

End-of-Life
Care Resources

Quality Standards for End-of-Life Care in Hospitals



The Four Standards

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

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.

3 The Patient

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

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.

For further information on the Quality Standards for End-of-Life care in hospitals, go to www.hospicefriendlyhospitals.net

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.”

Standard 1 The Hospital

1.1 A CULTURE OF COMPASSIONATE END-OF-LIFE CARE

The Hospital Service Plan¹² contains a clear statement on the hospital's ethos of end-of-life care.

How do we know that we are meeting this Standard?

- The Hospital Service Plan reflects a clear and transparent hospital ethos of end-of-life care and includes a statement of intent accordingly.
- A named senior member of the management team is allocated responsibility for ensuring that all hospital departments self-assess against the *Quality Standards for End-of-Life Care in Hospitals*.
- The Annual Report includes a section on Provision of End-of-Life Care.
- The hospital has a Standing Committee on End-of-Life Care with multi-perspective representation.

¹² The Hospital Service Plan may be an individual hospital plan or hospital network plan.

Standard 1 The Hospital

1.2 GENERAL GOVERNANCE POLICIES AND GUIDELINES

Governance policies and guidelines are in place in the hospital to ensure best practice in the implementation of the Quality Standards.

How do we know that we are meeting this Standard?

- Hospital policies and guidelines for end-of-life care are set within the currently prevailing legal and ethical framework¹³ and are based on best national and international practice.
- Policy and guidelines on end-of-life care in the hospital are available and are easily accessible to all staff in the hospital.
- All staff use and are trained to use these guidelines in accordance with their roles.
- Guidelines on advance care planning are available to support a culture of identifying patients' wishes and preferences.
- There is a system in place for regularly reviewing and updating all policies and guidelines relating to end-of-life care.

¹³ Health Service Executive (HSE), 2008. 'HSE Procedure for Developing, Policies, Procedures, Protocols and Guidelines'. Dublin: Health Service Executive (HSE). "Each health professional/HSE employee is accountable for their practice... This means being answerable for decisions he/she makes and being prepared to make explicit the rationale for those decisions and justify them in the context of legislation, case law, professional standards and guidelines, evidence based practice, professional and ethical conduct. It should be recognised that policies, procedures and guidelines represent a statement reflecting an expected standard of care and be introduced in law as evidence of the standard of care expected". Page 4.

Standard 1 The Hospital

1.3 EFFECTIVE COMMUNICATION

There is timely, clear and sensitive communication with each patient and his/her family as appropriate on matters relating to end-of-life care.

How do we know that we are meeting this Standard?

- All communication between hospital staff and patients and/or family members is governed by the wishes of the patient.
- Policy and guidelines are available for communicating with patients diagnosed as requiring end-of-life care. (Standard 1.2)
- The hospital communications policy includes evidence-based protocols for communicating prognostic information to patients.¹⁴
- The hospital communications policy includes direction on communication-related complaint practices for patients, family and staff.
- Advance care directives and patient preferences are clearly recorded in the Healthcare Record (Standard 1.4) and communicated to relevant staff.
- There is an acknowledgement across the hospital that staff other than clinicians and nurses may have an important role to play in ensuring effective communication with patients and families in respect of end-of-life care.

¹⁴ Clayton, J., M., Hancock, K., M., Butow, P., N., Tattersall M., H., N., Currow D., C., 2007. 'Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers'. The Medical Journal of Australia. MJA; 186 :(12 Suppl) S77-S108.

Standard 1 The Hospital

1.4 THE HEALTHCARE RECORD

The Healthcare Record¹⁵ supports and enhances governance and communication in respect of end-of-life care.

How do we know that we are meeting this Standard?

- The Healthcare Record is retrievable by all departments on a 24/7 basis.
- The Healthcare Record provides an accurate chronology of events and records all significant consultations, assessments, observations, discussions, patient preferences, decisions, interventions and outcomes.
- Members of the multidisciplinary team consult each others notes within the Healthcare Record on a regular and systematic basis.

¹⁵ Health Services Executive, 2007. National Hospitals Office. Code of Practice for Healthcare Records Management. Version 2.0. Available at:[http://www.hse.ie/About the HSE/Publications about HSE Services/National Hospitals Office Code of Practice for Healthcare Records Management Version 2.0](http://www.hse.ie/About%20the%20HSE/Publications%20about%20HSE%20Services/National%20Hospitals%20Office%20Code%20of%20Practice%20for%20Healthcare%20Records%20Management%20Version%202.0)

Standard 1 The Hospital

1.5 THE HOSPITAL ENVIRONMENT

The physical environment where end-of-life care is provided supports high quality care and facilitates dignity and privacy.

How do we know that we are meeting this Standard?

- Key areas of the hospital environment related to end-of-life care are assessed against the Hospice Friendly Hospitals Programme *Design & Dignity Guidelines for Physical Environments of Hospitals Supporting End-of-Life Care*.¹⁶ The annual service plan identifies and prioritises funding to refurbish these key hospital areas as required.
- The *Design & Dignity Guidelines for Physical Environments of Hospitals Supporting End-of-Life Care* are promoted throughout all relevant hospital departments and copies are widely available throughout the hospital and are easily accessible to all staff.
- All refurbishments and new hospital buildings take into account the *Design & Dignity Guidelines for Physical Environments of Hospitals Supporting End-of-Life Care*.
- End-of-life care patients are offered the choice of being accommodated in a single room.
- The hospital facilitates access to rooms and spaces where discussions between patients, staff and family members can take place in a quiet, comfortable environment where privacy is ensured.
- The hospital facilitates family members with overnight rest and refreshment facilities.

¹⁶ Hospice Friendly Hospital's Programme, 2008. 'Design & Dignity Guidelines for Physical Environments of Hospitals Supporting End-of-Life Care'. Dublin: The Irish Hospice Foundation.

Standard 1 The Hospital

1.6 MONITORING AND EVALUATING END-OF-LIFE CARE

End-of-life care in the hospital is continuously evaluated.

How do we know that we are meeting this Standard?

- All hospital departments self-assess against the *Quality Standards for End-of-Life Care in Hospitals*. (Standard 1.1)
- Where appropriate, the hospital utilises the individual hospital data arising from the National Audit to benchmark nationally and identify priorities for improvement.
- The hospital collects data on end-of-life care throughout the hospital. This information is recorded and reported electronically and published annually.
- Each hospital department identifies key performance indicators for end-of-life care relevant to the patient population it serves.

Standard 1 The Hospital

1.7 ASSESSING AND RESPONDING TO THE END-OF-LIFE CARE NEEDS OF PATIENTS

All patients who are at a stage where they may be approaching end of life are identified and provision for their individual care is made accordingly.

How do we know that we are meeting this Standard?

Advance Care Planning

- End-of-life care for each patient is guided by the principle of advance care planning and advance care directives (where they exist) are included as part of an individual care plan.¹⁷

Assessment

- There are effective mechanisms in place to identify patients who may be approaching or at the end of life.¹⁸
- The needs of a patient identified as approaching or at end of life are assessed in a holistic manner, with particular emphasis on pain and symptom assessment, and documented in the care plan within the Healthcare Record.

¹⁷ Care plan: A care plan is based on information gathered during patient assessment. It identifies the patient's care needs, lists the strategy to meet those needs, documents treatment goals and objectives, outlines the criteria for ending interventions, and documents the individual's progress in meeting specified goals and objectives. The care plan must be related to the patient's identified care needs and patient care processes are planned to achieve optimal outcomes for the patient. The care plan may include prevention, care, treatment and rehabilitation as components.

The care plan forms part of the Healthcare Record. As the patient's needs change, the care plan also changes. Changes are documented in the Healthcare Record as notes to the initial plan and/or as revised or new care goals. In some instances a new care plan may be required. The format of the plan in some organizations may be guided by specific policies and procedures, protocols, practice guidelines, clinical paths or a combination of these.

¹⁸ The concept of the 'Surprise' Question has been put forward by, among others, the National Gold Standards Framework (available at: <http://www.goldstandardsframework.nhs.uk/TheGSFToolkit/Identify/TheThreeTriggers>). The 'Surprise' Question: 'Would you be surprised if this person died within the next 6-12 months?' is described as an intuitive question to assist clinicians in recognizing patients who may be near the end of life. The 'Surprise' Question can be applied to years/months/weeks/days and trigger the appropriate actions. It is suggested that the 'Surprise' Question facilitates earlier recognition of people nearing the end of their life which leads to earlier planning and better care.

Standard 1 The Hospital

- Staff establish if patients have an Advance Care Directive in place and, where relevant, this is discussed, reviewed and updated with the patient or relevant third party.
- The outcome of the assessment of need is communicated in a format and language suitable for the patient and his/her family. (Standard 3.1 and Standard 3.2).
- There is ongoing consultation with the patient and with his/her family, the latter if the patient wishes, with regard to outcomes of treatment and progress.
- Policy and guidelines identify and address any additional or special needs a patient may have, e.g. intellectual disability, reduced capacity, mental health difficulties, ongoing difficulties in coping.

The Care Plan

- The patient's care plan, including pain and symptom management and preferred place of care, is reviewed and updated regularly in accordance with his/her clinical condition, needs and preferences.
- The care plan is accessible to all relevant healthcare staff and implemented by each person/team in carrying out their respective roles.
- Guidelines for "Diagnosing Dying" are available to assist staff to identify when a patient may be dying and are referred to as part of care planning.

Standard 1 The Hospital

1.8 CLINICAL RESPONSIBILITY & MULTIDISCIPLINARY WORKING

All patients who are approaching end of life are supported by a named lead clinician(s) working in consultation/partnership with the multidisciplinary team.¹⁹

How do we know that we are meeting this Standard?

- The lead clinician and/or the clinician responsible for the patient's care is identified and documented in the Healthcare Record.
- The patient is facilitated to discuss his/her care with the lead clinician.
- Policy and guidelines are in place for communication between disciplines, teams and service providers whether hospital-based or community-based in order to facilitate a planned approach to the patient's admission, care, and discharge/transfer out of the hospital. (See standard 1.2).
- There is clear allocation and documentation of responsibility within and between clinical teams involved in the care of the patient, regarding the patient's admission, care, and discharge/transfer out of the hospital.
- When the patient moves to a different clinical environment within the hospital and the responsible lead clinician changes for a period of the patient's care, there is formal handover of information and accountability for the overall care of the patient.
- The multidisciplinary team meets on a regular basis and these meetings include consideration of the views of the patient and family members, the latter if relevant.
- The patient and/or family are accommodated to be present at a multidisciplinary team meeting, if appropriate.

¹⁹ Department of Health and Children, 2008. 'Building a Culture of Patient Safety'. Report of the Commission on Patient Safety and Quality Assurance. Recommendation 5.9, page 22. Dublin: The Stationery Office.

Standard 1 The Hospital

1.9 PAIN AND SYMPTOM MANAGEMENT

Effective pain²⁰ and symptom management is provided as a key component of end-of-life care and staff education in the hospital.^{21 22} (See also 3.4).

How do we know that we are meeting this Standard?

- There is a written hospital/departmental ethos regarding pain and symptom management that is evident through attitude, action and documentation. (Standard 3.4)
- Evidence-based guidelines for pain and symptom management at end of life are easily accessible to all clinical staff and adhered to at all times.
- The hospital/department has Guidelines for use during initial assessments and reassessments that assist staff in identifying patients who are experiencing pain.
- There is documentation within the Healthcare Record of regular assessment, timely response, monitoring and review of pain and symptoms according to need and the patient's expressed experience of the pain/symptom(s) and intervention measures.^{23 24 25}
- The patient is referred to specialist palliative care services as soon as patient needs, symptoms and other care factors indicate a need for such expertise.

20 The British Pain Society, 2004. 'Understanding and Managing Pain: Information for Patients'. London: The British Pain Society.

21 Department of Health & Children, 2001. 'Report of the National Advisory Committee on Palliative Care'. Dublin: The Stationery Office.

22 The Royal College of Anaesthetists. The Pain Society, 2003. 'Pain Management Services. Good Practice'. London: The Royal College of Anaesthetists. The Pain Society.

23 Australian and New Zealand College of Anaesthetists and Faculty of Pain Medicine, 2005. 'Acute Pain Management: Scientific Evidence'. Second edition. Victoria: Australian and New Zealand College of Anaesthetists.

24 Australian and New Zealand College of Anaesthetists, Faculty of Pain Medicine and Joint Faculty of Intensive Care Medicine. 2008. 'Statement On Patient's Rights to Pain Management and Associated Responsibilities'. Available at: <http://www.anzca.edu.au/resources/professional-documents/professional-standards/pdfs/PS45-2008.pdf>

25 The Royal College of Anaesthetists. The Pain Society, 2003. 'Pain Management Services. Good Practice'. London: The Royal College of Anaesthetists. The Pain Society.

Standard 1 The Hospital

1.10 CLINICAL ETHICS SUPPORT²⁶

Hospital management ensures that each staff member has access to Clinical Ethics Support as appropriate to his/her role.

How do we know that we are meeting this Standard?

- All staff providing end-of-life care to patients adhere to the mission, vision and values of the hospital (Standard 1.1)
- Each staff member ensures that s/he is familiar with and guided by the Professional Ethical Code of Conduct appropriate to his/her role.^{27 28 29}
- Hospital management promotes a positive ethical climate within the organisation in which all employees feel comfortable raising and discussing ethical concerns.
- Transparent and equitable processes and mechanisms for ethical decision-making are in place and may be used to resolve disagreements about the interpretation of policies or to address potentially difficult or contentious ethical issues that may arise in relation to end of life.
- Mistakes are acknowledged and there is ongoing evaluation and review to ensure that ethical challenges are accurately identified and resolved.

²⁶ Hospice Friendly Hospitals Programme, 2010. 'An Ethical Framework for End-of-Life Care'. Dublin: The Irish Hospice Foundation.

²⁷ The Medical Council, 2009. 'Guide to Professional Conduct and Ethics for Registered Medical Practitioners'. 7th Edition. Dublin: The Medical Council.

²⁸ An Bord Altranais, 2000. 'Code of Professional Conduct for each Nurse and Midwife'. Available at: <http://www.aib.ie/Professional Practice & Education/Policies and Guidelines>

²⁹ An Bord Altranais, 2007. 'Guidelines to Nurses and Midwives Regarding Ethical Conduct of Nursing and Midwifery Research'. Dublin. Available at: <http://www.aib.ie/Professional Practice & Education/Policies and Guidelines>

Standard 1 The Hospital

1.11 CARE AFTER DEATH

Policies and Guidelines for care after death are respectful of the deceased person and his or her wishes and beliefs.

How do we know that we are meeting this Standard?

- Policy and guidelines are in place for 'care of the deceased person's body after death'. All relevant staff use and are trained in the use of these.
- A universal symbol, which is recognised by all staff and by the public as indicating that a death has occurred, is clearly visible in the ward/ department.
- Where appropriate, hospital staff consult the family members to ensure that the wishes, if known, of the deceased person, are respected.
- Information is provided to family members on matters associated with post-mortems where relevant.
- If the person's death is not referred to the Coroner, the hospital has a clear procedure for notification of death within three working days of the death occurring.
- The hospital notifies the deceased person's GP and other relevant primary and secondary care services as soon as possible, ideally on the first working day following the patient's death.
- A letter/sympathy card is sent to the patient's family within two weeks of the person's death.
- Any requests for payment of hospital bills are scheduled to ensure that they arrive after the sympathy letter/card.

Standard 1 The Hospital

1.12 POST-MORTEMS

The hospital manages all aspects of post-mortems in a transparent, timely and sensitive manner.

How do we know that we are meeting this Standard?

- The loss being experienced by the family is recognised and acknowledged, and staff are sensitive to avoiding the potential for further distress when communicating information about the post-mortem.
- Families are provided with verbal and written information regarding hospital post-mortems and coroner post-mortems.
- Policy and guidelines address:
 - Requesting informed consent for non-coroner's post-mortem
 - Dealing with questions relating to the role of the coroner and the formal identification of the deceased person
- A member of staff is available to speak with bereaved families where a post-mortem is to be carried out.
- Records are kept of all contact with the family regarding post-mortems.

Standard 1 The Hospital

1.13 BEREAVEMENT CARE

The hospital provides assistance and supports to families in dealing with loss during the period approaching and following a death.

How do we know that we are meeting this Standard?

- End-of-life care is managed in a multidisciplinary manner to ensure that all needs can be responded to effectively.
- Where there is clear indication that death may be imminent, family members are alerted as appropriate.
- Where families have differences of opinion, these are acknowledged and addressed sensitively.
- Families who are experiencing significant difficulty, for example, a high level of distress, are referred to the appropriate member of the multidisciplinary team.
- If requested, the patient's family can obtain further information or discuss concerns about the care and treatment of the patient with a member of the multidisciplinary team.
- Families are offered timely bereavement supports- beginning with information, identification of any risk factors and referral if appropriate.
- All supports and services consider and respond to individual, cultural and spiritual requirements. (Standard 4.6).

Identifying and responding to bereavement support needs

- Staff have an understanding of the range of responses to bereavement.
- Families are offered timely appropriate bereavement supports including information regarding awareness and understanding of normal and expected grief reactions. This information may be offered on more than one occasion. (Standard 4.6)

Standard 1 The Hospital

- Staff have an understanding of the types of risk factors, (e.g. personal attributes, the nature of the relationship with the deceased, whether death was perceived as sudden or expected, traumatic or peaceful), which may result in complicated bereavement and refer to relevant professional support as appropriate.
- Staff have information on and access to appropriate professional support to address different types of risk factors and possible complicated grief responses.
- The bereavement support needs of children and teenagers are assessed and responded to appropriately.

Bereavement Services

- Formal bereavement support is offered by the hospital and with reference to other community and professional providers.
- Bereavement services are guided by a standardised assessment process³⁰ and families' bereavement needs are kept under review.
- Families are assured of confidentiality and privacy when using bereavement services, in accordance with current legal and ethical legislation.
- The bereavement service organises events that facilitate the grieving process such as remembrance services and public talks.
- Families are offered the opportunity to provide feedback to the service – this feedback informs service development and provision.

³⁰ 'A standardised assessment process refers to a protocol adopted by the hospital which ensures that staff consider the same issues in assessing bereavement needs – e.g. personal strengths and risks; interpersonal resources or stresses; situational aspects concerning the death.'

See: Stroebe, M. S., S. Folkman, et al. 2006. 'The prediction of bereavement outcome: development of an integrative risk factor framework'. *Social Science & Medicine* 63(9): 2440 and Agnew, A., R. Manktelow, et al., 2010. 'Bereavement needs assessment in specialist palliative care: a review of the literature'. *Palliative Medicine*; 24(1): 46-59.

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.”

Standard 2 **The 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.

- 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 STAFF SUPPORT

Standard 2 The Staff

2.1 CULTIVATING A CULTURE OF COMPASSIONATE END-OF-LIFE CARE AMONG STAFF

All hospital staff have access to education and training opportunities in the delivery of compassionate end-of-life care in accordance with their roles and responsibilities.

How do we know that we are meeting this Standard?

- The Hospital Manager ensures that there are education, training and staff mentorship programmes in end-of-life care for hospital staff in accordance with the size, complexity and specialties of the hospital.
- The design of staff education and training programmes involves key stakeholders with relevant experience and knowledge.
- A core group of clinical and non-clinical hospital staff with the required expertise in end-of-life care are facilitated and supported to deliver end-of-life care education and training to hospital staff.
- The hospital facilitates staff, as appropriate, to undertake additional formal education and training in end-of-life care.

Standard 2 The Staff

2.2 STAFF INDUCTION

All newly recruited staff are inducted on the general principles and components of end-of-life care in the hospital.

How do we know that we are meeting this Standard?

- The hospital's general induction programme includes a component on end-of-life care.
- The *Quality Standards for End of Life Care in Hospitals* are introduced and explained.

Standard 2 The Staff

2.3 STAFF EDUCATION AND DEVELOPMENT NEEDS

The education and development needs of staff are assessed relative to their roles in end-of-life care and according to emerging national consensus on competencies and standards.

How do we know that we are meeting this Standard?

- Hospital staff are competent to deliver high quality end-of-life care in accordance with best practice.
- Competency statements are developed for different categories of staff in accordance with their individual roles, and performance management systems are used to measure this aspect of care.
- An audit of education and training needs in end-of-life care is conducted every two years.

Standard 2 The Staff

2.4 STAFF EDUCATION AND TRAINING PROGRAMMES

Staff education and training programmes have defined objectives that reflect evidence-based best practice and legislation.

How do we know that we are meeting this Standard?

- Staff education and training programmes cover the key elements of the *Quality Standards for End-of-Life Care in Hospitals*, and specifically address pain and symptom management and how to support patient preferences and values.
- The hospital provides and maintains resources and facilities for education, training and continuous professional development in coordination with the regional education and training services of the HSE.
- Education and development programmes relating to end-of-life care are revised annually by a team that includes the hospital manager and other disciplines directly involved in end-of-life care.
- Priority groups of staff members who would benefit from specialised education in end-of-life care are identified every two years and their participation in standard and accredited education programmes on an ongoing basis is facilitated by the hospital.
- If the hospital implements an Integrated Care Pathway in respect of End-of-Life Care, appropriate support and training is provided in accordance with specific guidance from the relevant experts.

Standard 2 The Staff

2.5 STAFF SUPPORT

Staff support services relating to end-of-life care reflect the need for peer support³¹ and professional support³² systems.

How do we know that we are meeting this Standard?

- The Hospital Management Team facilitates the provision of formal and informal structures and support systems for practical and emotional support to each member of staff. These supports address both the professional and personal needs of the individual involved in the provision of end-of-life care.
- Written information is provided to each staff member on:
 - Skills and techniques for effective self-care³³
 - Opportunities for reflective practice
 - Supervision
 - Recognition of burnout and compassion fatigue
 - Support services available and how to access these support services
- Each staff member takes personal responsibility for his/her self-care.³⁴

³¹ Peer support is usually contained within the team and can be informal and/or formal support. Informal support refers to expressed recognition, understanding and acknowledgement of the potential issues relating to end-of-life care. Formal support refers to structured support that is offered according to specific criteria such as individual or team support, timeframe of support, meeting place, issues to be addressed.

³² Professional support systems refer to supporting the individual regarding life events not directly involving workplace issues.

³³ 'Staff review the four main aspects of self care, physical, emotional/cognitive, relational and spiritual'. Hill Jones, S., 2005. 'A self-care plan for hospice workers'. American Journal Hospice and Palliative Care; 22; 125-128.

³⁴ 'Physicians working with patients at end-of-life frequently have to respond to overwhelming human suffering in the absence of adequate institutional support or resources. In this context, the idea of "self-care" may seem a selfish irrelevance and an unjustifiable luxury. In fact, self-care is an essential part of the therapeutic mandate. Self care enables physicians to care for their patients in a sustainable way with greater compassion, sensitivity, effectiveness and empathy'. Kearney M.K., Weininger R.B., Vachon M.L.S., 2009. 'Self-care of Physicians Caring for Patients at the End of Life: Being Connected...A Key to My Survival'. Journal of the American Medical Association JAMA; 301(11):1155-1164.

Standard 2 The Staff

- Each staff member has access to Clinical Ethics Support as appropriate to his/her role (Standard 1.10).
- Policy and Guidelines are in place to support staff involved in dealing with trauma or sudden deaths.
- Issues and challenges for staff arising from the delivery of end-of-life care, care of the dying patient and care of the deceased patient, form part of team discussions and are addressed in reviews of end-of-life care.
- Private space is available to enable staff to discuss and address issues that may arise when providing end-of-life care and dealing with death.
- Staff who use support services to address issues that may arise during provision of end-of-life care are facilitated to provide feedback on their appropriateness and value.

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."

Standard 3 The Patient

Standard 3 The Patient

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

- 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 PAIN AND SYMPTOM MANAGEMENT
- 3.5 DISCHARGE FROM HOSPITAL
- 3.6 THE DYING PATIENT

Standard 3 The Patient

3.1 COMMUNICATING A DIAGNOSIS OF A NEED FOR END-OF-LIFE CARE

There is timely, clear and sensitive communication with each person, as appropriate, in respect of a diagnosis that s/he may be approaching or at the end of life.

How do we know that we are meeting this Standard?

- The patient, unless s/he states otherwise, is always responded to directly and confidentially in respect of any matters relating to his/her possible need for end-of-life care.
- The communication to the patient of a clinical decision that s/he may be near the end of life is recorded in the Healthcare Record.
- The manner and style of communication takes account of the person's capacity for understanding and his/her religious, cultural and ethnic preferences.
- When the patient lacks capacity/is deemed not competent to give consent, this is noted and monitored on an ongoing basis.
- Where a patient has additional communication needs arising from a disability or from language or literacy difficulties, these needs are identified, documented and responded to individually.
- The patient is actively involved in discussions and decisions regarding admission, discharge home, or transfer to another setting for end-of-life care.

Standard 3 The Patient

3.2 CLEAR AND ACCURATE INFORMATION

Clear and accurate information is provided as appropriate to the patient about his/her condition, treatment options, prognosis and care plan in a timely and culturally appropriate manner and in accordance with the patient's needs and preferences.

How do we know that we are meeting this Standard?

- Information is shared sensitively with the patient and, if the patient wishes, with his/her family members.
- Any unexpected changes to the patient's condition or care plan are communicated to the patient, or to family members if appropriate, in a timely manner.
- Details of the information provided to the patient are documented in the Healthcare Record.
- Information on end-of-life care and supports is provided both verbally and in written form and in a format and language suitable for the patient and his/her family (See Standards Criterion 1.3).

Standard 3 The Patient

3.3 PATIENT PREFERENCES

The patient receives care in a manner and care setting of choice.

How do we know that we are meeting this Standard?

- Discussions are held with the patient on an ongoing basis about his/her needs and preferences and the outcomes of these discussions are documented in the Healthcare Record (Standard 1.4).
- The patient's capacity to participate in decisions and to make choices regarding end-of-life care is assessed, optimised and regularly reviewed.
- Consent by the patient is easily and clearly identifiable either on a consent form, which is retained as part of the Healthcare Record, or in the case of verbal consent, documented within the Healthcare Record.
- Where a patient has a written Advance Care Directive, this is recorded and forms part of the Healthcare Record (Standard 1.7).
- Where a patient does not have a written Advance Care Directive, s/he is made aware of the option to provide one in either a written form or verbally.
- Each patient's preferences are regularly reviewed in consultation with the patient.
- If a patient is unable or does not wish to participate in discussions and decision-making, this is documented in the Healthcare Record and reviewed regularly.
- The patient is facilitated to access an independent advocacy service when making decisions relating to treatment or care if s/he so wishes.
- If it is the patient's wish, and deemed to be in his/her best interest, family members are facilitated in assisting with the personal care of the patient.

Standard 3 The Patient

3.4 PAIN AND SYMPTOM MANAGEMENT

Pain and symptom management for each individual patient takes full account of the multifaceted nature and individual experience of pain.

How do we know that we are meeting this Standard?

- The patient's experience and description of pain and symptoms, including verbal, non-verbal and behavioral expressions of discomfort and pain, are identified, regularly assessed and responded to promptly.
- There is ongoing dialogue with the patient regarding his/her experience of pain, distress and other symptoms and the level of comfort obtained from different interventions.
- There is documentation within the Healthcare Record of regular monitoring of the patient's symptoms and the effectiveness of interventions.
- Specialist palliative care advice is sought as required and in accordance with the patient's wishes.

Standard 3 The Patient

3.5 DISCHARGE HOME/OUT OF HOSPITAL

The patient is actively involved in discussions and decisions regarding admission, discharge home, or transfer to another setting for end-of-life care.

How do we know that we are meeting this Standard?

- The hospital has a process of proactive admission and discharge planning that addresses the patient's individual needs.
- There is timely and clear communication with the General Practitioner and/or other service providers regarding the patient's admission and discharge.
- Written information provided to the General Practitioner/and or other service providers is formulated so that essential relevant information is easily identifiable and accessible.
- Information provided to the General Practitioner/and or other service providers includes:
 - Relevant clinical information
 - Patient /family awareness of prognosis
 - The patient's wishes regarding preferred place of death
 - Any other non-clinical information that is important
- The Community Pharmacist is notified of any unusual medication requirements.
- Prior to discharge from hospital, the patient, and family members where appropriate, is provided with information and advice both verbally and in writing on the various aspects of providing end-of-life care in the home.
- The core content of these discussions and communications is documented in the Healthcare Record.
- The GP and other service providers are notified of any patient decisions regarding preferred place of dying to minimise inappropriate return to hospital if the patient is seriously ill or unconscious.

Standard 3 The Patient

3.6 THE DYING PATIENT

The particular needs of a patient whose death is imminent are assessed and provided for in a sensitive and culturally appropriate manner.

How do we know that we are meeting this Standard?

- The needs of the dying patient are assessed and prioritised to ensure that as far as possible his/her wishes are respected and that the best possible level of comfort is provided.
- Particular attention is given to deploying staff to ensure that the patient is not left alone while dying, particularly if the patient's family are not present.
- The patient's family are advised as a matter of urgency when death may be imminent and are facilitated to be present with the patient, where this is not contrary to the patient's wish.
- The dying patient is cared for in a private and dignified space and as far as possible in a single room unless otherwise requested.
- Policies and guidelines for the care of the dying patient are adhered to by all staff. (Standard 1.2)

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.”

Standard 4 **The Family**

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 COMMUNICATION WITH FAMILY MEMBERS – 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.

Standard 4 The Family

4.1 COMMUNICATION WITH FAMILY MEMBERS³⁵: GENERAL

All communication between hospital staff and family members is governed by the expressed wishes of the patient and, where these are unknown, by the best interests of the patient.

How do we know that we are meeting this Standard?

- The hospital has a policy and related guidelines to assist in communicating with family members of patients who may be approaching end of life or dying. Staff use, and are trained in accordance with their roles, to use these Guidelines.
- Staff assist family members to come to terms as far as possible with the reality of what is happening and to support the patient during the period of his/her dying.
- Opportunities are provided by clinicians and nursing staff for family members to clarify issues and concerns about the patient's well-being, provided this is in keeping with the patient's wishes.
- Feedback from family members is acknowledged and noted in the Healthcare Record and complaints are dealt with promptly and sensitively.

³⁵ Family members may include the immediate biological family and/or other relatives, partners (including same sex and *de facto* partners) or friends. They may have a close, ongoing, personal relationship with the patient, be chosen by the patient to be involved in treatment decisions, and have themselves indicated that they are ready to be involved in such decisions.

Standard 4 The Family

4.2 COMMUNICATION WITH FAMILY MEMBERS: WHERE DEATH MAY BE ANTICIPATED

Where death may be anticipated, as in the advanced stages of progressive life-limiting illness, family members (with the consent of the patient) are given factual information to enable them to plan ahead and to access the supports they may require.

How do we know that we are meeting this Standard?

- There is timely information and communication with family members relating to the patient's condition throughout the advanced illness and dying period.
- There is ongoing consultation, with the patient's consent, with family members with regard to the patient's care plan.
- There are Guidelines for ascertaining and responding to the support needs of family members which are used by staff as relevant to their roles and in accordance with hospital communications policy (Standard 1.2).
- Relevant information is provided to family members (where the patient has consented to the sharing of information) both verbally and in written form as required.
- With the patient's consent, family members are advised of any Advance Care Directives made by the patient and of any specific patient wishes with regard to end-of-life ceremony or religious ritual.
- The core content of conversations between staff and patients/family members and the information provided is documented within the Healthcare Record.
- Relevant information leaflets/booklets are provided in accessible formats and language and their content is sensitively discussed with family members.

Standard 4 The Family

4.3 COMMUNICATION WITH FAMILY MEMBERS: SUDDEN/ UNEXPECTED DEATH OR SUDDEN IRREVERSIBLE DECLINE IN HEALTH LEADING TO DEATH

In cases involving a sudden change in the patient's condition likely to lead to death and in cases of sudden/unexpected death, the patient's family is provided with prompt and clear information as appropriate.

How do we know that we are meeting this Standard?

- The clinical decision that a patient may no longer be responding to treatment and may be dying is communicated clearly and sensitively to the patient's family as appropriate.
- The hospital has Guidelines on consulting families to ascertain the patient's known wishes in respect of resuscitation and organ donation (Standard 1.2). All relevant staff use, and are trained to use, these Guidelines.
- Family members are advised of any advance care directives by the patient that they may not be aware of.
- The core content of conversations between staff and patients/family members is documented within the Healthcare Record (Standard 1.4).
- Staff ensure that information regarding any changes in the patient's status is communicated clearly, sensitively and promptly to the family members as appropriate.
- Information provision to family members in the case of a sudden or unexpected death takes account of the person's capacity for understanding, any additional communication needs (Standard 1.3) and his/her religious, cultural and ethnic preferences.

Standard 4 The Family

4.4 PATIENT DISCHARGE HOME

When a patient is to be discharged home, this is organised, with the patient's consent, in consultation with the patient's family, and occurs when the appropriate supports and services are in place.

How do we know that we are meeting this Standard?

- Prior to the patient's discharge from hospital, family members are given opportunities to discuss the care plan with staff.
- Families are provided with advice on supporting the patient at home, e.g. assisting with personal care, medication, if the patient so wishes.
- Families are provided with detailed information concerning the level and source of ongoing supports and services following discharge.
- Families are provided with names and contact details of healthcare professionals to be involved in the ongoing care of the patient.
- As appropriate, families are provided with information and advice on the various aspects of providing end-of-life care at home (Standard 3.5).
- The views of the patient are fully taken into account in any discussions with family members about discharge home.

Standard 4 The Family

4.5 SUPPORTING FAMILY MEMBERS

Family members are treated compassionately and are provided with practical assistance in dealing with the different aspects of the end of life of a loved one.

How do we know that we are meeting this Standard?

- Guidelines are in place for identifying the needs of and supporting family members of a patient who may be approaching or at end of life. All relevant staff are aware of and use these Guidelines where appropriate.
- Families are offered timely bereavement supports before and after the death of a loved one which respond to their varied grief needs associated with their individual and cultural and spiritual experiences of dying and death (Standard 1.13).
- If the patient wishes, family members are offered the opportunity and practical guidance to assist in the personal care of the patient.
- If it is the patient's wish, family members are, as far as possible, facilitated to accompany the patient during treatments and/or procedures.
- When a death is believed to be imminent, the patient's family is informed and facilitated as far as possible and in accordance with the patient's wishes to spend as much time as they wish with the patient, including overnight stays if feasible.

Standard 4 The Family

4.6 RESPONDING TO THE NEEDS OF FAMILY MEMBERS AFTER A DEATH

Family members are treated with compassion and in a caring manner following the death of a loved one.

How do we know that we are meeting this Standard?

- Guidelines are in place for identifying the needs of and supporting family members after a person's death. All relevant staff are aware of and use these Guidelines where appropriate.
- Families are given time and space to mourn at the bedside; their needs are sensitively attended to.
- Families receive the deceased person's valuables and belongings in either his/her own bag/suitcase or in a designated relative's handover bag as appropriate.
- Where a Post-mortem is required (Coroner's Post-mortem) or requested (Hospital Post-mortem), family members are informed in a sensitive, timely and accurate manner (Standard 1.12).
- The Doctor completes the Death Notification Form within three working days of the patient's death (this will not apply where the Coroner is involved).
- A letter/sympathy card is sent to the patient's families within two weeks of the person's death.
- Any requests for payment of hospital bills are scheduled to ensure that they arrive after the sympathy letter/card. (Standard 1.13).
- All supports and services consider and respond to individual, cultural and spiritual requirements.
- Families are offered timely appropriate bereavement supports including information regarding awareness and understanding of normal and expected grief reactions. (Standard 1.13) This information may be offered on more than one occasion.
- Where a family member(s) may be vulnerable to risk factors, (e.g. personal attributes, the nature of the relationship with the deceased, the nature of the death) which may result in complicated bereavement, referral to relevant professional support is offered as appropriate. (Standard 1.13)