Introduction to the Ethical Framework

for End-of-Life Care
An Ethical Framework for End-of-Life Care

Developed for the Hospice Friendly Hospitals Programme of the Irish Hospice Foundation by

Dr. Joan McCarthy,
MA, PhD, Lecturer, Healthcare Ethics, School of Nursing and Midwifery, UCC

Dr. Mary Donnelly,
BCL, MA, MLitt, PhD, Solicitor, Senior Lecturer, Faculty of Law, UCC

Dr. Dolores Dooley,
MA, PhD, Lecturer, Healthcare Ethics, Department of General Practice, RCSI

Dr. Louise Campbell,
MA, PhD, Clinical Ethicist, ClinicalEthics Ireland

Dr. David Smith,
MSc, Bphil, MA, STL, PhD, Assoc. Prof. Healthcare Ethics, Department of General Practice, RCSI

Project Management:
Dr. Joan McCarthy (UCC-RCSI) & Mr. Mervyn Taylor, Hospice Friendly Hospitals Programme

Special Consultants:
Dr. Deirdre Madden, Senior Lecturer, Faculty of Law, UCC; Prof. Nigel Biggar, Regius Professor of Moral and Pastoral Theology, University of Oxford; Prof. Muiris FitzGerald, Board Member, Irish Hospice Foundation; Ms Orla Keegan, Head of Education, Research and Bereavement Services, Irish Hospice Foundation

Lead Researchers (empirical studies):
Ms Catherine O’Neill, Lecturer, Health Care Ethics, Faculty of Nursing and Midwifery, RCSI; Dr. Christina Quinlan, Department of General Practice, RCSI; Mr. John Weafer, Weafer Research Associates.

Research Assistants:
Mr. Mark Loughrey, School of Nursing and Midwifery, UCC; Ms Anna O’Riordan, School of Nursing and Midwifery, UCC

Special thanks to:
Shelagh Twomey, Joanne Carr, Denise Robinson, Helen Donovan (HFH Programme) and Bob Carroll, Research Consultant, for their feedback on early drafts of the modules and research reports; Claire Breen, Learning Consultant and Coach, FiBre Skills, for her feedback, guidance and ongoing support.
## Main Menu

<table>
<thead>
<tr>
<th></th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Background</td>
<td>2</td>
</tr>
<tr>
<td>2. National Research</td>
<td>3</td>
</tr>
<tr>
<td>3. Aim and Objectives of the Ethical Framework</td>
<td>6</td>
</tr>
<tr>
<td>4. Educational Philosophy</td>
<td>7</td>
</tr>
<tr>
<td>5. Ethical Framework</td>
<td>8</td>
</tr>
<tr>
<td>6. Module Format</td>
<td>10</td>
</tr>
<tr>
<td>7. References</td>
<td>12</td>
</tr>
</tbody>
</table>
1. Background
The Ethical Framework for End-of-life Care is part of a national programme, the Hospice Friendly Hospitals Programme (HfH) of the Irish Hospice Foundation, which is intended to improve the culture of care and organization regarding dying, death and bereavement in Irish hospitals. The Framework is an educational resource that consists of eight Modules of Learning for health professionals, patients, families and the general public.

The Framework is the outcome of a unique collaboration between University College Cork, the Royal College of Surgeons in Ireland and the Irish Hospice Foundation, with contributions from ethicists, legal experts, theologians, sociologists and clinicians. It draws on a range of values and principles that have been identified as important considerations in end-of-life decision making by international experts in bioethics and by professional codes of conduct, policy documents and laws. It is also informed by extensive international research on patients’ and families’ experiences of death and dying and the contribution of health professionals and organizations to quality end-of-life care.

In order to ensure that the Framework addresses the concerns of the Irish public and that it is relevant and useful to the work of health professionals involved in end-of-life care in Irish hospitals, the Framework is informed by reviews and studies involving hospice, palliative and acute care services especially commissioned by the Irish Hospice Foundation in the last decade. It also draws on a significant body of research, undertaken in 2007/2008, which specifically addresses ethical issues in relation to end-of-life care in Irish hospitals.
2. National Research
Reports of the national research undertaken in 2007/2008 are provided in the Appendix to the Framework and they include:

• Focus group interviews with members of the general public to identify issues of concern at the end of life (Weafer, 2009a).

• A national survey of the public’s understanding of, and concerns about dying, death and bereavement (Weafer, McCarthy and Loughrey, 2009).

• Interviews with public representatives in relation to ethical and legislative issues that arise at the end of life (Weafer, 2009b).

• A literature review to explore the concept of autonomy in theory and in hospital practice and to consider a range of initiatives and interventions to support dying patients’ decision making capacity (Quinlan, 2009b).

• An analysis of Irish and UK newspapers, television and radio treatment of issues arising in relation to death and dying in Irish society (Quinlan, 2009a).

• Individual and focus group interviews conducted with healthcare practitioners working in fifteen Irish hospitals, in order to gain an understanding of their experiences of caring for dying patients and their families (Quinlan and O’Neill, 2009).
Evidence from the national research indicates the following:

- The general public and Irish legislators are largely unfamiliar with, or have little understanding of, terms associated with end-of-life treatment and care, such as do not resuscitate orders, advance directives, artificial nutrition and hydration (Weafer, 2009a, 2009b; Weafer, McCarthy and Loughrey 2009).

- Most people want to be informed if they have a terminal condition (Weafer 2009a; Weafer, McCarthy and Loughrey, 2009).

- Information about diagnoses and prognoses is often shared with families instead of patients (particularly older patients) at the end of life (Quinlan and O’Neill, 2009).

- If they are unable to make decisions for themselves, most people prefer their families and/or loved ones (often, in conjunction with doctors) to make decisions about starting or stopping treatment for them (Weafer, 2009a; Weafer, McCarthy and Loughrey, 2009).

- One in five people have told someone how they would like to be treated if they were terminally ill and dying. One in twenty people have written a Living Will (Weafer, McCarthy and Loughrey, 2009).

Most people believe that

- If they were severely ill with no hope of recovery, the quality of their life would be more important than how long it lasted.

- Spiritual or religious support is important to them.

- Every competent person has the right to refuse medical treatment even if such refusal could lead to their death (Weafer, McCarthy and Loughrey, 2009).

- Patients who are dying have medical concerns; but they are also concerned about other things such as family relationships (Quinlan, 2009b).

- Patients who are dying value their autonomy but they also value other things such as the wellbeing of others (Quinlan, 2009b, Quinlan and O’Neill, 2009).

- The notion of patient autonomy is not well understood by many health professionals working in Irish hospitals (Quinlan and O’Neill, 2009).
• Health professionals face communication challenges in sharing decision-making with patients and families in end-of-life situations (Quinlan and O’Neill, 2009).

The eight modules of The Ethical Framework for End-of-Life Care address the concerns that have been highlighted in the research outlined above and consider a number of the narratives that have emerged from interviews and focus groups with health professionals.
3. Aim and Objectives of the Ethical Framework for End-of-Life Care
Aim: The Ethical Framework for End-of-Life Care is an educational resource that aims to foster and support ethically and legally sound clinical practice in end-of-life treatment and care in Irish hospitals.

Objectives

1. A key objective of the Ethical Framework is to enhance the reflective, critical and communicative skills of health professionals, hospital staff and hospital administrators so that they become more informed, confident and collaborative in addressing ethical and legal challenges that arise in the treatment and care of dying patients and their families.

2. A second objective is to provide patients, families and the general public with easily accessible information and opportunities for learning which will deepen their ethical and legal understanding of the issues that arise in relation to death and dying and enhance their decision-making capacity in relation to their own deaths and those of their loved ones.

3. A third objective is to increase the capacity of Irish healthcare organisations
   - to support health professionals to do their work and patients to receive their care in an ethically healthy climate
   - to create safe spaces where individuals feel free to raise ethical, professional and legal concerns and to express nagging doubts and fears
   - to encourage open, inclusive and respectful dialogue about ethical, professional and legal concerns.
4. Educational Philosophy
Research evidence clearly indicates that health professionals, patients and families must often make difficult decisions in tense, demanding, emotionally fraught and constrained circumstances. The Ethical Framework for End-of-life Care offers an opportunity to readers to take a reflective step back from their intuitive responses to ethically challenging situations and to examine received values, assumptions and emotional responses in light of general norms, professional codes and laws.

The philosophy underpinning the development of the Ethical Framework is one that views ethical work as a critically engaged process whose object is to negotiate, rather than eliminate, ethical uncertainty. The assumption is that it is precisely the experience of moral uncertainty, disagreement and diversity that forces us to critically reflect on our moral viewpoints: difference creates the need for moralizing to begin with.

The educational aim of the Ethical Framework, therefore, is not to tell people what to do, but to offer tools for thinking about difficult problems. The educational task is to foster a range of ethical skills and competencies to ensure that ethical decisions are arrived at in the most reasonable, sensitive and collaborative way possible. These include skills of reflection and analysis as well as the critical ability to evaluate the adequacy of reasons and arguments that support different positions and courses of action. To this end, the Framework Modules employ different moral perspectives – traditional and contemporary – to draw out different ethical features of each of the situations considered (See Module 1 for an account of different moral perspectives). In addition, Modules 3 and 4 have a particularly legal focus, which serves to illustrate the way in which very deeply-held moral values have been enshrined and expressed in laws and court decisions.
Readers are also introduced to the process of ethical reasoning and resolution through interactive learning and reflection on case studies drawn from practice. These bring into sharper focus the need for sensitivity to the unique stories and circumstances of individual patients and families. This is all the more important given the multicultural and socially diverse world that health professionals, healthcare staff, patients and families belong to.
5. Ethical Framework
The Framework is divided into 8 distinct Modules of Learning which:
(1) Identify relevant considerations in situations at the end of life that may be ethically and/or legally challenging;
(2) Explore and explain the ethical and legal issues at stake, and;
(3) Offer reasonable and well-supported approaches to addressing these issues.

Module 1:
Explaining Ethics

Discusses one key notion that is linked with death and dying; the meaning of a ‘good death’. Describes a range of different approaches to moral problems and distinguishes ethics from other perspectives such as religion and the law.

Module 2:
The Ethics of Breaking Bad News

Explains why telling patients the truth about their condition is important and reflects on the challenges that diverse cultural perspectives on patient and family relationships present to health professionals when they are considering breaking bad news. Presents arguments for and arguments against, breaking bad news.

Module 3:
Healthcare Decision-making and the Role of Rights

Considers the way in which deeply-held moral values in relation to dying and death have been enshrined and expressed in laws and court decisions. Explains the relationship between moral and legal rights and discusses the advantages and the limits of taking a rights based approach to the decision making process at end of life.

Module 4:
Patient Autonomy in Law and Practice

Explains the legal right of patients to refuse treatment as well as the positive right of patients to control and direct how their treatment and care proceeds. Evaluates the contribution of an autonomy-based model of decision-making and the limits of patient autonomy. Outlines the legal test of capacity, and the health professional’s obligation to facilitate the participation of patients who lack capacity.
Module 5:
The Ethics of Managing Pain

Describes the different kinds of pain and suffering that patients may endure and considers reasons why adequate pain relief may not be provided to different patient groups. Explains the challenge of determining adequate and proportionate responses to patients’ pain and ethically evaluates palliative measures that are sometimes provided to alleviate extreme and intractable suffering.

Module 6:
The Ethics of Life Prolonging Treatments (LPTs)

Explains the ethical and legal concerns that arise in relation to decisions not to start or to discontinue the use of life prolonging treatments. Presents and considers different positions on the ethical and legal status of euthanasia and assisted suicide.

Module 7:
The Ethics of Confidentiality

Describes the onus on health professionals to protect the confidentiality and privacy of patients who are dying and deceased. Discusses exceptions to the ethical and legal requirement of confidentiality and the relevant interests of others such as patients’ families.

Module 8:
Ethical Governance in Clinical Care and Research

Outlines and considers the role of Clinical Ethics Committees and the process of ethics consultation in clinical practice. Charts the emergence of Research Ethics Committees and their contribution to the regulation of research and the protection of research participants.
6. Module Format
Each of the modules is formatted in a similar way; it is divided into distinct sections that offer Key Points, Definitions, Background, Main Topics, Cases and Suggested Professional Responsibilities, ¹ Further Discussion, Summary Learning Guides, Activities, References and Further Reading.

The uniform presentation of the Modules enables readers to take or leave parts or all of any module. In addition, individual Case Studies are linked to specific Activities and Learning Guides so that these can be considered independently of the rest of the Module.

1. Key points
   Offers a brief summary of each of the main points that arise in the Module. These points are discussed more extensively in the main body of the Module.

2. Definitions
   Explains the meaning of key terms used in the Module. Readers may find it useful to return to it when, in the course of their reading, they come across terms that they are unfamiliar with.

3. Background
   Introduces the reader to the main topic of the Module and indicates the key ethical and legal challenges that it presents.

¹  Module 1 provides an overview of the task of ethical reasoning and does not consider individual cases.
4/5. Key Topics
Explains and explores the main ethical and legal issues that the Module is concerned with.

6. Cases
Describe situations from practice which give rise to ethical challenges for health professionals, patients and their families, e.g., decisions about pain relief and starting or stopping medical treatments. Many of the cases are concrete narratives drawn from the everyday experiences of patients, families, health and allied professionals in Irish hospital wards, operating theatres, clinics and other healthcare settings. Where relevant, cases are drawn from other countries. The narratives highlight a number of ethical and legal questions and issues that are then explained and discussed in the text. This section suggests some of the Professional Responsibilities that might arise in relation to each case for readers to consider.

7. Further Discussion
This material discusses in more detail the ethical and legal issues that are addressed in the Module.

8. Summary Learning Guides
Provide brief synopses of the key points that are made in the Module. These are presented in boxed format in order to facilitate a revision of concepts, definitions and arguments.

9. Activities
Questions for reflection or comments are offered to readers at the end of the Module to encourage them to tease out the ethical and legal questions raised in the discussion, the cases and the analyses that follow.

10. References and Further Reading
Includes a list of texts referred to in the body of the Module as well as additional reading relevant to the topic. Where possible; web sources and links are provided.
7. References


