



FORUM *on* END *of* LIFE

Bás in Éirinn

IN IRELAND

ACTION PLAN *2013-2015*



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1. Introduction

In a joint statement in 2008, the Irish Hospice Foundation (IHF) 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 realising this goal the 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.

The IHF made it clear on its website that the proceedings and outcomes of the Forum were to be governed by the principles and values of hospice and palliative care.

In the course of 2009 the Forum organised nine public meetings around the country and 23 workshops. It also received 166 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 baseline report of the proceedings which outlines the main themes, messages and issues raised by contributors to the Forum, *Perspectives on End of Life in Ireland: Report of the Forum on End of Life*, was published in 2009. It formed the basis for an initial Action Plan² based around 10 key action areas.

1. Availability and Access to services
2. Carers
3. Information and Communication
4. Spiritual and Psychological Support
5. Financial, Legal and Administrative Issues
6. Ethical Engagement
7. Physical Environment
8. Standards and Regulation
9. Planning and Co-ordination
10. Public Engagement

“Life is affirmed and dying is regarded as a normal process. Death is neither hastened nor postponed. Pain and other distressing symptoms are relieved.”¹

¹ *Ibid* and Report of the National Advisory Committee on Palliative Care (2001). Dublin: Department of Health and Children

² Available on the Irish Hospice Foundation website, www.hospicefoundation.ie

1.1 Principles underlying the Action Plan

Based on the Forum's findings there are a number of inclusive principles which must underpin the Action Plan:

- **Death is a part of the lifecycle:** In this country we have adopted a lifecycle approach in national policy and planning. Death is a significant part of the lifecycle. End of life, death and bereavement must be integrated in planning initiatives for all age groups. There should be a provision to monitor the development and implementation of national social policy in Ireland on dying, death and bereavement.
- **End of Life is everybody's business:** Contributions to the Forum 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. Separate action plans should be drafted for the attention of particular groups of people working in different sectors.
- **End of Life is a public health matter:** 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. 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. Community development, education, legislation and policy changes should be adopted using a public health approach to end-of-life.
- **High quality palliative care should be available to all:** High quality, person-centred palliative care should be available to all, regardless of age or circumstances, including psychological and spiritual care. Families and carers should also be supported.

- **Everyone is entitled to die with dignity:**

The National Council will campaign to ensure that conditions of privacy and respect prevail in end-of-life care, including improving availability of private rooms for those that want them.

1.2 Irish policy and implementation

Ireland has a tradition of being particularly innovative when it comes to formulating social policy, while tending to fall short in its implementation of that policy, and strategies are often implemented only at a pilot stage.³ Ireland is not alone in this and in practice the implementation stage is often the most difficult one facing governments.

The OECD, in its 2008 report, *Towards an Integrated Public Service*, cited a lack of implementation skills as one of the main challenges facing the Irish public sector⁴. The OECD drew attention in particular to the segmented nature of the public service and the challenges this posed for policy development, implementation and service delivery. Responding to more complex, cross-cutting issues will require an integrated public service that acts increasingly through networks rather than top-down structures and further interaction is needed between public service organisations and with stakeholders at local, national and international levels, and across these levels⁵.

³ NESF, 2007, McGauran & Moore, Measuring Implementation of Irish Policies

⁴ OECD, April 2008, Toward an Integrated Public Service: 12

⁵ OECD, April 2008, Toward an Integrated Public Service: 25



With regard to the current economic climate, the OECD defined the implementation challenge facing Ireland in the coming years as stemming from the necessity of meeting increased expectations with constrained resources. In order to meet these expectations, responsiveness will be essential and mechanisms for incentives will have to be developed⁶.

Commitments to the development of end-of-life care that have been made to date include:

- National Clinical Care Programmes
- Commitments to implement the recommendations made in the Report of the National Advisory Committee on Palliative Care (NACPC) (Dept of Health & Children, 2001)
- Shaping a Healthier Future (1994)
- National Strategy for Cancer Services in Ireland (1996)
- Quality and Fairness (2001)
- Primary Care Strategy (2001)
- Sustaining Progress - Social Partnership Agreement (2002)
- DOHC Business Plans - Services for Older People and Palliative Care (2004 & 2005)
- HSE Corporate Plan 2008-2011
- Commitment to Palliative Care Services - Five Year/ Medium Term Development Framework (HSE, 2009)
- Palliative Care for Children with Life-limiting Conditions: A National Policy (DOHC, 2010)
- HSE Service Plan 2013
- Future Health: A Strategic Framework for Reform of the Health Service 2012-2015

⁶ The Task Force on the Public Service was appointed in May 2008 to develop an action plan in response to the OECD report

2. Role and Mandate of the National Council on End of Life

The National Council as a voice to reflect the view of Irish People

The national consultation completed in 2009 provided the most comprehensive view of the Irish people on all issues concerning end of life to date. This consultation remains valid and adds to other public consultation work. The Council has a role in promoting the findings from this consultation where appropriate and engaging in other work to ascertain the views of the public on critical issues.

The National Council as a stimulus for the inclusion of dying, death and bereavement in Ireland in policy and societal development

The year-long consultation process for the National Forum on End of Life in Ireland confirmed that end-of-life issues are often difficult to articulate – as a consequence they are often not fully considered in public policy. Frequently public debate is a key driver of the direction adopted in public policy. A key role of the Council is to stimulate debate on critical issues as they arise and to ensure end-of-life issues are considered as part of the development of public policy and within societal debates.

The National Council as a Forum for discussion of broad end-of-life issues - beyond health

The year long consultation process for the National Forum on End of Life in Ireland confirmed that end of life issues are much broader than simply health care - they encompass legal, ethical, health, information, societal and policy issues. The Council has a role to keep that broader focus on broad end-of-life concerns.

The National Council as monitor of policy implementation

In a context of a deficit in the area of implementation, it will be important for the National Council to play a monitoring role to ensure there is steady progress against national policy commitments. This will be even more important given the straitened economic circumstances. It is essential that government is continually reminded of the need to ensure that stated policy statements and commitments can be translated into reality to improve the capacity of services to meet end-of-life needs and to ensure that everyone is allowed to achieve a 'good death'.

Government increasingly adopt a lifecycle approach to public policy - this commitment to a lifecycle approach is illustrated in Towards 2016; NDP 2007-2013; National Action Plan for Social Inclusion and the National Positive Ageing Strategy.⁷

We believe that death is a part of the lifecycle. In our work through the National Council, this translates into fostering appreciation at policy level of wider issues of death as a stage of life, and one that can occur at any age, while also bearing in mind that 75% of those that die are over the age of 65 years.

The National Council will work to promote the implementation of existing policy; to ensure that previous commitments with regard to the development of end-of-life issues are met by those with responsibility for policy implementation, and that future policy is designed with end-of-life in mind.

⁷ Towards 2016 states that the lifecycle approach places the individual at the centre of policy development and delivery, by assessing the risks facing him/her, and the supports available to him/her to address those risks, at key stages in his/her life, Towards 2016: 7



3. The 2013-2015 Action Plan

This action plan has been prepared to prioritise a programme of actions to inform the work of the National Council for the Forum on End of Life in Ireland, which was established to develop, oversee and support the Forum's ongoing work. In this way, the purpose of the Action Plan is to ensure the reform of end-of-life care in Ireland.

This present action plan is an updated action plan. It is informed by a process review of the Forum on End of Life completed in 2012.

3.1 Previous objectives and desired outcomes

Below are the original ten action areas that were identified in the first Forum Action Plan:

1. Availability and Access to services
2. Carers
3. Information and Communication
4. Spiritual and Psychological Support
5. Financial, Legal and Administrative Issues
6. Ethical Engagement
7. Physical Environment
8. Standards and Regulation
9. Planning and Co-ordination
10. Public Engagement

3.1.1 Progress against action areas

1. Availability and Access to services

- A document was drafted suggesting the National Council review progress in relation to recommendations made in the Forum Report. A decision was taken not to proceed with this for the moment

2. Carers

- Workshop at Forum 2011
- Document drafted suggesting the National Council advocate for increased State support of family carers, as is the case in the UK

- IHF work on carers includes: carers website (care.ie); education workshops for carers; development grants and bereavement support

3. Information and Communication

- Workshop at Forum 2011
- Public meetings in June 2012 on Do Not Attempt Resuscitation (DNAR) orders and organ donation
- Think Ahead developed

4. Spiritual and Psychological Support

- Workshop at Forum 2011
- Discussion paper on sacred spaces being reviewed

5. Financial, Legal and Administrative Issues

- Workshop in June 2011 on financial issues at end of life
- Consultations with financial organisations

6. Ethical Engagement

- Workshop at Forum 2011 on the Medicalisation of Dying

7. Physical Environment

- Workshop took place in September 2012 with key stakeholders
- Work plan being developed

8. Standards and Regulation

- Discussion documents developed on:
 - Funeral Services Industry Reform
 - Pronouncing, Certifying and Registering Death

9. Planning and Co-ordination

- Supporting HSE Group that has been established to look at the importance of advance care planning to ensure a coordinated approach across the health service, particularly in light of the forthcoming Mental Capacity Bill

10. Public Engagement

- Think Ahead project
- Public meetings in June 2012 on DNAR orders and organ donation
- Forum 2013

3.2 Action Areas 2013-2015

The following are the objectives set for a two year period: 2013 – 2015.

GOAL 1: Develop a framework for end-of-life strategy / roadmap for action for Ireland

Key Objectives 2013-15

1. Develop a comprehensive framework for end-of-life issues, which encompasses all policy commitments to date and includes recommendations for other areas, for Ireland. This would be based on a lifecycle approach and informed by public health principles as well as the findings from the 2009 national report on Forum on End of Life in Ireland and other public consultations
2. Present recommendations for a national end of life strategy to government and political stakeholders and look to secure commitment to develop a national strategy
3. Benchmark progress against national policy commitments with a bi-annual 'report card' statement from the National Council of the Forum on End of Life in Ireland
4. Encourage all sectors to consider end-of-life issues in their agenda

Deliverable

- Clear articulation on the needs of all sectors of Irish society and economy re dying, death and bereavement presented in a comprehensive way
- Greater awareness and acceptance of the benefits of a comprehensive end-of-life strategy

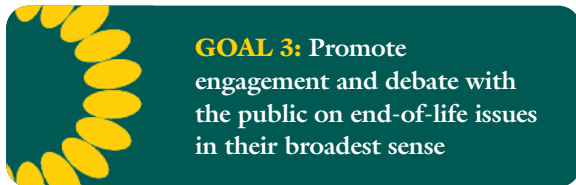
GOAL 2: Promote planning and organisation of end of life through advance planning tools, and in particular the Think Ahead tool

Key Objectives 2013-15

1. Promote the widespread adoption of a citizen engagement tool 'Think Ahead' which allows end-of-life care and related issues to be addressed in a comprehensive and understandable way
2. In partnership with the IHF, prepare a paper which provides the evidence base for advance planning at end of life
3. Develop comprehensive plans for the Think Ahead project to reach both the general public, as well as more vulnerable adults in the community
4. To continue to advocate for advance care planning as part of the Assisted Decision Making (Capacity) Bill and track the progress of the proposed legislation. A commitment was made by Government in March 2013 that provision for advance directives would be included in this Bill at Committee Stage
5. Support the development of advanced care planning in the Health Services by providing support to the HSE Advance Care Planning Group – to include capacity building with staff and development of approach towards advanced care planning
6. Support the introduction of DNAR guidelines based on adoption of guidelines developed by the HSE

Desired outcomes

- Citizens are encouraged and enabled to utilise a structure for understanding and planning for end of life
- Greater openness at end of life
- Think Ahead is used by the general public as a tool for planning for end of life



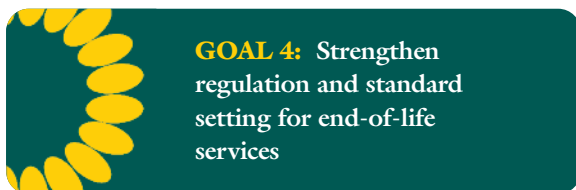
GOAL 3: Promote engagement and debate with the public on end-of-life issues in their broadest sense

Key Objectives 2013-15

1. To organise **Forum 2013**, the biennial event and ensure maximum attendance and a diverse audience
2. To develop an **annual communications programme**
3. To communicate with the public via the website and media regarding critical matters concerning end of life issues
4. To host public engagement sessions on issues of importance as they emerge
5. To promote knowledge of Think Ahead

Desired outcomes

- Initiatives in Ireland to develop public awareness of end-of-life issues and change public attitudes
- Changes in attitudes to end-of-life issues



GOAL 4: Strengthen regulation and standard setting for end-of-life services

To promote, through engagement with relevant statutory agencies and other bodies, discussion and progression on important matters concerning end of life, to include:

- Progress the work on pronouncement of death among nurses, paramedics and coroners and to review actions required on certification and registration
- Continue to advocate for the regulation and accreditation of the funeral services industry
- Encourage furthering consideration by local authorities on future planning for mortuaries / crematoria and cemeteries as part of development plans

- A review in 2014 of the Forum report and a revision of matters to be raised with statutory authorities and other bodies
- Lobby for enactment of the Assisted Decision Making (Capacity) Bill, especially the immediate implementation of the provisions relating to advance directives
- Lobby for the availability of statutory advocacy services for people who are losing capacity and who wish to participate in care planning

Desired outcomes

- Progress made with regard to extending authority to pronounce death to senior nurses and advanced paramedics
- Advocacy activities undertaken calling for the regulation and accreditation of the funeral industry
- Advocacy activities undertaken with the Department of Environment urging local authorities to include future planning for mortuaries / crematoria and cemeteries as part of development plans
- Forum review in 2014
- Advocacy activities undertaken calling for provision for advance directives in the Assisted Decision Making (Capacity) Bill 2013 and implementation of these provisions
- Advocacy activities undertaken calling for the availability of statutory advocacy services for people who are losing capacity and who wish to participate in care planning



Living to the end

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