

Draft Minutes of the Fourth Meeting of the National Council of the Forum on End of Life, held on 27th January 2011 at 32 Nassau Street, Dublin 2.

Present

Mrs Justice Catherine McGuinness, Chairperson

Bob Carroll, Honorary Secretary

Dr Brian Farrell

Dr Ita Harnett

Dr Deirdre Madden

Ita Mangan

Úna Marren

Gus Nichols

Sean O'Laoire

In Attendance

Sarah Murphy

Paul Murray

Mervyn Taylor

Apologies

Catriona Crowe

Dr Geoff King

Eugene Murray

Prof David Smith

Dr Max Watson.

1. Minutes

The Minutes of the meeting of 14 October, 2010 were agreed and signed by the Chairperson.

2. Matters Arising from the Minutes

There were no matters arising from the Minutes.

3. Matters Arising from Previous Meeting

3.1 Pronouncing, certifying and registering deaths

Mervyn Taylor said that a common understanding of the above functions is needed before the Council can make recommendations in regard to them. Members of the Council spoke about the distinction between pronouncing and certifying death, and changing practices in relation who

may be permitted to pronounce death in Ireland. Certifying death remains reserved to medical practitioners. It was noted that different procedures (regarding who can pronounce death) apply in the Republic and Northern Ireland and that the enactment of the Coroner's Bill will lead to improvements in practice in the Republic. It was also noted that the Charter for the Victims of Crime (Department of Justice and Law Reform) describes the role of the Coroner well, in plain English.

3.2 Scoping Document on End of Life Strategy

Mervyn Taylor referred to important scoping research undertaken by the Health Service Executive. However, this had not been made available to date and there was no longer an Assistant- National Director of Palliative Care and Chronic Illness. It was therefore agreed to write to the HSE to enquire who had taken over responsibility for the area and to establish if it would be possible to make the scoping document available to the Council.

3.3 Law Reform Commission, *The Legal Aspect of Carers*

The Chairperson said that because of staff shortages due to the recruitment embargo the above named document would not be available until the end of March 2011.

4. Work Plan Progress Report

4.1 Overview

Mervyn Taylor said that the Forum website was being revised and efforts were under way to establish small workgroups to advance parts of the Council's Workplan - on spiritual and psychological support and on financial issues in particular. Sean O'Laoire said that he and others with relevant expertise were establishing a voluntary task force to raise awareness of planning and environmental issues at end of life. This work would be undertaken in conjunction with the Forum.

4.2 Regulation of Funeral Industry: Draft Briefing Document

Sarah Murphy presented the discussion document, *The Funeral Industry in Ireland: The Road to Reform*. Gus Nichols commented on it and answered members questions about how the funeral 'industry' conducts its affairs. The financing of proposed reforms and in particular the financing of training for those engaged in funeral service provision and embalming was discussed. It was agreed that the document should not be prescriptive about levies or fees, but indicate rather that, as with other industries, the funeral industry would promote reform on a self-financing

basis. It would make clear that appropriate standard setting, regulation, registration and training would be introduced without additional cost to Government.

While it was agreed that legislation would be required to enforce standards, it was suggested that were it not possible to introduce the necessary legislation quickly (as part of the Coroners Bill or the Human Tissue Bill, for example), reform should be initiated on a voluntary basis. Mention was also made of EU concerns about cremations and 'green burials' and Dr Farrell advocated that all of these reform issues would be taken together in one Bill.

5. "ThinkAhead" Project

Mervyn Taylor gave a PowerPoint presentation of the "ThinkAhead" project and how it might be implemented. He said that Professor Jane Grimson, Director of Health Information at the Health Information and Quality Authority, advised that it would be best to be realistic in terms of expectations of what could be achieved in the short term.

There is no point in providing people with a mechanism to express their preferences without also having the means in place to ensure that those preferences are conveyed to the right people at the right time. It would therefore be best to tie the project in with health information initiatives currently being developed in keeping with the provisions of the Health Information Bill.

A number of potential challenges to the workability of the "ThinkAhead" project in the hospital setting were cited. These included practices and procedures relating to preservation of life by the emergency services, on the one hand, and Do Not Resuscitate Orders, on the other. There was a difference of opinion on whether hospital Ethics Committees would question the use of the Card.

Following discussion, it was agreed that, should sponsorship be sought for the project, care would be taken in the selection of appropriate sponsors and there was a clear preference for an institutional partner.

It was also agreed that care be taken with the language used to convey the purposes of the Card. It should be promoted primarily as a means of enabling people to express their preferences in advance in the event that they are unable to communicate at end of life, rather than simply as a

means of transmission of Advance Care Directives (ACDs). It would not be appropriate for the Council to promote ACDs on their own. The Card should not either be confused with organ donation/harvesting cards.

6. Election Manifesto

A draft Election Manifesto was presented by Paul Murray.

A number of amendments were suggested, primarily to simplify and enhance the clarity of the Manifesto:

- It was agreed to call for the introduction of the Coroners Bill. However, it was noted that there are IR issues relating to the establishment of a full-time Coroner Service.
- Rather than calling for the enactment of legislation on Advance Care Directives, the emphasis should be placed on a call for the introduction of the Mental Capacity Bill.
- A reference to Home Care Packages as providing the most economic care option should be dropped.
- Under "Regulation of the funeral industry", a reference to cremation should be inserted and the reference to the supervision of funeral *services* should be changed to the supervision of funeral *facilities*.
- It was suggested that the reference to the UK public education campaign, *Death Matters*, need not be included.

7. Forum 12th October 2011 (Prov.).

Mervyn Taylor presented preliminary thoughts on keynote speakers, other contributors and workshop themes for the 2011 End of Life Forum, which he proposed should have as its theme "Resilience". He explained that this theme would cover:

- resilience in difficult economic times (addressing suicide, for example)
- people's values, including their spiritual values, at end of life
- facing up to the over-medicalisation of dying.

He invited members to forward comments and suggestions to him.

8. Any Other Business

No other business matters were raised or discussed.

9. Date of Next Meeting

It was agreed that the next National Council meeting should take place on Wednesday, 13th April in the afternoon.

BC 3/2/'11

