National Council of the Forum on End of Life

UPR submission (Ireland, October 2011)

The National Council of the Forum on End of Life

The National Council of the Forum on End of Life was established in 2010 with a view to carrying forward the work and vision of the Forum on End of Life in Ireland which was launched in 2009. The National Council of the Forum on End of Life in Ireland takes a broad life cycle approach to end of life. Its members come from various sectors, including the medical and legal professions as well as architects and academics. While it is important that health care issues remain firmly on the agenda, the National Council is dedicated to addressing the legal, ethical, financial, educational and administrative aspects of end of life.

It is currently engaged with a Work Plan involving ten main areas. The National Council's founding Chairperson is Mrs. Justice Catherine McGuinness, the former Supreme Court Judge, and out-going President of the Law Reform Commission.

SUBMISSION

1.   Introduction

At the first meeting of the Forum on End of Life in Ireland, Dr. Maurice Manning, President of the Irish Human Rights Commission, spoke of the link between palliative care and human rights and said that the right to full human dignity cannot be enjoyed by people suffering unrelieved yet treatable pain.

Dr Manning referred to increasing calls for the recognition of the right to a good death. He cited the British writer Ken Worpole's observations of 'emerging signs of public demand for the 'right' to a good death arising from concerns with the institutionalisation of death and disquiet about how people die'.[1]

In 2002, the Irish Human Rights Commission said that while human rights to services were initially applied to empower disabled people who were in receipt of services, they were now being applied more widely as part of poverty reduction and social inclusion strategies and, more specifically, to people who are dying.[2]

As mentioned above, a rights-based approach toward services has empowerment as its goal. This can be achieved where rights are clearly laid out in legislation and when they are delivered in a consistent, fair and timely manner in order to ensure the respect and dignity of the individual.

In Ireland, access to palliative care is not supported by statute and is highly inconsistent across the country. This significant variation in the quality and

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[1] Worpole, *Modern Hospice Design: The Architecture of Palliative Care* (London: Routledge, 2009)
[2] http://www.ihrc.ie/download/pdf/research_elderly_in_institutions_200304.pdf

availability of services can result in many people being denied the right to die with dignity.

In an **international context**, Ireland has ratified the following:

- International Covenant on Civil and Political Rights (1966) and its Optional Protocols (1976 and 1989) (ICCPR).

- International Covenant on Economic, Social and Cultural Rights (1966) and its Optional Protocol (2008) (ICESCR).

- Convention on the Elimination of All Forms of Discrimination against Women (1979) and its Optional Protocol (1999) (CEDAW).

- Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (1984) and its Optional Protocol (2006) (CAT).

- Convention on the Rights of the Child (1989) and its two Optional Protocols (2000) (CRC).

The IHRC has noted that there is often interdependence between groups of rights. It has stated that full enjoyment of economic, social and cultural rights, which may include rights to palliative care services and welfare supplements for people who are dying, as well as for their carers and families, is necessary for a person to be an active citizen and enjoy civil and political rights.[3]

In a **domestic context**, the Irish Constitution provides guarantees to equality before the law, and enshrines rights to bodily integrity and individual privacy as well as freedom from torture and ill-treatment.

In 2009, the Government committed to a five-year plan for development of palliative care services,[4] following the recommendations in the 2001 Report of the National Advisory Committee on Palliative Care, which was adopted as official government policy.[5] While the goals of this plan have been partly implemented with the assistance of the Irish Hospice Foundation, developments have been predominantly in specialist palliative care and there is a need for these goals to be reviewed with a focus on general palliative care.

2.   **Current situation**

As mentioned above, human rights are currently being denied in Ireland due to the inequity of access to, and in some cases the complete absence of, palliative care services. There is significant geographical variation in the availability and quality of palliative care. For example, while the Mid West region has well developed services, the Midlands have no hospice beds and only one palliative care consultant.

A baseline study conducted in 2005 found that expenditure per capita in the Midlands of €7, compared with €33 in the Mid West.[6] This lack of development of palliative care ignores the fact that it delivers better outcomes for patients, their families, and for

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[3] http://www.ihrc.ie/download/pdf/research_elderly_in_institutions_200304.pdf
[4] http://www.hse.ie/eng/services/Publications/corporate/palcareframework.pdf
[5] http://www.dohc.ie/publications/pdf/nacpc.pdf
[6] http://www.hospice-foundation.ie/up_documents/Mar_06_baseline_study.pdf

health care professionals. It can also save money which can be put to other health uses. Many studies suggest strongly that hospice care reduces hospital admissions and hospital lengths of stay.[7]

Many hospices are currently prioritising care for cancer patients, allocating care and resources according to disease rather than objective need and symptom burden. Referral to palliative care services is often made too late, resulting in patients being denied effective pain relief and a comfortable environment.

The recent audit commissioned by the Hospice Friendly Hospitals programme (HfH), an initiative of the IHF, found significant differences in the perceptions of patients' families, nurses and doctors regarding whether patients were experiencing pain. This highlighted the need for enhanced education and training for health care professionals.

Palliative care is an elective module for disease specialists and there is no requirement for GPs to train in palliative care. The training currently provided to health care professionals is far from proportionate to the amount of time spent caring for patients who are dying.

Training needs in palliative care and bereavement are addressed in the Quality Standards for End of Life Care in Hospitals published by the IHF in 2010.[8]

Finally, it is essential to the full enjoyment of human rights that individuals exercise their autonomy, are enabled to state their preferences regarding their treatment and have these preferences respected, as far as is possible. Advance care directives are currently not recognised by Irish law and there are no national guidelines in relation to resuscitation.

It is also vitally important that patients are given adequate information about their condition, as desired. Most people want to die at home and up to 25 % of hospital deaths could be at home if there were proper supports provided.[9]

There needs to be acknowledgement of the universal right to a 'good death', which is in accordance with the wishes of the individual, free from treatable pain and surrounded by their loved ones.

The report of the Forum on End of Life upholds the importance on the right to die with dignity and states that the meaning of the term dignity must continue to be associated with upholding the sacredness of the life and death of each person.[10]

3.   Proposal for change

The National Council of the Forum on End of Life is calling for:

- Universality of access to palliative and hospice care, regardless of disease, disability, age[11] or geographical location in order to improve the quality of care for individuals and their families at end of life.

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[7] Eugene Murray. *Journal of Pain and Symptom Management*, Vol 38, No 1. July 2009

[8] http://www.hospicefriendlyhospitals.net/images/stories/pdfs/Quality_Standards_for_End_of_Life_Care_in_Hospitals.pdf

[9] *National Audit on End-of-Life Care in Hospitals in Ireland, 2009*

[10] *Report of Forum on End of Life*

- Patients' autonomy should be respected in terms of rights to make decisions such as refusing treatment and where they wish to die. They should be consulted about wider issues relating to their health and end-of-life care in a professional and caring way. In this context, the pending Mental Capacity Act should include provision for the recognition of advance care directives. Patients should also have their cultural, religious and spiritual wishes respected, as well as their preferences regarding funeral rites and burial or cremation.

- Patients should be facilitated to decide whether they are to be resuscitated. There should also be national guidelines on resuscitation.

- Access to pain management should be available to all without discrimination. The Forum on End of Life in Ireland showed that anxiety about pain was a major factor at end of life. Ireland should take steps to support the Declaration of Montreal 2010, which states that access to pain management is a fundamental human right.

- Patients should be enabled to access clear and truthful information on their condition, and on end-of-life care, where desired.

- Health care professionals should be provided with compulsory training in palliative care and bereavement, including skills in end-of-life decision-making and skills the communication of bad news.

- Family and professional carers of people at end of life should be supported by the State and local communities.

- National legislation should be updated and reformed in the areas of mental capacity, guardianship, care provision and succession.

- Health care and residential facilities where people die should be enhanced.

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[11] In Ireland there is a life cycle approach to national policy and planning: *Towards 2016/Transforming Ireland, a Better Quality of Life for All 2007-2013/Building an Inclusive Society*