

#### **Consultation Feedback Form**

The *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. The standards aim to enable dignity and comfort at the end of life in all care settings.

Each one of us will ultimately experience end of life - including dying, death and bereavement - many of us as patients and others as family members or friends. Many of us work daily within the health service and associated agencies and organisations to deliver high-quality healthcare. The standards seek to address the many issues that emerge as we ask ourselves, "What would matter most to me personally and for my loved ones when approaching or at the end-of-life?" The following are just some of the issues that you might like to consider when giving your feedback on the standards:

- Will my preferences be respected if I can no longer speak for myself?
- Will my family and friends be with me?
- Will I experience good pain and symptom control?
- Does the physical environment of the hospital support me when I am most vulnerable?
- What are my needs as a staff member, whatever my role, to ensure I am competent through education and training, and also supported emotionally and practically to deliver high quality end-of-life care?

The purpose of the consultation process is to identify if there is consensus that all the issues relating to end of life, including dying, death and bereavement, are comprehensively addressed by the standards and if the individuals and interested parties who respond to the consultation process support the widespread implementation of these standards across all hospitals.

#### The Standards document is presented in two parts:

Part 1 discusses the background and context for the standards. This document is presented in two parts. Part One provides the background and context for the standards. In Section 1.2, the rationale for developing the standards is explored. The multiple scenarios at end of life, ranging from long illness in old age to stillbirth or miscarriage, are discussed in section 1.3. Section 1.4 outlines a number of challenges to the provision of high-quality end of life care in hospitals. Section 1.5 describes the aims of the Hospice friendly Hospitals Programme and its four key themes and Section 1.6 outlines the purpose of these Standards.



Part Two focuses on the quality standards. Section 2.1 spells out the underlying principles. The 4 basic standards and their related criteria are stated and elaborated in section 2.2 covering patient care, support for families, staff training and support, and an integrated hospital system.

The Appendices include a detailed glossary of terms, an account of the development process of the standards, the process for implementing the quality standards and, finally, a synthesis of critical issues and challenges. The document contains a comprehensive Bibliography.

Interested individuals, groups and organisations are now invited to provide feedback on the consultation document. Feedback must be provided using the Consultation Feedback Form.

Further information on The Hospice Friendly Hospitals (HFH) Programme and the public consultation process are available at:

### www.hospicefriendlyhospitals.net

Completed responses can be posted or emailed to

Helen Donovan
HFH Programme Standards Development Coordinator,
The Irish Hospice Foundation,
4<sup>th</sup> Floor, Morrison Chambers,
32 Nassau Street
Dublin 2. **Email** helen.donovan@hospice-foundation.ie **Telephone** 01 679 3188

A printed copy of The Draft Standards may be requested.

The closing date for submissions is Friday, 31st July 2009.



### **Completing the Form**

This form is made up of boxes you type into and boxes you click on to select your choice.
Where a box like this appears, type your answer into the grey box – you can type as much text as you like. You can also 'delete' and 'cut' and 'paste' as normal from this bo
Where a box like this $\square$ appears, click on the box to select your answer. To deselect the box click on the box again.
Please 'save' regularly to ensure your changes are saved. Save the form at the end before e-mailing it.

#### Section A: Your details

Name	Address	E-mail address	Phone number
Irish Association	c/o Royal College of	fergal.hickey@hse.ie	See covering letter for contact details for
for Emergency	Surgeons in Ireland,	(A3)	IAEM
Medicine	123 St Stephen's Green,		(A4)
(A1)	Dublin 2.		
, ,	(A2)		

A.5 In what capacity	are you completing this form?
Individual 🗌	Organisation √



A.6 if 'individual' please indicate if you are a:
Member of the public ☐ Patient ☐ Family member ☐ Staff member ☐
Other If 'other' please specify
A.7 If 'staff member' please indicate your role:
Doctor √ Nurse ☐ Allied Health Professional ☐ Administrative/clerical ☐ Management ☐
Nurse Management 🗌 Porter 🔲 Household Staff 🔲 Catering Staff 🗌
Other If 'other' please specify
A.8 If 'organisation' please state organisation's name: Irish Association for Emergency Medicine
A.9 Please tick one of the following to indicate what type of organisation:
Acute hospital  Community hospital Public nursing home
Private nursing home ☐ Public body ☐ Professional body √ Statutory Organisation ☐
Charity ☐ Other √ If 'other', please specify IAEM is a professional body of doctors representing the specialty of Emergency Medicine in Ireland. Se www.emergencymedicine.ie for more details.



A.	10 Please indicate	if your response	represents the	views of a	particular	speciality by	y ticking <i>oi</i>	ne of the bo	xes below

OR

Standing Committee on Dying, Death & Bereavement

Administration/Clerical	Management		Nursing Management	П	Nursing	
Care Attendant	Medical		Surgical		Cardiology	
Respiratory	Endocrinology		Renal		Oncology	
Palliative Care	Operating Dept.		Emergency Medicine		Coronary Care Unit	
High Dependency Unit	Intensive Care/Intensiv Therapy Unit	e 🗌	Neonatal Intensive Care/ Intensive Therapy Unit		Maternity	
Paediatrics	Psychiatry		Psychology		Psychotherapy	
Social Work	Pastoral Care		Occupational Therapy		Out-patients	
Pathology	Mortuary Technician		Allied Health Professional		Porter	
Household Staff	Catering Staff		Care of the Elderly		Bereavement Service	
Research	Not applicable		Other			

I have amended the term in the above list to 'Emergency Medicine'. The Medical Specialty is Emergency Medicine. It is practiced in Emergency Departments.

If 'other', please specify



## Section B: Part One of the Document - Background and context

Background and context	
Please answer the questions in section B giving consideration to Part 1 of the standards document	
B1. Does the background and context clearly set the scene? Yes √ No □	
Comments:	
B2. Does Section 1.5, 'The Hospice Friendly Hospital', clearly explain what is meant by hospice philosophy and a palliative care approach?	Yes √ No [
Please indicate any areas that are unclear:	



# Section C: Part Two of the document - Quality Standards

C1. Is the purpose of the standards clearly set out?	Yes √	No 🗆
Comments:		

	Does the statement "Why this standard" set a clear context for the standard?	Are the criteria clear?	Are there any omissions from the criteria?	What do you consider the 3 most important criteria within this standard?
Standard 1 – Patient Care The patient receives end of life care that is appropriate to his/her needs and wishes, and every effort is made to optimise the patient's quality of life by providing the best possible care to the end.	Yes	Yes	No	Criterion 1.1.2 Consideration of pain - physical and spiritual Criterion 1.1.3 when cure no longer the aim a patient's palliative needs assessed documented Criterion 1.1.8 patients at end of life should be prioritised for in-patient bed
	(C2)	(C3)	(C4)	(C5)



			T A111	
Standard 2 – Supporting Families The dying patient, along with his/her family, is viewed as a single unit of care. Family members are supported by staff to care for the patient where that is their wish and the wish of the patient.	Yes	Yes	Although in the majority of cases the family and the patient can be treated as a unit, very occasionally there is conflict or discord betweer the patient and the family or between different members of families especially in case of family break-up or separation. Something addressing this might be	
	(C6)	(C7)	useful (C8)	
Standard 3 – Training & Supports for Staff in Providing End of Life Care Formal education in end of life care should be provided by the hospital for all healthcare professional staff, support staff and administrative staff.	Yes	Yes	Yes	Criterion 3.1 in relation to training of key staff in care of the dying and their families is by far the most important issue here. Development / enhancement of staff communication skills is an important training priority. Criterion 3.1.6 is also important in relation to development of staff knowledge in end-of -life care over a wide range of issues e.g. cultural differences Criterion 3.2 is also important in relation to staff support as long as this does not become suffocating. Different HCPs deal with difficult end-of-life issues in different ways. This should be appreciated.  (C13)
	(C10)	(C11)	(C12)	
Standard 4 – An Integrated Hospital System The hospital has a system in place to ensure that the different elements of care associated with dying, death and bereavement-which includes meeting physical, psychological, social and spiritual needs- are seamlessly connected and delivered		Yes	Yes	The three most relevant criteria here are 4.2 Integration and coordination of hospital services; 4.3 Links between hospital and community services and 4.4 Care after death.
as one integrated service.	(C14)	(C15)	(C16)	(C17)



#### **Section D: Overall Document**

Please ar	nswer the following questions giving consideration to the document as a whole.
D1.Overa	all is the document clear and easy to understand? Yes √ No □
p	f not how could the document be improved? Although it is not a long document, it could be made even shorter and more concise e.g. is there a need for a preface and an introduction? Why not just an introduction? After all, you want people to get to the very relevant body of the document as quickly as possible.
D2. Is th	e overall structure of the document helpful? Yes √ No □
li	f not, how could the document be improved? An appendix with a summary of key recommendations (one or two side of A4) would be helpful.
D3. Are t	there any omissions? Yes √ No □
	Comments: Overall this is a very positive development. It is encouraging to see that the relief of suffering is acquiring a higher profile in hospital care. The authors deserve credit for their work.
<b>D4. Do y</b> Yes √	ou support the implementation of these standards across all hospitals?  No   No
D.5 Plea	se indicate your reason(s) for supporting/ or not supporting the implementation of the standards.  Comments: IAEM represents doctors who have considerable experience in dealing with end-of-life issues. Most commonly for Emerge

Comments: IAEM represents doctors who have considerable experience in dealing with end-of-life issues. Most commonly for Emergency Departments (EDs), the end-of-life context is sudden death, either totally unexpected or the acute deterioration of a chronic medical condition. Increasingly however, patients are admitted to EDs who are expected to die and are close to death and in whom a cure is not expected. While it is our aim that these patients are admitted to in-patient beds where their needs and the needs of their families can be assured, it is increasingly the case that ED medical and nursing staff have to attend to these patients and their families entirely in the ED because of lack of access to beds.



IAEM strives to improve standards of care for all patients who present to EDs and to ensure that EM HCPs work in a suitable environment. The reality of present healthcare in Ireland is far from this ideal and due to circumstances entirely outside our control; EDs are overcrowded and appear chaotic. In these circumstances, an ED cannot afford the patient or his/her relatives an appropriate environment to share precious final moments or to die with dignity. Despite the best efforts of ED staff, these patients are being denied basic human rights by the failure of the HSE to meaningfully address ED overcrowding. We would encourage the Irish Hospice Foundation to use its influence to help resolve this issue. Until it is resolved, then no matter how 'hospice-friendly' a hospital tries to be, it will unable to guarantee that patients who become unwell acutely will be provided with the same quality of end-of-life care as that afforded to patients who are dying from a less acute cause.

Our members have a keen interest in using their medical expertise to alleviate the physical and psychological pain of these patients and relieving the anguish of their families or loved ones. The threats to providing high quality end-of-life care include lack of space, facilities and staff. Nonetheless, ED staff have considerable expertise in attending to end-of-life situations and are happy to learn from others, as well as contributing to any discussion of the issue as it relates to Emergency Medicine.

#### **Section E: Additional Comments**

Please use this space for any additional comments you would like to make. If your comments relate to a specific part of the document please specify which part.

Although this issue may be considered to lie at least partly outside the remit of the document, we nonetheless wish to highlight it as it is an ever-increasing problem, namely the issue of patients who are long-term residents in nursing homes who have chronic medical conditions particularly dementia and who are referred to acute hospitals, in extremis, although aggressive in-hospital therapy is not indicated either to relieve suffering or cure.

IAEM believes that it would be in the best interests of these patients to be cared for in their longterm residences rather than be brought inappropriately to hospital. It would also help in these cases for the carers and doctors to meet the patients and their relatives to discuss the appropriateness of resuscitation in these cases, if there was accurate up to date documentation available in these case which could be transported with theses patients it would help direct health professionals care to the preservation of dignity and relief of suffering rather than an inappropriate resuscitation with no hope of success.