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Making tough decisions at the end of life

By Dr. Joan McCarthy MA, PhD

In end-of-life situations, health professionals, patients and families must often make difficult decisions in tense, demanding, emotionally fraught and constrained circumstances. Every day, caring for dying patients, nurses and doctors find themselves faced with moral questions and challenges:

- What is good care in this case? How can I be a good nurse or doctor?
- What do I say if this patient asks "Am I dying?"
- Should we start or stop treatments such as dialysis, ventilation or nutrition and hydration?
- Will treatment prolong life or hasten death?
- Should I document a Do Not Attempt Resuscitation Order (DNAR)?
- What should I do if there is no DNAR order?
- How much involvement should this patient and/or family have?
- How far do my professional and legal responsibilities extend?

With medical technology we gain greater control over how and when we die. With greater control comes greater responsibility for the range of complex decisions medical technology makes available. The recently launched Ethical Framework for End-of-Life Care (McCarthy, Donnelly, Dooley, Campbell, Smith [2010] Dublin: Irish Hospice Foundation) is a set of educational resources that offers a constructive response to the challenges of such decision-making. The overall aim of the Framework is to foster and support ethically and legally sound clinical practice in end-of-life treatment and care in Irish hospitals and healthcare settings. It has emerged as part of a larger initiative, the Hospice Friendly Hospitals Programme (HfHP), of the Irish Hospice Foundation in collaboration with the Health Services Executive and with the support of The Atlantic Philanthropies.

The Framework, consisting of 8 Modules of Learning and 8 Study Sessions, is targeted at nurses, doctors and other health professionals, hospital and nursing home managers, allied workers, students, social workers, chaplains and also patients and families. It 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 national and international research on patients' and families' experiences of death and dying and the contribution of health professionals and organisations to end-of-life care.

After the launch of The Framework in Cork in October 2010, the Irish Times Editorial commented:

"The Ethical Framework for End-of-Life Care … draws on national and international research; is aimed at health professionals, patients, families and the general public; and is instructive in recognising the complexity of many situations. [It] performs a valuable public service in highlighting issues such as managing pain, confidentiality, governance in clinical care, breaking bad news, healthcare decision-making and life-prolonging treatments. In that regard, it should encourage open public debate and enable healthcare professionals to be collaborative, informed and confident in addressing these matters, however complex and contentious." Irish Times Editorial, 7 October 2010.

The educational aim of the Framework is not to tell people what to do, but to offer tools for thinking about difficult problems. The objective 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. Readers are introduced to the process of ethical reasoning and resolution through interactive learning and reflection on case studies drawn from practice in clinical settings in Ireland and elsewhere. These bring into sharper focus the need for sensitivity to the unique stories and circumstances of individual patients and families.

The 8 Modules of Learning are:

1. Explaining Ethics
2. The Ethics of Breaking Bad News
3. Healthcare Decision-making and the Role of Rights
4. Patient Autonomy in Law and Practice
5. The Ethics of Pain Management
6. The Ethics of Life Prolonging Treatments
7. The Ethics of Confidentiality
8. Ethical Governance in Clinical Care and Research

They are freely available online at:
www.hospicefriendlyhospitals.net/ethics

An additional 8 Study Sessions provide key material for small workshops on each of the 8 Modules.

Research in Ireland over the three year development of the Ethical Framework determined that there was a keen need and demand for education and support of health professionals, allied professionals and the general public in relation to decision-making at end of life. In response to this need and as a measure to support the dissemination of the Ethical Framework, University College Cork (School of Nursing and Midwifery, School of Medicine and Department of Philosophy) are offering an MSc End-of-Life Healthcare Ethics available from October 2011. This postgraduate course is a 2 year taught programme with exit awards (Postgraduate Certificate End-of-Life Healthcare Ethics after 12 months and Postgraduate Diploma End-of-Life Healthcare Ethics after 18 months). Inquiries about the course can be made to: School of Nursing & Midwifery, Tel No: 021 - 4901560/1555/2159, Fax No: 021 - 4901493, E-mail: nursing.studies@ucc.ie.

In order to support this innovative education programme and to promote ethical decision-making, the Irish Hospice Foundation is providing one scholarship to cover fees for the two years of the MSc programme. For further information on the scholarship, contact Orla Keegan, Irish Hospice Foundation, 32 Nassau Street, D2, Tel No: 01 6793188, E-mail: orla.keegan@hospice-foundation.ie.

To conclude, international research evidence indicates that in healthcare organisations where there is ethics support, health professionals and hospital staff:

- are more self-aware of their own beliefs and values
- are more sensitive to moral values at risk
- are less paralysed by moral issues
- engage more in dialogue, and less in debate, about the 'right' answer
- postpone judgement
- listen and feel heard
- are more willing to engage in a process that will involve some degree of negotiation
- bring reasons for decisions out into the open so there is greater transparency

Enhancing the ethical culture of organisations in this way preserves both patients' rights as well as professional integrity and leads to improved patient and family outcomes as well as less moral stress, desensitization and burnout for health professionals and hospital staff.

In short, we should recognise that the work of health professionals is centrally ethical and acknowledge that this often comes at a personal cost. In organisations that are increasingly driven by agendas focused on constraints of economy, efficiency and productivity, sight should not be lost of the fundamental bond between professional and patient. Drawing on the insights of ethicist Arthur Frank, it is important to remember that before, during and after, examination, diagnosis, surgery, wound dressing, feeding, bathing and medication, there is human relationship - and the opportunity to offer consolation, respect and dignity. With this in mind, it is intended that the Ethical Framework and the MSc End-of-Life Healthcare Ethics will contribute to a more open, inclusive and respectful national, local and organisational dialogue about the ethical, professional and legal issues that arise in relation to death and dying. Given the tough decisions that must sometimes be made in end-of-life care; it is hoped that health professionals, patients and families will be able to express and share nagging doubts and uncertainties more easily and that, for them, the personal cost of acting ethically will not be unbearable.