

What we don't talk about when we don't talk about death

“I want to live and die in an Ireland where Death is talked about and not hidden away”

[People's Charter on Dying, Death and Bereavement in Ireland 2017]

Have Your Say series paper 2



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INTRODUCTION

This is the second paper in a series looking at data from the Irish Hospice Foundation's (IHF) *Have Your Say* survey from 2016. The survey received almost 2,600 responses from the public, and formed the basis of the [People's Charter on Dying, Death and Bereavement](#).

This paper looks at the issue of openness about death, a clear theme of the *Have Your Say* survey, enshrined in the People's Charter on Dying, Death and Bereavement. Denial of death is often said to be the norm today, among the general population and among healthcare staff, and this tends to be linked to its professionalisation (discussed below) – to the fact that dealing with death is more and more the job of health care professionals working in hospitals, nursing homes, and community clinics.

The *Have Your Say* response, and data in other surveys, suggest however that Irish people are quite comfortable talking about death, and tend to believe we do not do so enough. The understanding of death is made more difficult not only by its medicalisation, but also by its representation in the media, which does not give an accurate or real picture of usual deaths, and contributes to distorted ideas. Death is in reality part of everyday life, and people should be encouraged to reflect on and talk about it, particularly in a supportive environment. The Irish Hospice Foundation encourages this through initiatives like Café Conversations and the use of its Think Ahead form.

KEY POINTS

- o There is a consensus among scholars and commentators that, when compared to most historical periods, death is denied and hidden away in contemporary western societies.
- o *Have Your Say* survey data from 2016 indicate that Irish people want to talk openly about death – more people want to speak more openly than is generally expected.
- o In 2014 polling data, a majority feel the Irish do not talk about death enough; but only a very small minority report themselves to be uncomfortable talking about death.
- o A report from Macmillan Cancer Support suggests that people prefer to get information about their condition in a straightforward, factual way. The *Have Your Say* data similarly show that honest, open discussion from clinical staff about death or its approach is desired.
- o Healthcare professionals need to be able to talk about death with patients and families – there is an identified unmet training need in this area.

- o Media representations of death tend to distort its realities.
- o IHF's Café Conversations initiative facilitates people talking about their fears, anxieties, beliefs and preferences.

DENIAL OF DEATH

It is commonly said that the denial of death is characteristic of our era. The idea is supported by scholarly work comparing historical attitudes to death. In *The Hour of Our Death*, his great study of the evolution of western attitudes to and practices surrounding death, the French anthropologist Phillipe Ariès identifies the seventeenth and eighteenth centuries as a period when what he calls 'the great fear' began, which from the early decades of the twentieth transformed into a denial of death (1981: 405–6, 559). Death, in contrast to earlier ages, is increasingly concealed, because it is feared, it is ugly and unpleasant or even because it is thought indecent, almost shameful. With increased life expectancy, meaning those dying during the twentieth century have on balance been older, death becomes more easily marginalised, and removed from areas of regular activities. Up to the nineteenth century, life expectancy was much lower, and death, occurring more frequently among younger cohorts, was in certain respects a more visible phenomenon.

This common observation maintains that death has today become taboo in a way it was not in earlier traditions or societies – that these earlier generations lived with an intimacy with death and acceptance of it that contemporary societies do not. 'In Victorian times,' writes Sallie Tisdale, 'children were kept away from anything regarding sex or birth, but they sat at deathbeds, witnessed deaths, and helped with the care of the body. Now children may watch the birth of a sibling and never see a dead body...many people reach the end of their own lives having never seen a dying person' (2018: 1–2).

We might assume that the concealment of death stems primarily from fear; that many are simply afraid to speak candidly of it, either because they cannot face their own, or because they might risk distressing others with a morbid subject. But there is evidence, first from the 2,586 responses to the *Have Your Say* survey, that this denial or evasion of death is not what people actually want: that they would welcome opportunities to reflect on what death means to them, and on their preferences for end-of-life care.

Polling data in a 2014 report commissioned by the Irish Hospice Foundation, which asked respondents whether death was talked about enough and whether they were comfortable talking about it, showed interesting results: while a majority (57%) felt that as a society we do not discuss death enough, only a very small minority (14%) said they were uncomfortable discussing it (and only 3% not at all comfortable) (Weafer 2014: 5). Putting these two results alongside one another suggests there is an appetite among the population for confronting and conversing openly about death and dying.

Have Your Say Voices:

'Nobody talks about the one and only certainty in this life. We're so afraid of upsetting the person, or not being able to handle their upset that we hide away and pretend it isn't happening'.

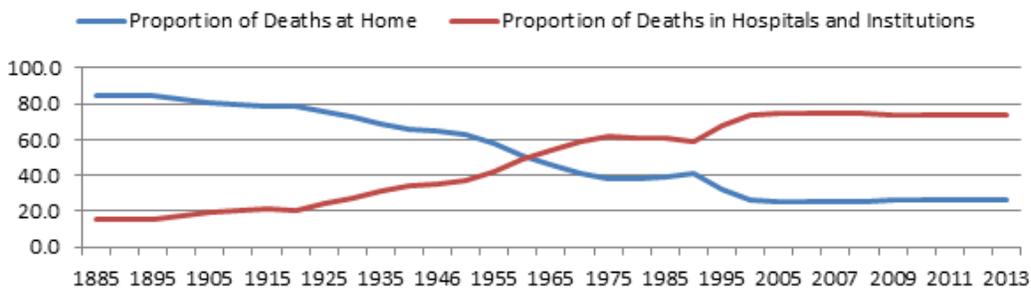
It strongly suggests, in fact, an unmet need to have these issues addressed – but perhaps in a supportive environment, given that another Irish study suggested more difficulty when the conversation is personal and specific (Weafer 2016).

DEATH'S PROFESSIONALISATION

It may be that, though a majority in broader society feels comfortable with reflecting on or discussing death, individuals do not realise there is this appetite or comfort: they assume that most people will be uncomfortable with the topic of death. Alongside such reasons for death's being hidden or avoided, however, is a deeper, historical reason which studies such as Ariès' have convincingly argued for: that is, the steady professionalisation (or 'medicalisation') of death. Ariès, who identified denial of death as characteristic of the twentieth century, speaks of the same era as one that sees 'the triumph of medicalisation' (1981: 583–8).

Professionalisation no doubt is somewhat inevitable; as there are more diseases which can adequately be treated, and from which fewer people will die, responsibility for governing life and death is shifted to the medical profession. Kathryn Mannix makes the connection between gradual professionalisation of death and it becoming unfamiliar: 'In the generations of humanity before dying was hijacked into hospitals, the process was common knowledge and had been seen many times by anyone who had lived into their thirties and forties' (Mannix 2017: 145). An Irish Hospice Foundation report on place of death shows that between 1885 and 2013, the percentage of annual deaths that took place in the home declined from 85% to 25%, while deaths in hospitals and institutions rose from 15% to 75% (McKeown 2014; see Figure 1).

Figure 1: place of Death in Ireland, 1885-2013
Based on original analysis by McKeown 2014; updated by IHF, 2016)



Medicalisation or professionalisation of death can lead to evasion of it; it is often said that it has become sanitised. There is an expectation among the public that death can be controlled; but even those medical professionals who must manage death in acute settings may not feel comfortable discussing it with a patient or family (Marcus and Mott 2014).

As one *Have Your Say* survey respondent recalled the experience of a hospital's failure to communicate the nearness of a relative's death:

'I feel even in hospitals, the word death is never spoken, and it makes me kind of angry. It gives the sense of false hope, to the person who is sick, and the people coming to see them. When my father was sick, we were told he was doing better, and that everything was fine (at least short term) but then got a call and he died within the half hour.

It was awful, but not once did a doctor, nurse or any other staff say that death was certain so soon. It's like it's a dirty word or something!'

If medical professionals who deal with it can find death difficult, it is little wonder members of the public can feel uninformed or uncomfortable. And if professionals are not up front about the nearness of death, family members may not realise it and be present at death.

REPRESENTATIONS OF DEATH IN CONTEMPORARY MEDIA

The idea that death is today hidden away has been challenged, specifically with reference to the prevalence of death in the media. Myers (2018), noting the amount of death in media and entertainment, memorialisation of the dead on social media platforms like Facebook and Instagram, and technological developments that allow the holograms of long-dead singers to go on 'touring', concludes that: 'we cannot reasonably argue that we live in a death-denying world, that the dead have been shunned or have disappeared. Quite the opposite, they have never been so alive'.

New media do not necessarily help with an understanding of or openness about death, however. As much as any sanitisation, the often brutal or sensational depictions of death in entertainment media (computer games, television) also serve to distort ideas of it. One might weigh, against the idea that media address denial or hiding of death, Tisdale's reminder that: 'Contrary to what our television watching habit may lead us to believe, most of us don't die at the hands of serial killers or from cancers that allow us to remain attractive or the malfeasance of a drunk driver. Most of us die as old or older than most people who have ever lived' (Tisdale 2018: 127).

Have Your Say Voices:

'[I want] honesty and truth from medical staff and the opportunity to talk honestly with friends and family. No avoidance of the D word'.

The core of the matter is media misrepresentation of the general reality of death. To imagine death more manageable, palatable or better understood because of the prevalence of (mainly violent) death in film and television is a mistake.

To talk about death and not hide it away, as the People's Charter states, should be read as two separate but related elements of the same desire: it is important to remember that death can in a sense be concealed while being talked about. It is concealed by being presented inadequately or unhelpfully, by distortion, most especially by euphemism. Media bear a good deal of responsibility for this. Overestimations of the prevalence of cancer and especially of suicide as causes of death (Weafer 2014: 6) are surely owed to their relative prominence in a range of news and entertainment media. This tells us that, though media may indeed be dealing with or talking about death, it is not necessarily in a useful or informative way. A report from Macmillan Cancer Care in Northern Ireland suggested that people preferred factual information about cancer to the common rhetoric of battle and survival (Macmillan 2018). 'Hiding away' means in the broader sense not only observing silence, but also, perhaps more importantly, sanitising death or resorting to euphemisms to avoid it. The desire for open and honest reckoning with and conversation about death, without euphemism and stripped of the filters of popular media, emerges clearly in the *Have Your Say* data.

THE IMPORTANCE OF TALKING

Over 10% of individual responses mentioned the need for greater 'openness', 'open conversation', 'open dialogue' speaking more openly, or other variants. This was a notably common response to a specific question posed as to how we could support the dying and bereaved better in the community; these responses accounted for 80% of total occurrences of the terms. 5% of total responses advocated a 'frank' or 'honest' facing of death. To know the truth about an illness, and for doctors not to give 'false hope', was a concern in about 1% of responses.

Just over 25% of all individuals who participated in the survey offered the simplest word: talking, or to talk, was important, talking about death, grief and bereavement, as a means of supporting others and being supported themselves.

Speaking specifically to the matter of bereavement, almost 10% of respondents wanted to 'talk' – to have someone there for them, for their family to talk openly if they themselves died, or not to hide away the fact that someone had died. It was important not to avoid the subject of their loved one around someone who was bereaved. One respondent expressed the wish that people 'realise the importance of hearing our loved one's name'; another pointed to how it helped to have others '...remembering the person at birthdays, anniversaries and at many other times over many years.' A third put the matter frankly: 'Irish people are brutal for talking about this. It's like after two months you're expected to snap out of it. In reality it's only getting worse then.' Another simply advocated 'Celebrating life, talking about those who have passed away.'

Have Your Say Voices:

'Grief cannot be understood unless you have experienced it closely yourself. It is a very personal journey and it's important to talk and acknowledge your grief'.

The survey data support the findings of IHF 2014 polling data mentioned above, and suggest a most curious situation: many Irish people are not only willing to talk about death, and comfortable with it, but believe we should talk about it more; yet, strangely, they believe the majority of Irish people do not feel this way.

'A PART OF EVERYDAY LIFE'

That more people wish to discuss death and are open to advance planning is indicated by the success of 'death cafés', begun in the UK in 2011 and replicated in many countries, and of the Irish Hospice Foundation's 'Café conversations' held throughout Ireland. These conversations facilitate the discussion of dying and death, invite people to share their feelings, fears or experiences and open up the issue of advance planning for death. Similarly, the IHF's CEOL (Compassionate End of Life) programme aims to give staff in residential care centres the confidence to open or manage conversations on end-of-life care with residents or their relatives. The network of CEOL centres helps to build wider competence in this area through staff feedback and suggestions for best practice. The IHF 'Final Journeys' programme meanwhile trains hospital staff so that they are comfortable with dealing with death and communicating with patients near to death and their families.

A common theme in *Have Your Say* responses was that death should not be hidden away, that it should be understood and accepted as 'a part of life'. A representative response said: 'Death should be talked about with the very young and the not so young, not only when someone is dying, or has died, but as part of everyday life'. This wish for death not to be hushed up applies also to the bereaved: those who have lost someone commonly regret the fact that friends and relatives do not mention the dead person, for fear of causing upset, where in fact the bereaved would prefer to know their loved one is still remembered.

This is what openness about death would finally mean: its acceptance as a part of life, willingness not to shy from it; and the recognition that, as polling and the IHF's public engagement shows, many people are comfortable talking about death in facilitated ways, and even those who are not comfortable may want the extra support needed to do so. The IHF continues to facilitate this public conversation, and it is an important message for both healthcare professionals and members of the public that the desire to talk openly about death in fact is much more common than we seem to realise.

Have Your Say Voices:

Death should be talked about with the very young and the not so young, not only when someone is dying, or has died, but as part of everyday life'

Note: We invite comment and discussion on the topics covered in these papers. Please contact paul.omahoney@hospicefoundation.ie with any queries or comments.

FURTHER IHF RESOURCES

Irish Hospice Foundation. [CEOL Programme](#)

Irish Hospice Foundation. [Final Journeys programme](#)

McKeown, K. (2014) [Enabling More People to Die at Home: Making the Case for Quality Indicators as Drivers for Change on Place of Care and Place of Death in Ireland](#). Dublin: Irish Hospice Foundation

Weafer, J.A. (2014) [Irish Attitudes to Death, Dying and Bereavement, 2004-2014](#). Dublin: Irish Hospice Foundation

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