF LIFE CARE

About 3,560 people die from cancer each year. This figure is expected to rise with the predicted increase in people with cancer. Palliative and end of life care focuses on all aspects of care needed by patients and their families, physical, emotional and spiritual. It involves relief of symptoms, making thoughtful decisions, supporting families and providing ongoing care in the appropriate setting. It is important that people in the last phase of life get the appropriate care, at the right time, in the right place, in a way that they can rely on. The following standards are designed to improve the patient and family experience of palliative and end of life care through *holistic assessment* of need, improved coordination of care and a greater focus on choice at end of life.

Overarching standard 50:

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 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:

Living Matters: Dying Matters – A Strategy for Palliative and End of Life Care for Adults in Northern Ireland. DHSSPSNI (2010)

http://www.dhsspsni.gov.uk/855_palliative_final.pdf

National Institute for Health and Clinical Excellence (NICE) (2004) Improving Supportive and Palliative Care for Adults with Cancer

<http://guidance.nice.org.uk/CSGSP>

Definitions of levels of palliative care, National Council for Palliative Care

<http://www.ncpc.org.uk>

Gold Standards Prognostic Framework Programme, NHS End of Life Care programme. England 2006. Prognostic Indicator Paper vs 2.25

http://www.goldstandardsframework.nhs.ukcontent/gp_contract/Prognostic%20Indicators%20Guidance%20Paper%20v%2025.pdf

DHSSPS (2006) Regional Cancer Framework: A Cancer Control Programme for Northern Ireland DHSSPSNI

http://www.dhsspsni.gov.uk/eeu_cancer_control_programme_eqia.pdf

Responsibility for delivery / implementation

HSC Board
Public Health Agency
NICaN Supportive and Palliative Care Network
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 a cancer diagnosis, 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 level to be determined once baseline established	March 2011
Percentage of patients with a cancer diagnosis on the palliative care register/database who have had an <i>holistic assessment</i> 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

<p>Percentage of staff (professional and non professional) with appropriate generalist and/or specialist palliative care training to prescribed level of competency (as per NICE S&PC Education)</p>	<p>Trust Training Records</p>	<p>Establish baseline Performance level to be determined once baseline established</p>	<p>March 2011</p>
<p>Percentage of cancer team members who have had training in appropriate palliative care competencies</p>	<p>Trust Report</p>	<p>30% 70% 90%</p>	<p>March 2010 March 2011 March 2012</p>

Overarching standard 51:

All patients, carers and families 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:

Living Matters: Dying Matters – A Strategy for Palliative and End of Life Care for Adults in Northern Ireland. DHSSPSNI (2010)

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National Institute for Health and Clinical Excellence (NICE) (2004) Improving Supportive and Palliative Care for Adults with Cancer

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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/respice/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 cancer diagnosis 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 a 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

<p>Establish a system to ensure that all patients on the Trust palliative care register/database with unresolved symptoms and complex psychosocial needs who have been referred to specialist palliative care services for advice or management in accordance with the Regional Criteria for Specialist Palliative Care</p>	<p>Trust palliative care register/ database</p> <p>Trust report</p> <p>Audit</p>	<p>All Trusts</p>	<p>March 2011</p>
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Overarching standard 52:

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 Resuscitation (DNAR) decision making and preferred place of Care in the event of deterioration to include hospitalisation, and intensive care, where appropriate

Evidence:

Living Matters: Dying Matters – A Strategy for Palliative and End of Life Care for Adults in Northern Ireland. DHSSPSNI (2010)

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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 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 cancer diagnosis who are enabled to die in their appropriate preferred place of care (identified as part of regularly 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
Percentage of appropriate professionals trained in advanced communication skills (Breaking Bad News)	Trust report Trust Training Records	Establish baseline Performance level to be determined once baseline established	March 2010