

HAVE YOUR SAY

Dying, Death and Bereavement in Ireland

Have Your Say series paper 1



CHY 6830
Registered Charity Number 20013554

INTRODUCTION

The Irish Hospice Foundation's (IHF) *Have Your Say* project was launched in 2016, coinciding with the Foundation's 30th anniversary (as well as with the 100th anniversary of the 1916 Rising and proclamation of Irish independence). The project presented an opportunity for Irish people to reflect, reimagine and remember what dying, death and bereavement mean to them, and consider what they felt was important. A core part of the project invited people to complete a survey in their own words about what concerned them, and what they wished for themselves and those close to them when they thought of death and grieving.

The survey allowed the Irish Hospice Foundation to gain a greater understanding of what related wishes, fears and intentions occupy people's minds and focus their imaginations throughout the country when they thought of death or of grieving – to gauge, in a sense, what aspects of death had a hold on the national consciousness. After the collection and analysis of responses, a report was prepared (McLoughlin 2017; this provides further background to the design of the survey). From this, a People's Charter on Dying, Death and Bereavement was drawn up, reflecting the main themes and trends, and highlighting what was of real importance to people.

KEY POINTS

- o 2,586 people responded to the Irish Hospice Foundation's *Have Your Say* survey in 2016
- o From the responses, the People's Charter on Dying, Death and Bereavement was created, first launched at the IHF's Forum on End-of-Life 2017
- o The People's Charter sets out what the survey showed Irish people feel is needed for a good death and healthy grieving
- o Its content echoes international studies on what is needed for 'a good death'
- o The idea of a 'good death' is a dynamic one, which has been subject to some criticism, but the survey responses suggest it is acceptable to and intuitively understood by the public
- o There have been important developments in end-of-life care policy announced since the survey, making it an opportune time to revisit it

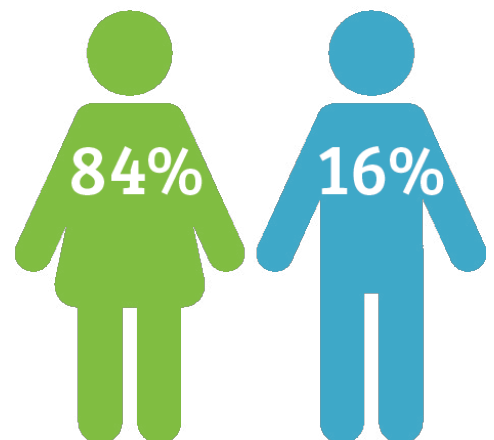
GEOGRAPHY & AGE OF RESPONDENTS

The response was considerable, with almost 2,600 people submitting responses to the survey. This exceeded expectations considerably. The profile of respondents showed some interesting trends. The geographical distribution of respondents by province (Munster, Connacht, Leinster and Ulster) closely matched the overall population distribution. Age range data indicate a good distribution among the adult population, which when mapped onto the overall population shows which groups are overrepresented or underrepresented in the sample. There are 2,586 responses in the dataset: 8 are under 18 years, and 368 respondents (14.2%) did not record their age. Of the remaining age categories, each taken as a percentage of the total remainder (2,210 responses) and mapping them against those same ranges within the population of Ireland recorded in the 2016 Census, we see that 18-29 years is significantly underrepresented (5.2% of respondents vs. 14.5% of population); 30-44 years is overrepresented (35.8% vs. 23.3%); and 45-59 years significantly overrepresented (41.6% vs. 18.8%). In the 60+ category, the level of underrepresentation is negligible (17.3% vs. 18.4%).

GENDER OF RESPONDENTS

Across all age-ranges, it was also overwhelmingly women who responded to the survey. There was significant overrepresentation of female respondents. While 384 respondents did not record their gender, of the remaining 2,202, fully 1,849 were female (84%), and only 353 (16%) male. One reason for this, from the IHF's experience, is that we have generally found women are more engaged in civic society and social groups, which were targeted in dissemination of the survey. It is interesting to consider whether we might see the concern about death and dying as reflecting an extreme form of what sociologists call 'emotional labour', which tends to fall disproportionately to women; this includes everyday matters like remembering family members' birthdays and sending cards or buying presents, or in a professional context, maintaining a pleasant and positive aspect in interactions with patrons, clients or members of the public.

The collected survey responses represent valuable information on people's preferences, and capture what the variety of respondents' voices has to tell us about death, dying and bereavement in Ireland. The information can be taken as reliable – there is no plausible reason for anyone to respond in a way that does not represent their true thoughts or wishes (and respondents could choose to be anonymous or provide their details). Additionally, the concerns and the emerging themes in analysis echo feedback encountered in ongoing IHF public engagement.



THE PEOPLE'S CHARTER ON DYING, DEATH & BEREAVEMENT

The People's Charter which arose from *Have Your Say* presented a set of priorities 'needed for a good death and healthy grieving'. It was launched at the IHF's Forum on End of Life in October 2017. The Charter's content, which was based solely on trends in the survey responses, echoes academic studies into what matters most to people at end of life, which reflects the fact that it captures deep and universal concerns. The Charter shows remarkable overlap for example with the six 'hypothesized domains of the quality of dying and death' identified by Downey et al. (2009). These concerns and priorities in turn echo those most prominently discussed in a 1998 article which set out a 'framework for a good death' (Emmanuel and Emmanuel 1998), and many subsequent studies (Kehl 2006; Scarre 2012; Meier et al. 2016).

'A GOOD DEATH'

The concept of a 'good death' was central to the survey and to the People's Charter, though it is known and acknowledged to be a difficult concept to define and for some people to accept. It is commonplace in literature on dying, but also attracts criticism. One article by O'Mahony sums up the common reservations, conjuring a fiercely polemical picture of a pain-free and lucid death at the age of 100 or so, surrounded by loved ones for whom the death is a sort of spiritual experience (O'Mahony 2016).

A paper focusing on the 'good death' idea commissioned by the IHF acknowledged that it is a dynamic and sometimes difficult concept, and gathers together a variety of attempted clinical definitions. This paper also contains a very useful review of perspectives on a good death in international literature from different groups, e.g. patients, the public, family carers and healthcare professionals, and shows that what the *Have Your Say* data suggest Irish people feel are determinants of a good death reflect summary international responses (Weafer 2018; see figure 1). The responses received to the *Have Your Say* survey did not take issue with the idea or phrase 'good death', which suggests quite definitely that it is acceptable; it also suggests that it does not require a clinical definition to be provided to be understood quite intuitively.

A good death from the perspective of the hospice ideal of care might be one where the dying person as far as possible is afforded comfort, respect and support: where all the components that make up what Cicely Saunders, founder of the modern hospice movement, called 'total pain' – that is, physical, psychological, emotional, social and spiritual – are alleviated. The People's Charter lays out the most important factors which Irish people feel ought to be present for a good death, and should prompt some reflection in members of the public as well as giving broad direction and mandate for action and advocacy to anyone involved in end-of-life care.

Figure 1: Determinants of a good death (Weafer 2018)

1. Access to pain and symptom management
2. Personal autonomy and control of the dying process
3. Individual dignity and affirmation of the whole person
4. Spiritual and psychological supports
5. A supportive culture by staff and carers
6. Appropriate care setting
7. Individual lifestyle factors
8. Access to palliative care resources
9. Formation and implementation of national policy guidelines
10. Socioeconomic support

POLICY & RESEARCH CONTEXT

The People's Charter, as noted, gives in summary form a reliable idea of Irish people's hopes, fears and anxieties when they contemplate their own death or the death of loved ones, or reflect on the grieving process. It has since its inception informed the Irish Hospice Foundation's advocacy and public engagement.

Some of the notable policy developments since the survey include the HSE'S 2017 launch of a Palliative Care Three Year Development Framework (HSE Primary Care Division 2017), and the scheduled full commencement of the Assisted Decision-Making (Capacity) Act 2015, which will set out the context for advanced care planning in Ireland. Similarly, the National Cancer Strategy 2017–2026 makes palliative care central to its vision, and incorporates it into its Key Performance Indicators (HSE 2017). In April 2019, the National Clinical Programme for Palliative Care published its model of care for adult palliative services (HSE 2019). In particular, a new palliative care policy is to be drafted in accordance with the cross-party Sláintecare programme, which will reform the health services, reorienting it from acute to community settings (Dept. of Health 2019). There is in addition a series of reports available from the IHF and its partners promoting end-of-life care for a range of conditions (see further resources, below).

Regarding the idea of a 'good death', this formed the focus of a 2014 report from the Irish Ombudsman on end-of-life care in Irish Hospitals, and this has recently been updated in a 2018 progress report, which details considerable progress and notes that the recommendations in the initial report have been acted upon, resulting in marked improvements (Office of the Ombudsman 2018). All of these developments are to be welcomed, and it is worth looking back at the database of responses to see how related concerns came through. By the same token, the IHF's advocacy work and public engagement shows clearly that some issues prominent in the responses to the survey remain relatively unaddressed. Chief among these is pain. 'Pain' was one of the most

common significant terms in responses, indicating that it remains the greatest fear people have when they consider death. An earlier Irish Hospice Foundation report showed that, when compared with the opinions of doctors and nurses, relatives' perceptions of a patient's death registered higher levels of pain, breathing difficulties and anxiety (McKeown et al. 2010), while another showed that 13% of patients' relatives perceived their loved one was in pain all or most of the time during their last week of life (McLoughlin 2015). A major study of bereaved relatives carried out in the Mater Hospital and St James's Hospital noted that 'while pain is managed well for the majority of patients, for others, it does not appear to be the case' (Ó Coimín et al. 2017). An apparent gap between clinical perception that pain is well managed at end of life in all but a very small number of cases, and bereaved relatives' perception that a far higher proportion of people endure uncontrolled or constant pain, is a matter that should be addressed.

In the realm of bereavement, interesting recent international studies on its impacts show that it is a predictor of adverse health outcomes, and could be identified as a risk factor in an individual's health profile. Data from the most recent wave of The Irish Longitudinal Study of Ageing (TILDA), offer some confirmation of this, showing that, when factors like age are controlled for, widowhood was more associated with frailty in older adults than being single or separated (O'Halloran and O'Shea 2018). In this light, it is worth looking back at how *Have Your Say* survey respondents speak about, or reflect on, their own experiences of bereavement, how they felt the bereaved could better be supported in their community and their anxieties about loved ones they would leave behind. The database presents an interesting qualitative supplement to the quantitative data on bereavement impacts.

It is with such recent developments and reflections in mind, and building on ongoing feedback from the IHF's public engagement, that we are now looking back at the data gathered in the survey. We conducted thematic analysis on the survey dataset; selective coding was employed whereby instances of information (i.e. support or palliative care) were searched for in the data and then coded accordingly. The analysis process was aided by the use of the qualitative data analysis software NVivo to help identify and code the data to feed into the themes that were created. This allowed for interpretation of responses in a meaningful way, in an effort to ensure those who 'had their say' were fully heard. From the data, we will produce a series of short briefing papers guided by the overarching themes in the People's Charter, which allow a fresh opportunity to reflect on the priorities which emerged from the survey and the particulars of responses, assess developments or persistent gaps in policy, services or supports, and contribute to the new and developing national palliative care policies. Finally, it will afford us the opportunity to look again at the concerns that dominate when people in Ireland consider the subject of death, and related issues like grief or the legacy a person might leave, an exercise that, based as it is on such a large base of responses from across the country, will give some interesting insight into the deeply-held personal beliefs and priorities of our society.



FURTHER IHF RESOURCES

- HSE and Irish Hospice Foundation (2008) Palliative Care for All: integrating palliative care into disease management frameworks
- HSE and Irish Hospice Foundation (2013) End-of-Life Care in Major Acute Hospitals
- Irish Hospice Foundation (2015) The End-of-Life Care Toolkit for staff working in residential care centres for older people
- Irish Hospice Foundation (2016) Palliative Care for the person with dementia Guidance Documents (6 vols.)
- McKeown, K. et al. (2010) Dying in Hospital in Ireland. Dublin: Irish Hospice Foundation
- McLoughlin, K. (2015) Hearing the Voices of Bereaved Relatives. Dublin: Irish Hospice Foundation
- McLoughlin, K. (2017) Have Your Say: Initial analysis of data from a national survey to inform the development of an Irish Charter on Death, Dying and Bereavement in Ireland. Dublin: Irish Hospice Foundation
- Weafer, J.A. (2014) The Palliative Care Needs of People with Advancing Neurological Disease in Ireland. Dublin: IHF/Neurological Association of Ireland
- Weafer, J.A. (2018) A Perspective on How We Die. Dublin: Irish Hospice Foundation

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- HSE (2019) Adult Palliative Care Services Model of Care for Ireland
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- O'Halloran, A. and O'Shea, M. (2018) Results from Wave 4 of The Irish Longitudinal Study on Ageing Chapter 7: Frailty. Dublin: TILDA
- O'Mahony, S. (2016) The way we die now: a personal reflection. Journal of Royal College of Physicians Edinburgh 46, 281–287
- Office of the Ombudsman (2018) A Good Death: A Progress Report: Developments in End of Life Care in Irish Hospitals.
- Scarre, G. (2012) Can there be a good death? J. Eval. Clin. Pract. Oct. 18.5, 1082–1086
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