

Thinking Ahead

“I want to live and die in an Ireland where I can prepare for what lies ahead, and, I can get information to understand what is happening to me”

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

Have Your Say series paper 3



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INTRODUCTION

This is the third 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](#).

In this paper we look at issues surrounding preparation for death, including the question of 'death literacy', and the benefits of advance care planning, which in the future will be informed by the Assisted Decision-Making (Capacity) Act 2015, and is promoted by the IHF's Think Ahead booklet.

KEY POINTS

- o People want to be able to plan ahead for their own death.
- o People want more and clearer information about the dying process: they want to be more 'death literate'. Death literacy is 'a set of knowledge and skills that make it possible to gain access to understand and act upon end-of-life and death care options'.
- o Some research suggests advance planning may improve end-of-life care and reduce stress among loved ones.
- o Support from professionals, advocates, friends or family makes planning ahead easier.
- o Healthcare professionals need training to open, or respond to, conversations about dying with patients.
- o International studies show that advance planning is much more common among those with higher education and greater wealth; steps should be taken to address this in Ireland pre-emptively, as the Assisted Decision-Making (Capacity) Act is commenced and advance healthcare directives become more commonplace, so that these inequalities are avoided.
- o There is widespread misunderstanding about the rights of next-of-kin
- o The Irish Hospice Foundation's Think Ahead booklet facilitates advance planning and end-of-life discussions, and has been shown to be acceptable to patients in Irish GP practices.

PREPARATION FOR DEATH

It is widely accepted today that people prepare for death in a variety of ways. There does seem, however, to be a sense in which we cannot reasonably prepare for death: its finality means it is not something which we can practise. Death represents an ultimate horizon of our activities; as Hamlet called it, 'the undiscovered country from whose bourn no traveller returns'. Sallie Tisdale has written about the relationship between the substance of a life and its inevitable end:

We spend our lives creating our future, by creating habits, learning from experience, examining our weaknesses and strengths. Our lives as we live them day by day create the person we will be at the moment of death. You see this at the bedside of a dying person. You see it in the way a body rests or fights, in the lines of the face, in the faint shadow of a smile or a scowl, worry or peace. With every passing day we create the kind of death we will have (Tisdale 2018: 14).

On this view, dying is a life-long process, and how someone lives determines to a great extent how they will die: there is a knack for living well, and certain art of dying. The ideas have merit. Still, no one would suggest that a person fixate on death or devote a great share of their actions to preparation for it; this would be paralysing. What these ideas indicate is that preparation, even stopping occasionally to take stock and reflect on one's wishes, can begin while a person is in the fullness of their health, or at least has not yet had a reckoning with their death forced upon them.

'DEATH LITERACY'

The two themes of this paper taken from the Charter – information and planning – are closely related. To prepare for death is difficult without access to reliable information. The themes come together in the notion of death literacy. This is defined as 'a set of knowledge and skills that make it possible to gain access to understand and act upon end-of-life and death care options' (Noonan et al. 2016). With the right information and education about death and dying, people can become death literate, just as health promotion campaigns have long aimed at making people 'health literate'. Basic death literacy might consist in an understanding of the primary causes of death, the trajectories of the most common diseases and conditions causing death, what general or specific symptoms to expect when a person is dying, and some knowledge of what care options are available. Death for most people remains an abstraction, and it is never the most attractive or stimulating subject; but we want control

Have Your Say Voices:

"There are not enough facilities for those that are terminally ill, there is also a lack of proactive engagement with families on what to expect, what practical things they can do to prepare a home for a loved one to come home. Yes, the answers are there, but everyone is so stressed about the diagnosis they don't think of the practicalities. It should not be such an effort to find out information"

and empowerment in this area, and that requires knowledge. As mentioned, no one would suggest the average person should begin to devote significant amounts of time to contemplating and planning their death: a person does not need to know everything at all times. They simply need to understand where information can be accessed when needed.

ADVANCE PLANNING

The most concrete and comprehensive form of planning is to prepare documents such as a will, which dictates what is to be done with property and possessions after one's death, and an advance healthcare directive or 'living will', which can state a person's preferences for types of care in different circumstances, or a plan for their funeral and how the body is disposed of. The commencement of the Assisted Decision-Making (Capacity) Act 2015 will determine the context for living wills and advance healthcare directives in Ireland.

As with general health literacy, international literature shows that engagement in advance planning shows marked socioeconomic inequalities. There are comparatively low take-ups of advanced healthcare directives, where they are legal, among ethnic minorities, the less well-off and the less educated (Porensky and Carpenter 2008; Carr 2012; Waite et al. 2013; Koss and Baker 2018; Eun-Hi 2019). Work must be done, as the legislation governing advance planning in Ireland comes into effect, to ensure these kinds of inequities are addressed as much as possible. Other obstacles to end-of-life planning, as well as common drivers of it, are laid out in an IHF paper on advance planning in Ireland (Weafer et al. 2016). Advance care planning is not a 'magic bullet' that guarantees a patient the best of care; but some research suggests it can help to improve end-of-life care and reduce stress for families and carers (Detering et al. 2010; Green et al. 2015; Weafer et al. 2016; Thomas et al. 2018: 9).

In the second paper on *Have Your Say* data, on the topic of death not being hidden away, it was noted that death is today said to have become taboo, and that, as the work of Philippe Ariès has amply shown, this concealment of death has a deep connection with its increased medicalisation. The inability to face death in everyday conversation leads to the use of euphemisms which are wrongly thought to soften the reality of death. This hiding of death represents a clear barrier to planning – people can even be superstitious about mentioning death – and for this reason planning always begins with comfort in discussing death. Kathryn Mannix makes this connection explicitly:

It has become taboo to mention dying. This has been a gradual transition, and since we have lost familiarity with the process, we are now also losing the vocabulary that describes it. Euphemisms like 'passed' or 'lost' have replaced 'died' or 'dead'. Illness has become a 'battle', and sick people, treatments and outcomes are described in metaphors of warfare...Reclaiming the language of illness and dying enables us to have simple, unambiguous conversations about death. Allowing each other to discuss dying, rather than treating the D-words as magic ciphers that may cause harm merely by being spoken aloud, can support a dying person in anticipating the last part of their living, in planning ahead in order to prepare their loved ones for bereavement, and can bring the notion of death as the thing that happens at the end of every life back into the realm of the normal (Mannix 2017: 107).

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.

The data from the *Have Your Say* survey tell us that preparation and information are much on people's minds, and that it is both for their own sake and for their loved ones that they wish to prepare for death.

The wish to plan or prepare for death in a general way, or to have 'affairs in order', feature in about 10% of responses; it was noticeable that preparing family was important, and doubled as preparation for a person's own death.

In line with the wish, enshrined elsewhere in the Charter, to be supported to stay in control of decisions, it was important to a number of people to be kept aware of what was happening to them and told the truth, not only in preparation for but if possible during the dying process. About 3% of respondents expressed this wish, which is not the insignificant figure it might seem, given the specificity of the wish and the similarity across responses of the language in which it was expressed.

Have Your Say Voices:

"I'm prepared and my family are prepared for what is going to happen. Everyone knows I'm prepared for death, I'm okay with it. All my affairs are left in order and there will be no squabbles..."

11% of *Have Your Say* survey respondents worried about finances

2% mentioned living wills or advance care directives

2.5% of respondents explicitly mentioned funeral arrangements; for just under half of these, the cost was their concern (and this excludes those who simply mentioned general costs or end-of-life costs as a worry). This general anxiety is reflected in the 11% of respondents for whom 'cost' or finances, their own or (more usually) their family's, were a concern.

2% of respondents explicitly mentioned advance care directives, formal or legal advance planning or a 'living will', suggesting they are not unknown among the general population, but more needs to be done to promote these (for example through the IHF's Think Ahead form, discussed below) as the Assisted Decision-Making (Capacity) Act 2015 becomes law.

Turning thinking into action of course requires work; popular models of behavioural change would indicate that, if people are to take up advance planning, it needs to be made something desirable to do (people must have a positive attitude toward planning ahead); something that those important to a person would want them to do; something feasible – showing that an advance care plan will be honoured; and something easy to do. Use of behavioural theories in end-of-life care research generally is limited (Scherrrens et al. 2018); the relatively low engagement with advance planning in Ireland, taking account of noted obstacles to it among various cohorts internationally, needs to be addressed in tandem with the commencement of the legislation.

THE PLACE OF CARERS, FAMILIES AND PROFESSIONALS

The need for information extends also to a patient's family and carers; if someone understands what is happening to a loved one, their anxieties are eased. In the same way, a patient who knows their family are informed does not need to worry about it. The leaflet *When someone you care about is dying in hospital: What to expect* (HSE/IHF 2018) is an example of simple material developed to provide just this information, and feedback from carers and families has been very positive.

The family or other trusted people play an important role also because comprehensive and effective advance planning must involve someone who will be the executor of a person's wishes and see that their care preferences are honoured. It is often thought that next-of-kin have automatic rights to make decisions for a person who cannot decide for themselves, but this is incorrect (Sage Advocacy 2018). Part of an advance healthcare directive and advance planning in general is identifying who a person would like to make sure their wishes are met, and giving them legal permission in official documents to make decisions.

Finally, professional healthcare providers who care for the dying play an important role in supporting planning, and need to be able to talk about death. Even where the management of physical symptoms is well within their competence, they may feel unequipped to deal with aspects of dying such as delivering bad news to patients or explaining to them or to their families that the patient is dying. The inability to explain the reality of a condition, or to discuss end-of-life issues with a patient, may be a source of 'moral distress' for healthcare staff ('moral distress' arises when a professional wants to help but feels powerless to). Professional staff also must be able to prepare for what lies ahead, and to provide the information an individual or their family requires, for the sake of their own health and wellbeing as well as to serve better the dying person and their family and loved ones. The experiences of acute hospital staff with death and dying can be difficult, and characterised by uncertainty about protocols (IHF 2013).

Have Your Say Voices:

"It is important for patients and their families to be supported with information about the medical and holistic services available to them to help relieve symptoms, suffering, pain, anxiety and fear. Education and early discussions about advanced care planning and end of life preferences are vitally important especially for those diagnosed with a life-limiting and progressive condition."

The IHF's CEOL Programme equips residential care staff for end-of-life discussions with patients, while its 'Final Journeys' programme for hospital staff and 'Delivering Bad News' workshops, for all healthcare professionals, aim to improve communication skills, confidence and competence for healthcare staff breaking bad news to patients and families or supporting them after bad news. As one *Have Your Say* survey respondent put it:

“Advanced care planning and end of life matters and preferences should be discussed more openly, and healthcare professionals educated on the importance of open, honest and empathic communication especially in relation to difficult conversations about diagnosis, prognosis and end of life.”

THINKING AHEAD

Reflecting on death is important, to clarify what a person wants. But planning for and beyond death is a difficult prospect. Many people must work up the resolve to prepare for death, to make a will or an advance care directive. Support makes this considerably easier. This may come from a healthcare or legal professional, from family and friends, from an informed acquaintance, even from literature. The IHF's Think Ahead booklet provides information and a template for discussion of a variety of topics related to planning for the end of life, and a study in Irish GP practices has shown its effectiveness and acceptability as a tool for planning ahead (O'Shea et al. 2014).

If we are to prepare for what lies ahead, and understand what happens to us and to others as death approaches, this means living in an Ireland where relevant information can be accessed in a timely fashion and advance planning is adequately facilitated; where everyone is encouraged to plan for end of life, and resources are available and accessible when they decide to (including where necessary trained professional staff); where it is not overly burdensome to access information, and a moderate time devoted to the preparation for death will be well repaid.



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

Health Service Executive/Irish Hospice Foundation (2018) [When someone you care about is dying in hospital: What to expect.](#)

Irish Hospice Foundation (2013) [Dying and death in an acute hospital.](#) Dublin: Irish Hospice Foundation

Weafer, J.A., Murphy, S., Foley, S. (2016) [A Perspective on Advance Planning for end-of-life.](#) Dublin: Irish Hospice Foundation

[Compassionate End of Life \(CEOL\) Brochure](#)

[Think Ahead Form](#)

[Final Journeys Review](#)

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CHY 6830
Registered Charity Number 20013554

Morrison Chambers (4th Floor)
32 Nassau Street
Dublin 2

T: 01 679 3188
www.hospicefoundation.ie

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