



FORUM *on* END *of* LIFE

Bás in Eireann

IN IRELAND

Draft

Action Plan



THE IRISH
HOSPICE
FOUNDATION



1. Introduction

In a joint statement in 2008, the Irish Hospice Foundation and the National Council on Ageing and Older People recommended that the advocacy base for the reform of end of life care, driven primarily by the hospice and palliative care movements, be broadened.

As a first step towards realizing this goal the Irish Hospice Foundation (IHF) inaugurated a Forum on End of Life in Ireland at the beginning of 2009 to identify what matters most to the public regarding end of life from a wide range of perspectives: social, health, economic, legislative, administrative, educational, cultural and religious. The aims of the Forum were:

- To promote a national conversation on dying, death and bereavement
- To ascertain the key issues at end of life
- To explore the views and concerns of the public and varying organisations
- To ensure that a wide range of views are heard
- To report on the issues emerging from the Forum workshops and submissions
- To prepare the ground for a National Coalition to advance the views emerging from the Forum.¹

The proceedings and outcomes of the Forum were to be governed by the principles and values of hospice and palliative care as set out in the IHF website. “Life is affirmed and dying is regarded as a normal process. Death is neither hastened nor postponed. Pain and other distressing symptoms are relieved.”²

In the course of 2009 the Forum organised nine public meetings around the country and 23 workshops. It also received 167 submissions from organisations and individuals. The exercise was very much a listening one, designed to identify participants’ views on end of life issues in Ireland, and their wishes and aspirations for the care and treatment of those at end of life in this country, and those who survive them. A report of the proceedings of the Forum has been drafted by Bob Carroll, the former Director of the National Council on Ageing and Older People,

¹ www.endoflife.ie

² Ibid and Report of the National Advisory Committee on Palliative Care (2001). Dublin: Department of Health and Children

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which outlines the main themes, messages and issues raised by contributors to the Forum. This baseline document, *Perspectives on End of Life in Ireland: Report of the Forum on End of Life*, on which this Draft Action Plan is based, is available on the website, www.endoflife.ie and the Irish Hospice Foundation website, www.hospice-foundation.ie.

Before finalising an Action Plan, the IHF wishes to provide an opportunity to members of the public and interested parties to comment on this draft. Following completion, the Action Plan will then inform the work of a National Council for the Forum on End of Life in Ireland, which the IHF has decided to establish to develop, oversee and support the Forum's ongoing work.

The proceedings of the Forum act as a point of reference for those developing an Action Plan on end of life in Ireland. It provides an illustrated guide to those navigating complex issues in changing times. The following are some of the prominent themes and issues raised in the Forum which might inform the Action Plan. Items 2 to 4 refer to the breadth of the work and the inclusive principles which must underpin it, while items 5 to 18 detail a range of potential actions.

2. Death is part of the life cycle

In this country we have adopted a life-cycle approach in national policy and planning:

- in the Social Partnership Agreement, *Towards 2016*,
- in the National Development Plan 2007 - 2013, *Transforming Ireland - A Better Quality of Life for All*, and
- in the National Action Plan for Social Inclusion, *Building an Inclusive Society*.

This approach, which accords with the direction set by the OECD report on an integrated public service for Ireland,³ should ensure:

- that no population group - children, younger and older adults of working age,

³ OECD, (2008). Ireland - Towards an Integrated Public Service. Paris: OECD

older people or people with disabilities - is overlooked by society

- that an integrated approach obtains across policy areas
- that the citizen rather than the provider is at the heart of public services planning and provision.

Death is, of course, part of the life cycle - the last part in this world so far as the individual is concerned. However, death can occur at any age and therefore must be taken into account in policies governing all of the above mentioned groups. End of life, death and bereavement must be integrated in planning initiatives for all age groups and that planning must be informed, first and foremost, by the lived experiences of end of life: of infants and children; of their families; of younger and older adults, (whether of working age or otherwise); and of people with disabilities. It is hoped that the report of the Forum's proceedings, which expressly seeks to give equal voice to citizens as to service providers, will prove useful to those responsible for service planning and development in all fields and for all groups.

It is recommended that the Action Plan include provision to monitor the development and implementation of national social policy in Ireland to ensure that dying, death and bereavement are appropriately provided for. In this regard, for example, the Government is committed to the development of a Positive Ageing Strategy and Palliative Care Services – Five Year/Medium Term Development Framework (HSE, 2009). Given that 75% of those who die in Ireland are over 65 years of age, it will be important that the strategy address the critical end of life issues which particularly apply to older people, as identified by the Forum and by others.

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3. End of life is everybody's business

End of life is everybody's business, not just the business of the caring professions. It is the business of lawyers, bankers, architects, town planners, teachers, public representatives, journalists, public and private sector employers and managers, just as it is the business of medical, social and pastoral care providers. This was clear from contributions to the Forum, which identified a wide range of financial, legal, environmental, administrative, cultural and educational measures which might be taken to improve the quality of life of those at end of life and of bereaved persons. Drawing on the baseline report of the Forum's proceedings, separate agendas for action might be drafted for the attention of particular groups of people working in different sectors, such as those mentioned above.

4. End of life is a public health matter

By their contributions to the Forum, people from all walks of life and people representing organisations with very different responsibilities also demonstrated that the responsibility for articulating and responding to end of life questions, including questions about end of life care, should not be left only to those who provide hospice and palliative care services. How end of life services are organised, and how people at end of life are provided for, are matters of interest to everybody, for open discussion by society as a whole.

An International Work Group (IWG) on death, dying and bereavement proposed a "charter for the normalisation of dying, death and loss"⁴, with this in mind, rather than hiding them away or giving responsibility for them to a few.

We must see and treat dying, death and loss as public health matters; they must be anticipated, and any harm that they cause the individual must be minimised by building our capacity to show solidarity with the dying and the bereaved. This, the IWG says, requires "community development, education, participatory health care approaches, legislative and policy change". It identified the following as essential elements of a public health approach to end of life care:⁵

⁴ International Work Group on Dying Death and Bereavement, *Charter for the normalisation of death, dying and loss. Mortality*, May 2005; 10(2) 157 -161, Routledge Taylor and Francis group

⁵ Ibid

- recognition of the inevitability of death and the inevitability of loss
- cultural sensitivity and adaptability
- culture/settings approach
- social justice by promoting equal access for all
- a population health approach
- sustainability.

The Action Plan must adopt a similar public health approach and include provision for initiatives in the above areas identified by the IWG, which are very much in keeping with views expressed by contributors to the Forum.

5. Broaden the advocacy base for the reform of end of life care in Ireland

It is important to maintain and develop the interest shown by Forum participants in working together to reform end of life care and welfare in Ireland. The following are some of the ways in which this might be done:

- Explore and promote community development approaches to addressing end of life issues at the local level
- Welcome the offers of organisations such as the Citizens Information Board (CIB) and the Money Advice and Budgeting and Service (MABS) to work together to further develop public information on end of life matters
- Support the organisation of End of Life Forums for groups who may wish to explore further end of life issues as they affect their client group
- Resource and jointly organise workshops for organisations whose members or staff lack confidence to address the end of life issues of their members
- Make common cause with organisations who seek to prevent premature death; support the work of accident and suicide prevention groups, for example.

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6. Develop public awareness about end of life issues and change attitudes to death, dying and bereavement

The End of Life Care Strategy for England sets out the intention of the government to make end of life care a priority. However, as it says, “government action alone cannot change attitudes towards death and dying, nor raise awareness of the issues involved.”⁶ The Strategy therefore made provision for the establishment of a broad based national coalition of organisations, building on the involvement and commitment of the wide range of stakeholders who contributed to this strategy, in promoting greater public discussion and awareness of issues involved with death and dying. This has since been established and is called *Dying Matters*. It is recommended that the Action Plan seek to involve all those who contributed to the Forum in 2009 in the development of a similar public education and awareness-raising initiative in Ireland.

7. Develop an end of life strategy

There is a need too to develop an End of Life Strategy in its own right. Perhaps recognising the danger of neglect of the dying, other countries are increasingly placing end of life on their public health agendas and developing strategies to address end of life issues, such as those raised by Forum participants.

The report, *Palliative Care for All - Integrating Palliative Care into Disease Management Frameworks*, recommended that an end of life strategy should be introduced in this country too. In the light of the Forum’s deliberations, however, its aim should not be limited to ‘supporting and guiding all healthcare staff who work with people at end of life’. It should have a wider brief with a view to developing a national engagement with end of life and community based solidarity with those at end of life. It is recommended that the Action Plan include a provision to develop an End of Life Strategy which addresses the issues raised by the Forum.

⁶ End of Life Care Strategy - promoting high quality care for all adults at end of life (2008), p. 38. London: Department of Health

8. Strengthen the information base for end of life planning and services development

As indicated by the National Council on Ageing and Older People in its presentation to the Forum, “The World Health Organisation in its report, Better Palliative Care for Older People (WHO, 2004), noted that ‘needs during the last years of life have not been a research priority ... and in general much more money is spent on research into potentially curative treatment.’”

Contributors to the Forum frequently alluded to deficits in information for end of life planning and services development purposes. The Action Plan should therefore include provisions:

- for a review of data deficits identified by contributors to the Forum
- for a review of the adequacy of the data available for the planning of end of life care provision nationally in all care settings, and
- for the development of an end of life research strategy.

An All Ireland Institute of Hospice and Palliative Care, should it be established as proposed, might take responsibility for some of this work.

9. Strengthen regulation and standard setting

Regulation and standard setting will not, of themselves, ensure that service providers display the sensitivity and interpersonal skills needed to maximise the quality of life of those they care for at end of life. However, it is clear from the Forum that there are a number of regulation and standard setting measures which might be considered for inclusion in the Forum’s Action Plan, as follows:

- regulation of the funeral industry
- regulation of domiciliary care services, particularly end of life care services, and development of quality standards for end of life care at home
- implementation of the *Quality Standards for End of Life Care in Hospitals* to be launched by the Irish Hospice Foundation in May 2010
- review and promote the development of bereavement care training, structures

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- and standards in the voluntary and statutory sectors
- campaign for the widespread introduction of household or “teaglach” model of residential care
- campaign for the provision of single rooms to enable those at end of life who want one to die in privacy and with dignity
- develop mortuary standards, including standards for the treatment of remains after death; following clarification of policy on the use of body bags and embalming practices, standards governing these practices in particular need to be developed
- review and promote improved standards to meet psychosocial care and service needs at end of life in Ireland
- review and promote improved standards to meet spiritual care needs at end of life in Ireland.
- Consistent provisions of comprehensive community based hospice services as per The Report of the National Advisory Committee of Palliative Care (Dept of Health & Children, 2001)

10. Implement national policy on palliative care

It is proposed that the Action Plan include a campaign for adequate resourcing and full implementation of:

- The Report of the National Advisory Committee on Palliative Care (Dept of Health & Children, 2001)
- Commitments on palliative care in the 2007 programme for Government
- Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks (HSE & IHF, 2008)
- Palliative Care Services - Five Year/Medium Term Development Framework (HSE, 2009).
- Palliative Care for Children with life-limiting conditions in Ireland – A National Policy (DOH&C 2010)

The campaign should be designed to promote greater access to palliative care and should take account of the following recommendations proposed by contributors to the Forum:

- Ensure equity of paediatric with adult palliative care
- Resource Community Hospitals to provide more palliative and end of life accommodation and services closer to people's homes
- Provide access to consultant led palliative care for those in continuing care
- Monitor HIQA reports detailing end of life care services and staff competences in continuing care facilities where people die
- Provide palliative care for all at home on the basis of need, through the provision of integrated services on a 24/7 basis
- Treat and work with family carers as partners in the provision of end of life care at home. Identify and provide supports to them in a timely manner, including respite care and Home Care Packages. Provide them with training as required
- Incorporate end of life care in guidelines and pathways for all life-threatening diseases and conditions
- Introduce the legislation promised in the National Health Strategy, *Quality and Fairness* (2001)⁷, which would provide entitlement to palliative care services for all.

11. Explore the possibility of developing a distinctly Irish dimension to end of life care and welfare

As noted in Chapter Four of *Perspectives on End of Life in Ireland: Report of the Forum on End of Life in Ireland*, in other cultures end of life care has characteristics distinctive to those cultures, with benefits beyond end of life care provision itself. Care at end of life can be an indicator of the performance of the whole care system and a catalyst for its reform. It is clear that if certain of the problems in end of life care in Ireland documented in the Forum report were comprehensively addressed, the whole health care system would stand to benefit. Likewise

⁷ Department of Health and Children, *Quality and Fairness. A health system for you.* (2001), pp 74 - 75. Dublin: The Stationery Office

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the Forum should seek to act as a catalyst to preserve and promote what is best in the Irish approach to dying and death, including sympathy and solidarity with the bereaved following a death. It is proposed that provision be made in the Action Plan to explore the possibility of adopting a theme for a number of years to give a particular focus and character to end of life care and welfare in this country.

It is further proposed that the theme selected should have relevance for the healthcare system as a whole. This is in order that it may enhance the possibility of the initiative serving as a model with a wider application. Examples of possible themes include:

- interpersonal communication in end of life care
- partnership working in end of life care
- valuing carers in end of life care
- promoting the art of healing in end of life care

12. Promote transparency of decision-making at end of life

It is proposed that the Action Plan should include support for a campaign for openness and transparency in the way end of life decisions are taken. The campaign might focus particularly on:

- Advanced Care Planning, based on patient participation, and with related training in communications skills for staff
- good practice in communication by healthcare providers with patients on the range of options open to them, explaining each in terms of the expected quality of life, the emotional and other costs, the likelihood of success and the effect on length of life
- good practice in establishing with the person at end of life whether family carers or others should be included in decision-making processes
- the development of evidence based guidelines for end of life decision-making where they do not exist
- the preparation and observation of nationally agreed procedures and guidelines for Do Not Resuscitate (DNR) orders
- ensuring that the procedures and guidelines for DNR orders used in different

hospitals and ambulance services are freely available, preferably in one place or on one site, pending the introduction of national procedures.

13. Promote discussion of proposed Code of Practice on Advance Care Directives

The report on the proceedings of the Forum sets out views expressed by participants on Advance Care Directives (ACDs). While there are differences of opinion on ACDs, from the terminology used to the need to provide a legal framework for them, the initiatives taken to address the matter by the Irish Council for Bioethics and the Law Reform Commission, among others, have raised further questions which require discussion. In its workshop presentation, the Law Reform Commission suggested that these issues be taken up by the Forum. They are set out most succinctly in the Code of Practice on Advance Care Directives, which the Law Reform Commission proposes should be developed by the Office of Public Guardian⁸. The Action Plan might therefore seek to promote discussion on the following:

- treatment that constitutes basic care
- treatment that constitutes palliative care
- treatment that constitutes life-sustaining treatment
- the circumstances in which artificial nutrition and hydration may be considered to be basic care and, as the case may be, life-sustaining treatment
- the process of putting in place a Do Not Resuscitate Order including the need for a prior consultative process, that this is documented on a person's medical chart and that it is made by the most senior available member of the healthcare team.

The Hospice Friendly Hospitals Programme of the Irish Hospice Foundation has published an *Ethical Framework for End of Life Care*, which will be of assistance, if the Action Plan includes the promotion of discussion on the above issues.

⁸ See: Law Reform Commission (2009) Report. Bioethics: Advance Care Directives, Appendix: *DRAFT MENTAL CAPACITY (ADVANCE CARE DIRECTIVES) BILL 2009*.

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14. Develop information provision

Individual people and families need to have sufficient, accessible and dynamic information to allow them:

- to prepare for end of life
- to maximise living in the time left following a diagnosis of a life-limiting illness/ condition
- to make informed choices and to act as equal partners in their own treatment and care
- to cope with bereavement.

The Action Plan should include joint initiatives with the Citizens Information Board and others to explore how their information content and delivery might be enhanced in the light of the deliberations and outcomes of the Forum. It should also review standards of information provision by those who provide end of life care services in the community, in continuing care, in hospitals and in hospices. The Action Plan should be proactive in fostering the development of comparative information on end of life and bereavement care services provision in all settings.

15. Enhance end of life education and training

The importance of end of life education and training was a constant theme of the Forum and many emphasised inadequacies in education and training received. There was notable diffidence on the part of some, particularly people in the private nursing homes and intellectual disabilities sectors. Training and education around death, dying and bereavement should be comprehensive and tailored at different levels – for the public, for volunteers, for health professionals and for specialists. Professional education and training for all those who care for people at, and following, end of life must be an important focus of the Action Plan. It should include:

- public education on end of life and bereavement
- support for the development of the Palliative Care Education Framework at all levels
- engagement with specific sectors to determine more precisely their education and training needs
- advocacy on behalf of those sectors most in need of resources and opportunities for end of life education and training.

16. Address financial concerns at end of life

A constant theme of the Forum was the contrast between people's preferred place of death (at home, for the majority) and their actual place of death, usually in a hospital or other institutional setting. There are different reasons for this, including the availability and affordability of community and palliative homecare services. Pending the introduction of the statutory entitlement to palliative care, it is recommended that the Action Plan include provision to campaign for a medical card for everyone with an advanced incurable illness and/or for a Palliative Home Care Package, or its monetary equivalent, for those being cared for at home. The Irish Hospice Foundation has already called for an entitlement to a medical card⁹, saying that people with advanced incurable illnesses should have access to a full range of free medical and health services including basic supports at home such as oxygen supplies, a hospital bed at home and access to the services offered by a community-based, multi-disciplinary team.

Consideration should be given to including in the Action Plan support for a campaign encouraging people to avoid dying intestate by making a will. The campaign should also promote separate legal representation for those making wills and those benefiting from them. It should further promote greater use of Enduring Power of Attorney. The Action Plan might also support the establishment of a register of wills.

⁹ Call for a Statutory Entitlement to a Medical Card for People with Advanced Incurable Illnesses. Irish Hospice Foundation Press Release, 28 November 2008

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17. Improve the organisation of end of life and bereavement care

It is clear from the contributions to the Forum that good end of life and bereavement care requires:

- coordination across organisational and sectoral boundaries
- interdisciplinary collaboration, and
- integrated team working.

It is recommended that the Action Plan include measures to foster good practice in coordinated, collaborative and integrated end of life care by promoting:

- the development of care pathways and frameworks where such are needed
- the introduction of new end of life care models where current models are inadequate.

18. Ensure that the Action Plan is balanced

Through the Forum on End of Life in Ireland we have been able to get a glimpse of how end of life is perceived in this country, of what matters most to people when they think about their death and the death of people close to them. While end of life constructs are far from uniform, some themes have emerged from this national conversation. Taken together, rather than singly, these themes facilitate the development of a shared vision of how contemporary Ireland can address the challenges of dying, death and bereavement. The Action Plan can contribute to the realisation of that vision, providing it too does not allow one of these themes to dominate to the exclusion of others.

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As we have already seen in this country, in common with people in other Western societies, we place a great emphasis on individual autonomy at end of life, perhaps because we fear increasing dependence on others at that time. On the other hand, the Forum also revealed an equally strong emphasis on positive interpersonal communication at end of life, perhaps because we do understand our social nature, our interdependence with others. The Action Plan should therefore seek to ensure that its programme of work balances efforts to promote greater autonomy at end of life with efforts to enhance the manner in which we communicate with and treat each other at this most sensitive of times.

Bob Carroll,

15th April 2010.

