

Quality Standards for End-of-Life Care in Hospitals - an overview

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**Chairman, National Steering Committee
Hospital *friendly* Hospitals (HfH) Programme**

Hospice *friendly* Hospitals Programme (2008-2012)

A two phase 5-year programme

- focus on the **patient**
- focus on the **family**
- focus on the **staff**
- focus on the **hospital**



Multidisciplinary Care

Pharmacist

Physiotherapist

Speech & Language
Therapy

Day Hospital / Ambulatory
Day Care

Family

Occupational Therapist

Day Centre

Patient

Chiropodist / Podiatrist

PHN / C. Care Team

Clinical Nutrition / Dietician

Liaison Nurse / MSW

Nurse (CNM) /
Clinical Nurse Specialist

General
Practitioner

Hospital
Doctor







End of Life Care in the context of the Hospice *friendly* Hospitals Programme



No one should have to face death or bereavement without the appropriate care and support.

HfH Programme

Hospice principles

into

Hospital practice

Key Themes of the HfH Programme

- **Integrated Care**

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- **Integrated Care**

- **ALL** dying patients and their families will benefit from the application of hospice / palliative care principles and philosophy in the care that they receive

Key Themes of the HfH Programme

- Integrated Care
- **Communication**

Key Themes of the HfH Programme

- **Communication**

- Breaking bad news to:
 - patient / relatives
- Documentation in patient's chart re conversations around end-of-life care
- Multidisciplinary Team working?
- '**What** do I say?' / '**How** do I say it?' / '**Where** do I say it?'
- Communication Skills programme
 - For **ALL** staff
 - some feel / are uncomfortable

Key Themes of the HfH Programme

- Integrated Care
- Communication
- **Design & Dignity**

Key Themes of the HfH Programme

- **Design & Dignity**

- Tribal Consulting – Baseline Survey launched on 6th Nov '07
- Does the design of the physical environment of our hospitals promote dignity and privacy for patients and their family at end-of-life?
- Prof. Roger Ulrich

Hospice *friendly* Hospitals PROGRAMME

Design & Dignity Guidelines for Physical Environments of Hospitals Supporting End-of-Life Care

Irish Hospice Foundation

February 2008



www.hospicefriendlyhospitals.net

Putting Hospice Principles into Hospital Practice

Key Themes of the HfH Programme

- Integrated Care
- Communication
- Design & Dignity
- **Patient Autonomy**

Key Themes of the H/H Programme

- **Patient Autonomy**

- Patient **CHOICE**
- Patient **CONSENT**
- The **certainty** of symptomatic relief
- Balancing **beneficial** v. **futile** interventions

- Addressing the legitimate concerns of **MULTIPLE** family members

The cycle of Life & Death



Also.....

- ascertaining when a patient:
 - is at the **End-of-Life** (months, weeks.....)
 - is **Dying** (weeks, days, hours.....)

and then.....

- the issue of **Sudden** vs. **Anticipated** Death
- The 'uniqueness' of **Death**
- **Bereavement**

Hospital *friendly* Hospitals (HfH)

Care at the End-of-Life

v

End-of-Life **Care**

Era of Assessment and Accountability



‘ We can no longer afford to provide healthcare without knowing more about its successes and failures. The *era of Assessment and Accountability* is dawning at last; it is the third and latest, *but probably not the last*, phase of our efforts to achieve an equitable health care system, of satisfactory quality, at a price we can afford.’

Arnold Relman '88

Development of Standards
a **central objective** of the
HfH Programme

Public Consultation

152 submissions received



**Draft Quality Standards for
End of Life Care in Hospitals**
A Consultation Document



PUBLIC CONSULTATION
on
Quality Standards for End-of-Life Care in Hospitals

Draft **Quality Standards for End-of-Life Care in Hospitals** have been developed to support and enhance the provision of high-quality end-of-life care within all hospital settings, but particularly in the acute care setting.

Submissions are invited from members of the public, hospital user groups, health and social care providers, professional and staff organisations and statutory agencies.

The draft standards & consultation feedback form are available to download or complete online at:

www.hospicefriendlyhospitals.net

Hard copies of the documents are also available on request from:

Helen Donovan, Standards Development Coordinator,
The Irish Hospice Foundation,
4th Floor, Morrison Chambers, 32 Nassau Street, Dublin 2.
Tel. (01) 679 3188 Email: helen.donovan@hospice-foundation.ie

Closing date for submissions: Friday 31st July 2009

Putting Hospice Principles into Hospital Practice.



**HospiceFriendly
HOSPITALS**

Putting Hospice Principles into Hospital Practice.

Quality Standards for End-of-Life Care in Hospitals

Making end-of-life care central to hospital care



The
ATLANTIC
Philanthropies



Medical audit

Rationale
and
practicalities

Edited by
Simon P. Frost
Philip J. Barr
W. Angus

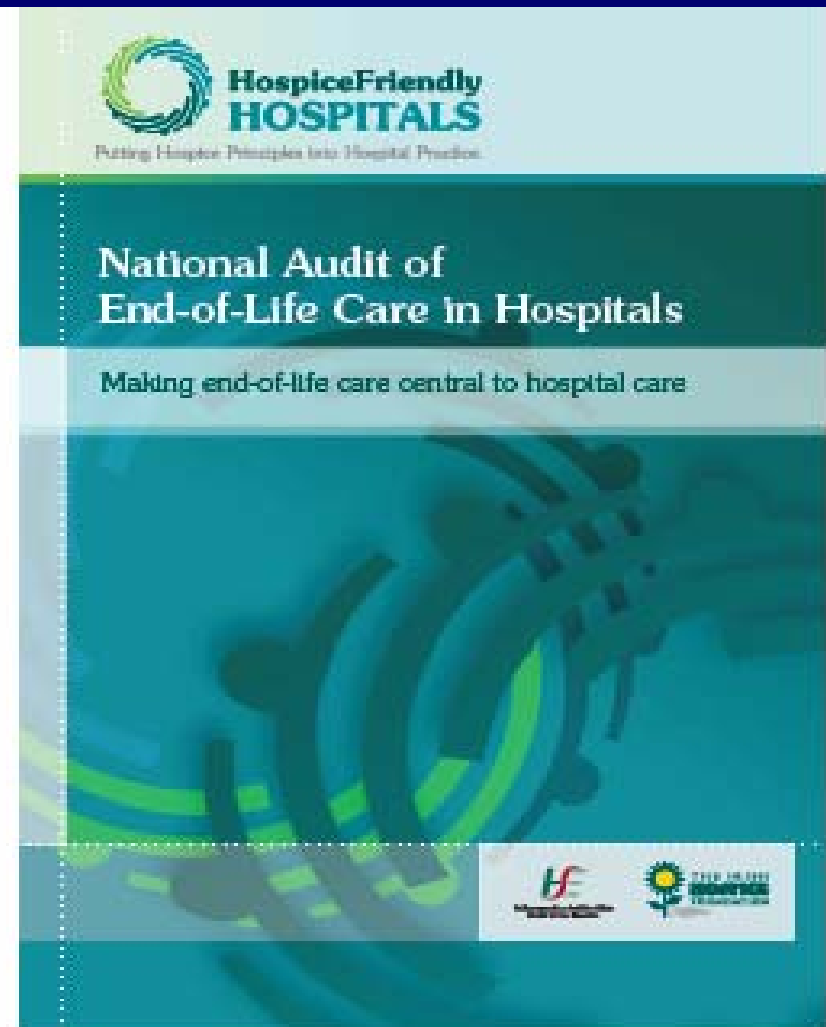
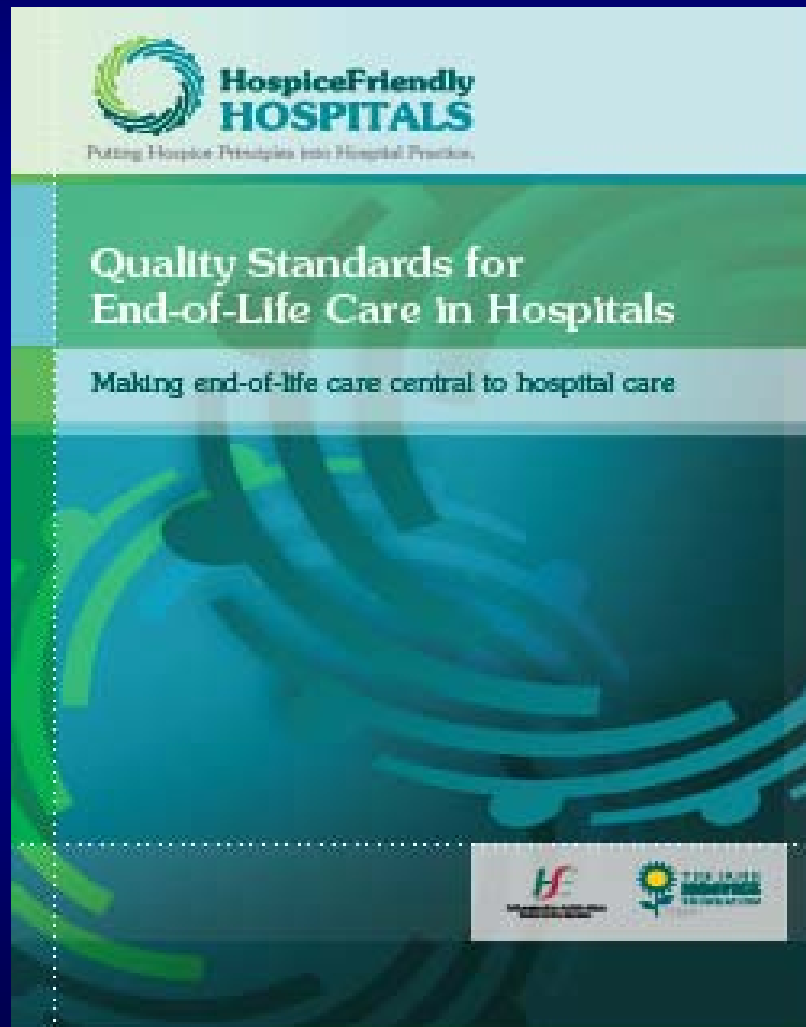
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KEY TOPICS

EVIDENCE-BASED MEDICINE

D.P.B. MCGOVERN • P.M. VALORI • W.S.M. SUMMERSKILL • M. LEVI

Regression
Cohort
Stratification
Meta-analysis

The Link between Standards and Audit



National Audit - 8 Key Inputs

- Disease & Cause of Death
- Quality of Communication with Patients & Relatives
- Route of Admission
- Facilitating Relatives
- Physical Environment
- Staff Readiness
- Team Meetings
- Hospital Governance

The Link between Standards and Audit

Standard 1. The Hospital

The hospital has systems in place to ensure that end-of-life care is central to the mission of the hospital and is organised around the needs of patients.

- 1.1 - put End-of Life objectives in the Hospital's **Service Plan**
- 1.2 - move from Emergency to Planned **Admissions**
- 1.3 - improve the Hospital's **Physical Environment** and usage of **Single Rooms**
- 1.4 - improve documentation in the **Healthcare Record**
- 1.5 - ensure **sufficient Ward Staff**
- 1.6 - improve Hospital **Information Systems**
- 1.7 - facilitate patients to **die at home**

Standard 1 The Hospital

The hospital has systems in place to ensure that end-of-life care is central to the mission of the hospital and is organised around the needs of patients.



"A member of the management team is responsible for end-of-life issues."

- 1.1 A Culture of **Compassionate** End-of-Life Care
- 1.2 General **Governance Policies and Guidelines**
- 1.3 Effective **Communication** with Patients and their Families
- 1.4 The **Healthcare Record**
- 1.5 The Hospital **Environment**
- 1.6 **Monitoring** and **Evaluating** End-of-Life Care
- 1.7 Assessing and Responding to the End-of-Life Care **needs of Patients**
- 1.8 Clinical Responsibility & **Multidisciplinary** working
- 1.9 **Symptom Management** – N.B. Pain
- 1.10 Clinical **Ethics** Support
- 1.11 Care **after Death**
- 1.12 **Post Mortems**
- 1.13 **Bereavement Care**

The Link between Standards and Audit

Standard 2. The Staff

Staff are supported through training and development to ensure they are competent and compassionate in carrying out their roles in end-of-life care.

- 2.1 - develop **skills to diagnose** End-of Life and Dying
- 2.2 - improve End-of Life Care **Decision-making**
- 2.3 - hold **Team Meetings**
- 2.4 - provide **Training** in End-of Life Care
- 2.5 - **prepare** staff for the Death of Patients
- 2.6 - build on the **Experience** of Staff

Standard 2 The Staff

Staff are supported through training and development to ensure they are competent and compassionate in carrying out their roles in end-of-life care.



"Each one of us knows what happens next."

- 2.1 Cultivating a Culture of **Compassionate** End-of-Life Care
- 2.2 Staff **Induction**
- 2.3 Staff **Education and Development** Needs
- 2.4 Staff Education and **Training** Programmes
- 2.5 **Specialised Education** in End-of-Life Care

The Link between Standards and Audit

Standard 3. The Patient

Each patient receives high quality end-of-life care that is appropriate to his / her needs and wishes.

3.1 - extend to **ALL Patients** the Quality of Care for Cancer Patients

3.2 - improve the **Quality of Communication** with Patients

3.3 - strengthen the role of **Specialist Palliative Care**

Hierarchy of Illness

- **Cancer** →
- **Circulatory** (heart & brain) →
- **Respiratory** →
- **Dementia / Frailty**

Standard 3 The Patient

Each patient receives high quality end-of-life care that is appropriate to his/her needs and wishes.



"Ask me what I want"

- 3.1 **Communicating Diagnosis** of the possibility of a need for End-of-Life Care
- 3.2 Clear and Accurate **Information**
- 3.3 **Patient Preferences**
- 3.4 **Symptom Management** N.B. **pain**
- 3.5 **Discharge** from Hospital
- 3.6 The **Dying Patient**

The Link between Standards and Audit

Standard 4. The Family

Family members are provided with compassionate support and, subject to the patient's consent, given information before, during and after the patient's death.

4.1 General **Support for Families**

4.2 Support for families following **Sudden Deaths**

Standard 4 The Family

Family members are provided with compassionate support and, subject to the patient's consent, given information before, during, and after the patient's death.



"We would like to be involved, but our mother's wishes are paramount."

- 4.1 **Communication** with Family members **in general**
- 4.2 Communication with Family members –**where Death may be anticipated**
- 4.3 Communication with Family members **sudden / Unexpected Death** or **sudden Irreversible Decline** in health leading to death
- 4.4 Patient **Discharge Home**
- 4.5 **Supporting Family** Members
- 4.6 Responding to the **needs of Family Members after a Death**

How do we know that standards are being met?

- **Symptom Control**
 - PAIN
 - nausea
 - sleep disturbance
- **Hospital Guidelines** (evidence-based)
 - on prescribing for pain
 - on documentation
 - on referral for specialist opinion
 - Palliative Medicine
 - Radiotherapy
 - Pain Specialists

How do we know that standards are being met?

- **Staff Education & Training**

- Hospital provides opportunities, time & resources to staff
- regular reviews of content / format
- for ALL staff (e.g. 2-year cycles)
- more detailed training for clinical leads in End-of-Life Care

The Dying Patient

The particular needs of a patient whose death is imminent are addressed and provided for.....

- Patient's wishes are known / respected
- optimum symptom control
- specific staff deployed
- Family advised / involved
- privacy, space
- apply EoL Care Guidelines / Pathways

Quality Standards for End-of-Life Care in Hospitals



Information Notes to support the **Quality Standards** for **End-of-Life Care in Hospitals**

- Why Clinical Ethics Support is Important
- The Healthcare Record
- Guidelines on End-of-Life Care
- Post-Mortems
- Staff Competencies
- Education & Training Programmes

Information Notes to support the **Quality Standards for End-of-Life Care in Hospitals**

- Symptom Management – especially **PAIN relief**
- Communication
- Ascertaining Patient Preferences
- Supporting Family Members after a Death
- Monitoring & Evaluating End-of-Life Care

Information Notes to support the Quality Standards for End-of-Life Care in Hospitals



Information Notes to support the Quality Standards for End-of-Life Care in Hospitals

NOTE 1

Why Clinical Ethics Support is Important

- The provision of healthcare involves achieving a balance between promoting the well-being and best interests of patients and respecting their right to be partners in decisions made about their treatment. This balance requires accommodating a number of different value-systems, some of which may be in conflict with one another. Clinical ethics support contributes to the clarification and resolution of these value-conflicts.
- The ethical climate of an organisation has a significant impact on staff attitudes, turnover rates and absenteeism, and on the prevalence of moral distress and burnout among health professionals; in organisations in which staff feel respected and fairly treated by colleagues, they report higher quality of care ratings, increased job satisfaction and greater trust in management.
- Excellence in the delivery of end-of-life care requires ongoing education of staff in relation to patients' rights, relationships, treatment decisions, communication methods and mediation techniques.
- Excellence in the delivery of care requires ongoing education of staff in relation to patient rights, issues of consent and confidentiality, communication methods and mediation techniques.
- Mechanisms and frameworks for ethical decision-making are needed to assist health professionals, patients and families in making difficult decisions.
- There is a need for a fair and reasonable process for the resolution of conflicts arising in the context of the provision of care.
- There is a need for past mistakes to be acknowledged and skillfully converted into learning opportunities for health professionals and staff, in order to prevent recurrence.
- There is a need for advocacy on behalf of those who do not have a voice because they lack power in the medical hierarchy (patients, members of minority populations, staff in vulnerable positions, low-paid contract employees).

*Hospice Friendly Hospitals Programme 2007: An Ethical Framework for End-of-Life Care: Dublin: The Irish Hospice Foundation Available at: www.hospicefriendlyhospitals.net/ethical-framework Accessed 19th April 2010



Information Notes to support the Quality Standards for End-of-Life Care in Hospitals

NOTE 2

The Healthcare Record

The Healthcare Record includes

- The patient's overall care plan
- The clinical diagnosis that a patient may be approaching end of life and/or dying
- The name of the lead clinician responsible for the patient's care
- Assessment of the patient's initial capacity to give consent and make decisions, and subsequent reviews
- The core content of conversations with the patient and his/her family, where appropriate, relating to diagnosis and prognosis
- Monitoring of the patient's pain and symptoms
- Patient preferences across a range of aspects of end-of-life care
- Any changes in respect of clinical responsibility for the patient
- Transfer/discharge plans
- Referral (if made) to the specialist palliative care service
- Any engagement with or interventions by the specialist palliative care service.



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Information Notes to support the Quality Standards for End-of-Life Care in Hospitals.

NOTE 3

Possible Guidelines on End-of-Life Care

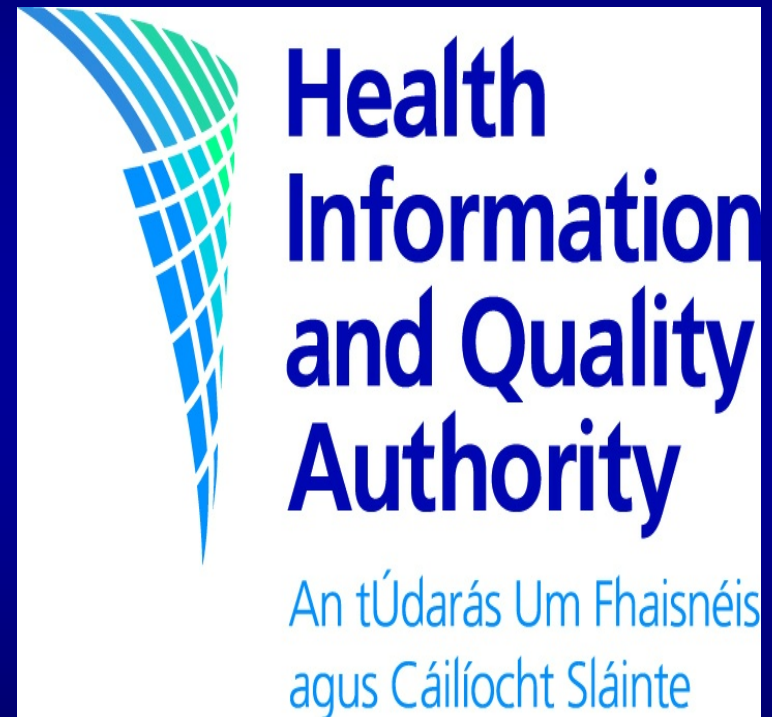
- Recognising the possibility that a patient may be approaching end of life
- Advance care planning
- Resuscitation
- Identifying and addressing any additional or special needs a patient may have, e.g., intellectual disability, reduced capacity, mental health difficulties, significant difficulties in coping
- Pain and symptom management
- Communicating between disciplines, teams and hospital and community based service providers
- Referring to specialist palliative care services
- Transferring patients home/elsewhere to die
- Responding to patients' different cultural & religious practices/beliefs
- Use of interpreters
- Diagnosing dying
- Caring for the dying patient
- Organ Donation
- Care of the deceased patient's body at the time of death including verification of death & last offices
- Care of the deceased patient's body after death, including meeting religious and cultural needs
- Care of personal belongings and handover to family.
- Transferring a deceased patient to the mortuary/elsewhere
- Supporting families of patients at the end-of-life
- Addressing issues arising from sudden death
- Death notification and death certification
- Providing care and support to parents who experience a miscarriage
- Providing care and support to parents who experience an intra-uterine death, a stillbirth or a neonatal death
- Formal identification of the deceased person and viewing by families
- Post-mortems, including hospital and coroner post-mortems, organ/tissue donation, storage and return
- Repatriation of the deceased person's body
- Making funeral arrangements
- Mortuary services/practices
- Burial or cremation by the hospital
- Provision of bereavement care
- Support for staff caring for patients at end of life and their families

HIQQA

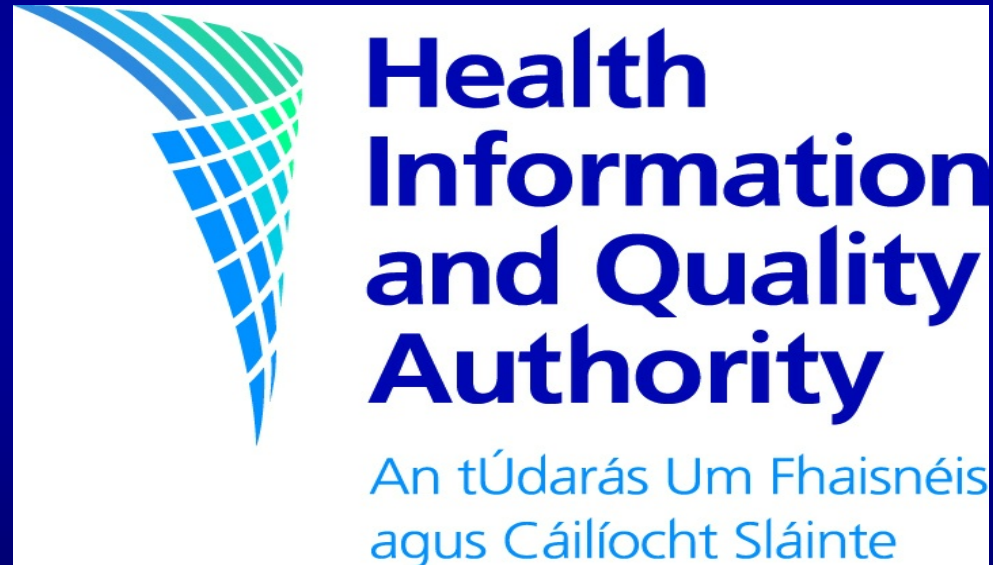
Implementation of the Quality Standards for End-of-Life Care in Hospitals

HIQA has endorsed the work of the H/H Programme in relation to the development of standards for End-of-Life Care in hospitals.

The H/H Programme envisages that its standards will be referenced within the **National Standards for Safer Better Healthcare**, and will inform future reviews carried out by HIQA.



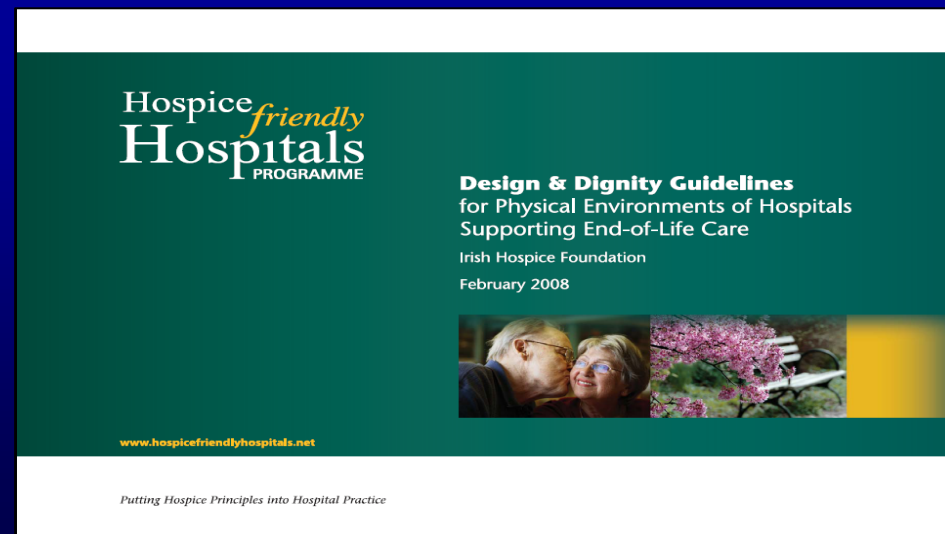
Implementation of the National Standards for Safer Better Healthcare - towards licensing



Implementation of the Quality Standards for End-of-Life Care in Hospitals - towards Licensing.....

Vision

Knowledgeable patients receiving safe and effective care from skilled professionals in appropriate environments with assessed outcomes



Action Plan

Using the Standards

- **Development Plans** linking standards, audit and specific hospital / network initiatives / projects
- Progress monitored by **NSC**
- **Feedback to HSE** at Management Team level

National End-of-Life Forum

National End-of-Life Strategy

Transparent decision-making at End-of-Life

Advanced Care Planning

Implementation of National Policies on Palliative Care

National Council on Forum on End-of-Life Care

Chair: Mrs. Justice Catherine McGuinness

- The Council's structure will reflect the need to **engage with all sectors** of society on death issues
- The Forum will host an annual event
 - to address issues,
 - act as a sounding board and
 - to learn about progress in implementing the Action Plan

**“Primum non
nocere”**

Raison d'être of HfH Programme

1. Design & Dignity Guidelines

2. Quality Standards for End-of-Life Care

3. National Audit findings

are offered to each hospital to support it becoming a **HfH** i.e.

- a more **hospitable** place to die
- a more **friendly** place
- a **less fearful** place for patients & relatives

Some Challenges for the Groups

for:

- Hospitals
- Patients
- Relatives
- Staff



CARPE DIEM



HospiceFriendly **HOSPITALS**

Putting Hospice Principles into Hospital Practice.

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