



The Public Health Approach to Dying, Death and Bereavement

An Irish Hospice Foundation Discussion Paper

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Introduction: 'Describing the Elephant'

There is a famous old Indian parable of the blind men trying to describe an elephant. Each feels only one part of the elephant – the trunk, tusk, side, tail, etc. – and each comes away with a completely different idea of what an elephant is as a creature.

The public health approach to palliative care – or to dying, death and bereavement – might be likened to the elephant, and its promoters to the band of blind men: how it is conceptualised depends on perspective.

There is a lot of advocacy for a public health approach to palliative care, and myriad initiatives that promote it, but their focus is often different. There is a fragmented, rather than agreed, coherent approach. A primary health-care professional may have a different concept of it to that of a member of a specialist palliative-care team, and these may be different, again, from the concept of an advocate or academic researcher.

Why a public health approach, and why now?

'Public health' is, broadly, the scientific analysis and the practical management and improvement of the health of whole populations, using evidence-based interventions to improve population health, and information and education to promote and maintain better health outcomes. An essential part of any public health approach is identifying and addressing health inequalities in populations. This paper offers an overview of the issue of a public health approach to palliative and end-of-life care in the broadest sense.

It is important for the Irish health system to look at the issue for a number of reasons: first, there has been steadily increasing attention towards, and interest in, the topic for the past few decades, and especially in the last twenty years, which have seen debate, cooperation and knowledge-sharing improve.

There is a groundswell of support for such an approach, but a distinct lack of consensus marks the debate, in part because of persistent conceptual issues. Nevertheless, it is easily recognised that there is a definite public-facing aspect to dying, death and bereavement, and to end-of-life care promotion. Further, the public health approach is embedded in *Healthy Ireland* (Department of Health 2013). In addition, the development of new palliative care policies (HSE 2019) and the advent of Sláintecare, which aims to reorient health care away from acute to community settings, recommends ring-fenced funding for palliative care and further endorses the public health approach (Department of Health 2019). All this makes the examination of the relationship between public health and end-of-life care in an Irish context important and timely. It is necessary, for any advances, that health-care practitioners and policymakers promote and involve themselves in a robust discussion of the merits of the approach.

The purpose of this paper is to review the current debate and to further the discussion of what a public health approach to dying, death and bereavement might look like in Ireland.

The paper begins with what we call 'the public health and palliative-care conundrum', looking at conceptual or implementation issues that have troubled any formal public health approach to dying, death and bereavement – whether a theoretical framework or practical initiative. These are important to acknowledge, as they contribute to the divergent conceptions of, and approaches

to, the issue. It subsequently suggests what would currently be helpful in furthering the debate, and looks at arguments in favour of a public health approach. Elements of a model that could progress thinking are highlighted, along with some interesting concepts that can give direction and impetus to future debate. Appendix 2 looks at how Irish Hospice Foundation (IHF) programmes would fit into a public health framework rooted in the Ottawa Charter (examined as follows) and outlines our hopes for the future.

The paper is certainly not a solution to all the problems. It doesn't propose a comprehensive programme for a public health approach to dying, death and bereavement. There is neither the history of debate in Ireland nor the consensus internationally to attempt this. At present, we can do no more than outline some proposed models, highlight commonly identified problems and where models might offer solutions, and examine where resources might be usefully directed in Ireland.

Challenges: The Public Health and Palliative-Care Conundrum

The public health and palliative-care conundrum has to be faced. The suitability of the fit between the two disciplines has been questioned by some researchers – querying the conceptual coherence of a public health approach and highlighting that evidence for the effectiveness and sustainability of various initiatives is not robust.

A review of research literature on public health approaches to palliative care identified divergence in conceptions that influenced the variety of approaches. The three identified paradigms 'were defined as a health-promotion approach focussed on empowerment at community level, a World Health Organisation approach which focussed on systems at country level, and a population-based approach which typically viewed palliative care issues from an epidemiological perspective (Dempers and Gott 2016).'

The review insisted on the importance of any survey of or advocacy for a public health approach to palliative care defining which of these paradigms it used – or if it advocated for a mixture of them, or understood something different again.

The first issue is that public health approaches are most commonly associated with population-level initiatives that promote healthy living. The greatest triumphs of public health – campaigns that reduce smoking or drink-driving, or education about sexual health, come to mind – are preventative measures, not curative, rehabilitative or palliative. Palliative care, particularly, seems to be an area of specialisation that doesn't fit with the popular image of public health promotion. Kellehear recognised, acknowledged and addressed this seeming contradiction in his foundational text *Health Promoting Palliative Care* (Kellehear 1999: 3-24). His response was to detail the more comprehensive meaning that palliative care had taken on, insisting that it encompassed education, social care and more, making it a suitable object of public health approaches.

Kellehear now explicitly includes prevention as part of any public health approach (Abel and Kellehear 2018; cf. Smith 2019 and Rumbold 2011). This did not settle the issue, however. Though 'health promoting palliative care' found its way into policy documents in Australia (which has been at the fore in promoting public health approaches to palliative care), a 2015 report on home deaths noted, 'In particular, we found that the Australian policy of health promoting palliative care (HPPC) is not substantially translating to practice. [...] Our research looked at how service providers connect and/or normalise the existence and role of informal networks. We found little or no evidence that public health policy is being translated into practice (Horsfall et al., 2015: 6, 10).'

Two decades after Kellehear's book, he could characterise palliative care itself as still an 'emerging field', with public health posing new questions for it (Abel and Kellehear 2018). The same year, an article by Whitelaw and Clark (2018), helpfully reviewing the historical development of palliative out-of-hospice care – as well as the debate about public health approaches to it – found the lack of interest from public health professionals in palliative care telling.

The fit between the disciplines, Whitelaw and Clark concluded, pessimistically, is not self-evident and, historically, has been rather artificial. Engagement

between the two areas is shallow. Evidence of effectiveness of the public health framework for palliative care is lacking, and the assertion of a productive engagement between them is a construction based on the ‘symbolic capital’ that public health has gained. In the authors’ view, palliative-care initiatives can get along independently of any public health framework.

These reservations must be noted, along with some further risks that the public health approach to palliative care runs. First, with the broadening of end-of-life care to encompass preventative measures comes the risk of initiatives extending more and more over the life course and becoming fully preventative, until they are no longer distinguished as ‘end of life’ in a meaningful way. There is the somewhat related risk in public health initiatives of trying to be all things to all people (everyone must die, so education about death is, arguably, relevant to everyone). Designing programmes that require buy-in from multiple parts of society, however, makes coordination and marshalling sustained support difficult. School curricula, for example, are a useful place to begin any educational initiative, but they are already crowded, and their change or expansion can meet resistance from educators. Solicitors may have potentially very useful roles to play, in informing or referring on clients as appropriate, but, from a feasibility perspective, they cannot be expected to devote professional time to something in which they have not chosen to specialise.

The grander the scope of the vision, the less apparent is its feasibility and sustainability, and this is something that must be squarely faced – which doesn’t mean rejecting the potential usefulness of multiple social channels. Audience and ‘target segmentation’ must be carefully considered, to maximise reach. There is a third risk, of drawing resources away from frontline services, where they might be more urgently needed. Finally, there is the risk suggested by Whitelaw and Clark’s paper, of beginning with a conclusion and building evidence for it, rather than with a hypothesis and testing its validity – in other words, of artificially fitting end-of-life care within a public health framework, particularly where there might be non-scientific incentives to do so.

There is the possibility that a final definition of an approach is not yet possible. Despite the work put in over recent decades, conceptually and in practice, public health approaches to end-of-life care are, arguably, still in their infancy. We are still, it would seem, in a stage of divergence, marked by competing and even conflicting paradigms, and a lack of consensus among exponents. Even the summary presented here indicates that no approach has yet resolved the conceptual and implementation issues in a model that is readily transferable. If it had, it would be expected to have become mainstream, if not the new orthodoxy in palliative care (See Appendix 1 for a recent attempt at agreeing a definition).

As will be further examined herein, the one area in which there has been some transfer of practice and an approach similar to traditional, population-level public health is bereavement care, specifically the three-tier model of intervention (Aoun et al., 2015). None of this disqualifies the notion of a public health approach – a cause for optimism is the spread of progressive thinking about the issue. Reaching a stage of real convergence will be possible, however, only through robust debate and collaboration, with the input of policymakers, researchers and relevant specialist and generalist health-care professionals. It is likely that debate that encompasses many viewpoints will emerge. Any proposed model, programme or initiative in the area should demonstrate whether it is feasible, sustainable, scalable or transferable.

What would be helpful at this point?

It is clear that this isn’t a simple matter, and multiple issues must be addressed. We know, however, that there are multiple factors that may influence whether a person has a ‘good death’, and many of them non-medical (Weafer 2018).

As the Ottawa Charter and, later, Dahlgren and Whitehead’s idea of wider determinants of health opened the field of public health and gained wide acceptance (see as follows), a guiding question for public health approaches to dying, death and bereavement might be: what are the wider determinants of a good death, or good dying, including bereavement care?

Some determinants will, naturally, fall outside the scope of the approach, as they will apply to the entire life course of particular individuals and concern satisfaction with general, family and working life, etc. That there is a social dimension to dying, death and bereavement that might helpfully be captured and addressed by a public health approach is also clear. In surveying the current state of the debate, we see themes emerge that would be helpful in advancing the matter.

1. Assessing what is shared in current approaches

It is helpful to examine recent and current initiatives in public health approaches to palliative care, to determine whether any features are shared among all. As aforementioned, the questions that should be asked of any programme, beyond whether it delivers impact or improvement, are whether it is feasible, sustainable, scalable or transferable. Different initiatives may have different goals, of shorter or longer duration. Differences in health and legal systems may affect transferability from one country to another, for example, or questions of scale – the fit of a rural initiative to an urban setting within countries. Similarly, there exist different forms of what Kastenbaum (2001) called a ‘death system’ – basically the set of legal, ethical, social and religious norms, as well as the physical and logistical practices, by which a society most usually deals with death. The time between death and burial or cremation of a body, for example, varies widely across countries, and other, deeper differences may affect the perception and processing of death. Shared elements of approaches across cultures and jurisdictions might point to a core set of principles for any programme.

2. Clarity

In light of some criticisms previously mentioned, it is clear that greater clarity and consensus have to be achieved as to what a public health approach to dying, death and bereavement entails. Parameters have to be set, to determine what it legitimately should include and what falls outside its scope. Agreement on the latter is essential to a coherent definition of an approach. How different is such an approach from traditional

and established public health models such as Dahlgren and Whitehead’s? How much can the latter inform the public health approach to dying, death and bereavement, and how might existing public health models have to be adapted to fit these areas?

3. Addressing the asymmetry

Whitelaw and Clark’s assertion of an ‘asymmetrical relationship’ between public health and palliative care, wherein the interest in public health by palliative care practitioners or theorists is not reciprocated by public health professionals, is something that has to be addressed. If a public health approach to dying, death and bereavement is to progress, conceptually and practically, it will have to involve those charged with promoting or designing public health programmes looking at incorporating palliative care. The ‘push’ has to come from both sides, and the greater involvement of experienced public health professionals in this debate would be extremely helpful.

4. An honest discussion of resourcing

We know there are multiple factors that may influence how well people face dying, death and bereavement. Resources will inevitably be split between supports like education – which addresses the preparative and preventative aspect of public health – and clinical supports. The question of where best to invest resources and for what purpose, so that the public benefits, has to be raised and debated robustly and sincerely.

5. Early and ongoing involvement of policymakers

As mentioned, despite some decades of work in the area, it cannot yet be said that, broadly, incorporation of end-of-life care has internationally become the norm in health policy. As with the involvement of public health professionals, the involvement of policymakers from the earliest stages of advancing the debate will be beneficial. If decision-makers are brought along and see something in its emergence, dealing with problems and assessing benefits, it is more likely to become established as policy in a sustainable way.

6. Assessment of mechanisms for public engagement

All public health approaches generally, including all attempts at a public health approach to end-of-life care, entail some element of education and outreach – or what is called ‘health promotion’. Assessment of possible channels for education and promotion of end-of-life care will be crucial to the ‘social’ dimension of the approach, including the potential role of various forms of media (e.g. print, broadcast, digital). This assessment must address the feasibility of any programme or campaign – whether and how it might use health-care professionals, the media, NGOs, or other channels to reach the public – and be realistic about its scope.

Arguments for a Public Health Approach

The critical reservations of researchers have been previously noted, but progress in debate on the issue is shown by the buy-in from a variety of palliative-care theoreticians and practitioners. The public health approach to dying, death and bereavement has definite impetus, and there are substantial grounds for its increased popularity.

1. Demographics and population-level health concerns

Demographics represent one of the most immediate arguments in favour of a public health approach to dying, death and bereavement. The number of annual deaths is rising in Ireland, which also implies more people involved in caring for the dying or who are bereaved. At the same time, people are living longer, which will lead to an increase in demand for palliative care (Department of Health 2018: 75). The greater prevalence of life-limiting illnesses in the population (including dementia, counted as a discrete cause of death from Q1 of 2018 in Ireland) will ensure that end-of-life care becomes more and more a population-level issue and a matter for coordinated public policy.

2. Health service capacity and community resources

An ageing population makes it likely that the capacity of the health system will come under strain. It is almost inevitable that government and services must consider ways of tapping the resources of the community to meet increased demand, even as home deaths have shown a gradual decline in Ireland (see Figure 1). If this is to be done well, and not to mean simply placing a greater burden on informal carers, then responsible, coordinated initiatives to equip individuals and communities to absorb some of the work in an appropriate and supported way are necessary.

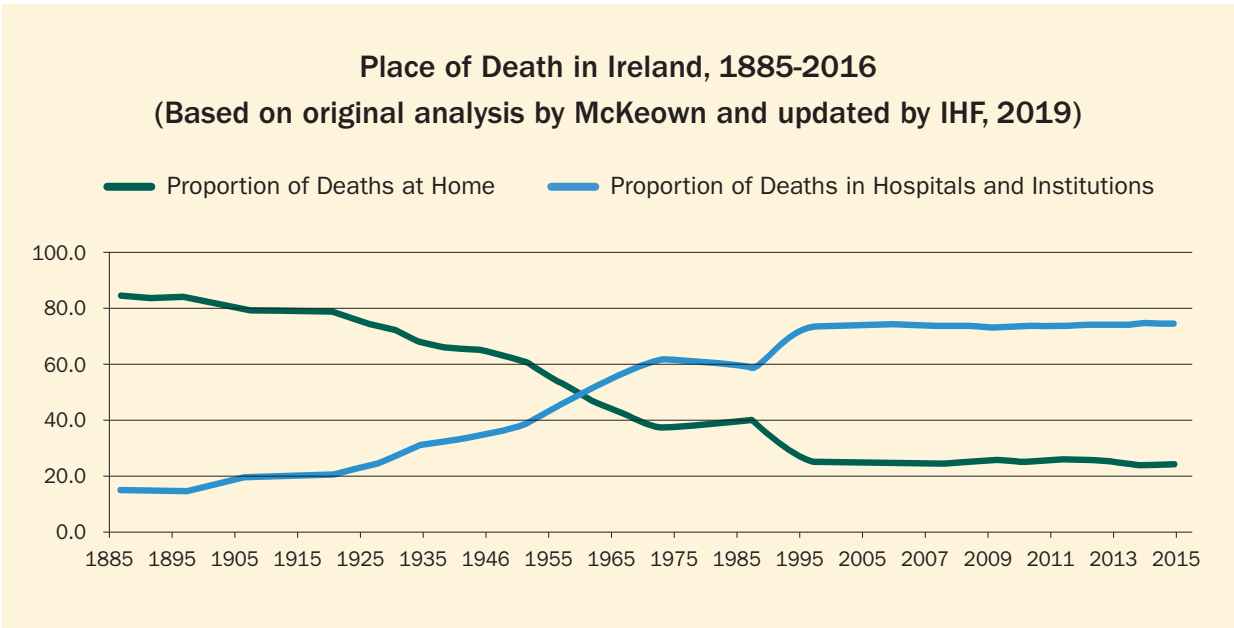


Figure 1: Trends – Place of Death in Ireland

3. The appetite for discussion about death

Despite its appearance as a difficult subject, the evidence is strong that there is a public appetite in Ireland for an open discussion about death, and for treating it as a societal issue. Polling data in a 2014 report commissioned by the Irish Hospice Foundation, which asked respondents (n. = 891) whether death was talked about enough and whether they were comfortable talking about it, showed interesting results. While the majority (57%) felt that, as a society, we do not discuss death enough, only a very small minority (14%) said that they were uncomfortable discussing it, and only 3% were not at all comfortable (Weafer 2014: 5). Putting these two results alongside one another suggests that there is an appetite within the population for confronting and conversing openly about death and dying. 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 was personal and specific (Weafer 2016). The IHF's *Have Your Say* survey, carried out in 2016, which asked the Irish public about its wishes, concerns and opinions regarding dying and bereavement, received almost 2,600 responses (McLoughlin 2017). This appetite is further reflected in the take-up of the IHF's ongoing public engagement programme 'Café Conversations', which facilitates members of the public to discuss and reflect on death, dying and bereavement.

4. End-of-life care support beyond care recipients

It is clear that end-of-life care concerns more than the direct recipients of palliative care. As Kellehear insisted, palliative care included a social aspect – something implicitly recognised in Cicely Saunders' statement that hospice care addressed 'total pain', not only physical, but also psychological, emotional and spiritual. The network of family or friends who support a recipient of palliative care also requires education, support and respite. This is most evident in the case of family carers. We know that most people who are asked will express a preference to die at home. This is seldom possible unless there is a family carer present (Ahlner-Elmqvist et al., 2004; Woodman et al., 2016).

As research by Grande and Ewing (2008) has shown, one of the key variables that allow it is a family carer who shares the wish. When this desire is not shared, it is usually because a family carer fears that s/he will not be able to cope with escalating care needs or provide an adequate level of care, and that s/he will suffer burnout (Gott et al., 2013). Grande and Ewing's further research also showed that the single best means of preventing carer burnout was for carers to receive adequate training for their caring role, which may be complex, especially if they care for someone with a life-limiting illness. Better support of carers also shows improvements in their processing of grief following bereavement (Grande and Ewing 2009). Improved systemic care for those at the end of life requires integrated support of those who provide family or informal care. To do this requires outreach, so that the health system understands what carers need, and carers understand what is realistically available in their county or region.

5. Fears and misunderstanding – the issue of pain

Public feedback in the Irish Hospice Foundation's 'Café Conversations' has shown that the fear of pain at the end of life is dominant. The same fear was prominently reflected in our *Have Your Say* survey in 2016: 'pain' was the second-most common significant word in the 2,586 responses (after 'support'), totalling 1,677 mentions and occurring in the answers of 1,200 respondents.

The fear of physical pain at the end of life remains the greatest fear when members of the public contemplate death. Fear is learned, and for some people, the fear may reflect the experience of watching a loved one die in pain. Clinical opinion suggests that these fears are misplaced.

Two American authors reassure us quite frankly on this point. Sallie Tisdale, a popular writer and palliative nurse, has written that research in hospice and palliative care shows that only about one in a hundred people suffers uncontrolled pain while dying (Tisdale 2018: 84). In a piece published in *The New York Times*, neurologist Sara Manning Peskin (2017) writes, 'Some symptoms, like the death rattle, air hunger and terminal

agitation, appear agonizing, but aren't usually uncomfortable for the dying person. They are well-treated with medications. With hospice availability increasing worldwide, it is rare to die in pain.'

There may well be some disconnect between clinical opinion and public perception on this point. This is a sensitive issue. It would be wrong to dismiss the perception of the public on the grounds that it lacks clinical experience and, as the case might be, mistakes existential distress or agitation for physical pain.

Even if this divergence of views were grounded in the layperson's lack of clinical knowledge about the dying process, meaning that they wrongly perceived certain things as painful, that lack of understanding (and the distress and fear that it causes) needs attention. One Irish Hospice Foundation report showed that, when compared to 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). Another showed that 13% of patients' relatives thought that their loved one was in pain all or most of the time during his/her last week of life (McLoughlin 2015: 17; cf. Gallagher and Krawczyk 2013). 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).'

This is certainly a public issue. There is a need for a greater public understanding of palliative care, the realities of end-of-life care, and the dying process. Clinical staff members should be aware of these anxieties and address them – not only the management of pain is necessary, but also management of the fear of it, as is greater education among the public.

6. Bereavement and public health

When we speak of dying, death and bereavement together, bereavement has tended to be the most neglected. This continued neglect is more and more surprising, as the status of

bereavement as a public health issue in the most common sense – a large-scale issue that leads to poorer population-wide health outcomes and increased public expenditure – is increasingly well established.

Richard Smith has noted that grief 'is the least understood area of palliative care, and probably much more pervasive than we realise and an important ingredient of many social problems—from gang stabbings through alcoholism and loneliness to suicide (Smith 2019)'. It is difficult to quantify these effects, or other forms of what one might call the 'ripple effect' of grief – for example, the effect of parental grief on the development of a child's surviving siblings.

Data from the most recent wave of *The Irish Longitudinal Study on Ageing* (TILDA), run out of Trinity College Dublin, offers confirmation of this, showing that, when factors like age are controlled for, widowhood is more associated with frailty in older adults than being single or separated (O'Halloran and O'Shea 2018). Results from a large study led by the Karolinska Institutet, in Stockholm, which have been presented at conferences, show an increase for bereaved spouses (against a control population) in all-cause mortality, as well as a higher risk of a range of fatal and non-fatal outcomes (Morin et al., 2018). An Australian study that looked to measure resilience according to multiple factors found 'that resilience in the face of spousal bereavement is less common than previously thought' (Infurna and Luthar 2016).

A paper from Samar Aoun examining Australian bereavement supports in palliative care services, which urges a public health approach to bereavement care, stresses the necessity of recognising and evaluating bereavement interventions (Aoun 2012). She proposes tiered levels and different types of interventions, depending on the identified need (Aoun et al., 2015; Aoun et al., 2018). Not everyone will need bereavement support, but research suggests that its effects are underestimated and eluding projections of health-care utilisation and projection of demand for services. A small number of people will also suffer complicated grief, where the reduction in their feeling of grief over time does not happen. Their grief becomes stuck, and they experience disabling and persistent symptoms

that don't improve. Complicated or prolonged grief is recognised as a diagnosable disorder – being added to the International Classification of Diseases – with up to 10% of bereaved people at risk (Lundorff et al., 2017). The recognition by the WHO of complicated grief opens up new horizons for its formal study and treatment in health care.

This range of emerging research demands recognition of bereavement as a risk factor for adverse health events and a decline in quality of life. Its effects should, accordingly, be incorporated into clinical programme models of support and capacity projections for health-care utilisation. Bereavement is manifestly a public health issue.

7. Advance care planning

We have noted that the appetite for open (and structured) discussion of death is there among the Irish public. The most concrete form that such discussion takes is advance care planning. This is an issue that will command more and more attention in Ireland, with the commencement of the Assisted Decision-Making (Capacity) Act 2015.

Advance planning can afford people the opportunity to state their preferences about medical and other care, take care of their finances, state preferences about their funeral and burial, and more. An advance healthcare directive can also appoint a decision-making representative for a person in the event of a loss of capacity. It is commonly assumed that next-of-kin have automatic rights to make decisions for a person who cannot decide for him- or herself, but this is incorrect; in fact next of kin have no automatic legal standing as decision-makers (Sage Advocacy 2018).

Part of an advance healthcare directive and advance planning in general is identifying who a person would like to make sure that his/her wishes are met, and giving them legal permission in official documents to make decisions. Advance planning gives people autonomy to decide on their future and the assurance that their wishes will be honoured. Again, there is a clear appetite for instruction and support in the matter. From January through May 2019, the Irish Hospice Foundation saw an 80% year-on-year increase in

demand for the *Think Ahead* form, and response to the form in public engagement programmes has been extremely positive, among professionals and the public.

International research does show that, where they are legal, advance care plans are made overwhelmingly by wealthier and more educated individuals, and they are rare among lower socioeconomic and other disadvantaged groups, and among ethnic minorities (Porensky and Carpenter 2008; Carr 2012; Waite et al., 2013; Koss and Baker 2018; Eun-Hi 2019). Knowing this, much could be done pre-emptively by public initiative to address this imbalance in Ireland in advance of the commencement of the Assisted Decision-Making (Capacity) Act 2015. Emphasis on, and promotion of, planning further fits with the values of autonomy and responsibility generally promoted in public health initiatives, and the rise in interest in advance planning reflects an increased desire for self-determination and autonomy in a person's life and decisions, up to and after death. Given the relevance of advance planning for end-of-life care, and the importance that commencement of the act may have for community and acute health-care staff in a variety of settings, this is another aspect of broader end-of-life care that has a definite public dimension.

The aforementioned represents issues and realities that support and can advance a public health approach to dying, death and bereavement. In their critique, Whitelaw and Clark (2018) posed the frank question to all working in this area: if you can do your work anyway (deliver services, or advocate, educate and influence as appropriate) without reference to public health, why the need for any such framework? No one can avoid the question. If 'public health' becomes a theoretical trapping, rather than a coherent and substantial programme that improves these areas, or becomes something that breeds more disagreement and delay than cooperation and advance, it should be dropped.

What is ultimately wanted – better-quality services and support for those facing dying, death and bereavement – can easily be agreed upon.

Within the IHF, the mandate of *The People's Charter on Dying, Death and Bereavement in Ireland* (Appendix 3) – informed by responses to the 2016 *Have Your Say* survey – suggests areas in which more could be done. Defining the parameters of a public health approach for actions that secure these better services is important. In setting out elements of such a model, we will focus on the pillars of the Ottawa Charter, as it is one of the best-known basic approaches to public health and because its pillars can help to define actions. As an adaptable model, elements of it can help to advance thinking and invite dialogue on the topic.

Aspects of a Model

Population-based approaches to dying, death and bereavement: International examples

There is considerable impetus behind the idea of a public health approach to palliative care, as evidenced by numerous international initiatives. Australia has been a particular leader, with examples like the Groundswell Project, led by Kerrie Noonan, which has subsequently informed redirected efforts to promote 'death literacy' among the population, and La Trobe University's Healthy End of Life Project (Grindrod and Rumbold 2018). The Compassionate Communities project, meanwhile, led by Allan Kellehear, has been transferred to and trialled in numerous locations throughout the world. Kellehear now promotes the

Compassionate Cities project with Julian Abel, who directs the Frome Model as part of Compassionate Communities UK. These and other initiatives have resulted in a growing network of professionals whose contributions and collaborations are detailed on the Public Health Palliative Care International website (www.phpci.info).

When looking at these initiatives, all have some common bases: they are oriented toward public engagement and information provision, and many have a particular focus on family carers. If they were to be fitted to one of the traditional and foundational models of public health, their work streams could be divided under the pillars of the Ottawa Charter, which still informs subsequent statements of health promotion such as the Vienna Declaration, (EUPHA 2016). The original charter (WHO 1986) marked a turning point in health promotion, through its then groundbreaking insistence that actions are required on a number of fronts, beyond or complementing clinical interventions at an individual level, in order to achieve good health outcomes.

The Ottawa Charter's five domains of action were:

- developing personal skills;
- strengthening community action;
- building supportive environments;
- engaging with health services; and
- building healthy public policy.

This framework allowed those interested in health, but coming from different parts of the health- and social-care system, to work together productively to a common agenda. At the time, it was not commonly appreciated or understood how the physical, economic, emotional and environmental conditions in which people live impacted their health. The charter paved the way for a far broader conceptualisation of health care.

'Death literacy'

In a population-based model, such as is promoted by the Ottawa Charter, the supported individual is empowered through education to take responsibility for his/her own health. Such an approach promotes what has been called 'health literacy'. Being 'health literate' means understanding and knowing how to access information on improving and sustaining good health through personal action. A public

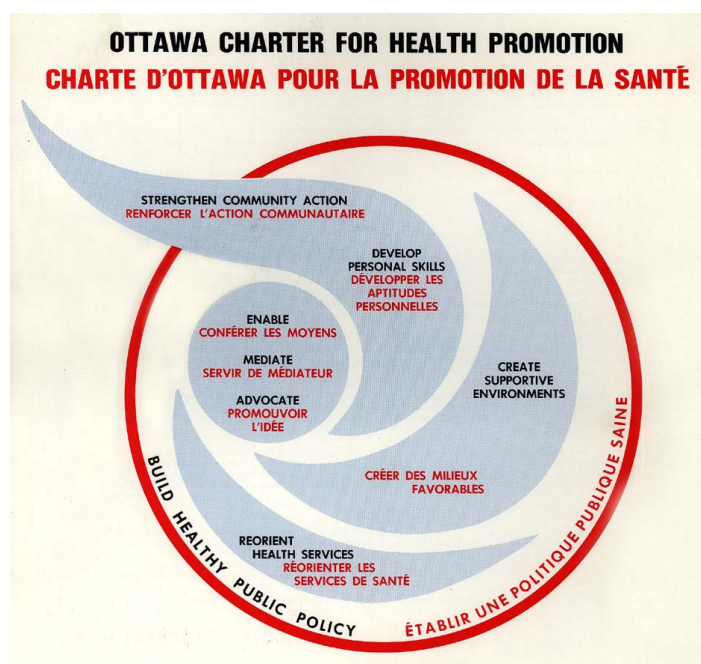


Figure 2: The Ottawa Charter

health approach to dying, death and bereavement and to end-of-life care could similarly find a focus in the concept of 'death literacy'. Developed by Kerrie Noonan, 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 2016).

Wider determinants of a 'good death'

A subsequent model, building on the Ottawa Charter's ideas, was developed in the work of Dahlgren and Whitehead (1991) and widely adopted as a way to explain what it called the 'wider determinants' of health. In this model, wider determinants of health are the variety of factors, from the personal to the societal, that can impact upon people's health. In terms of a population-based, public health approach to dying, death and bereavement, as 'death literacy' would mirror 'health literacy', so the wider determinants of health might find counterparts in the idea of the wider determinants of a good death. As aforementioned, many such determinants will fall outside the scope of reasonable public action on dying, death and bereavement, but when people's ideas of a good death are enumerated and taken into account, those aspects that can be influenced by health- and social-care systems, education, or community action are better understood. Weafer (2018) provides a very useful review of perspectives on a good death in international literature from different groups (e.g. patients, the public, family carers, health-care professionals), along with a summary table.

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

Figure 3: Determinants of a Good Death (Weafer 2018)

Use of epidemiological data

As noted in O'Hara (2017: 9), epidemiological study could inform all public health approaches. Indeed, the use of routine or administrative data, and particularly the rapidly developing potentials of Big Data studies of whole populations, make data-based epidemiological study of the population integral to every area of health and social care, with the end of life and bereavement no different.

There is considerable scope for better collation and analyses of data to build up an evidence base for palliative-care provision. Despite its acceptance, systematic reviews have not yet shown robust and high-quality evidence for the effectiveness of palliative-care interventions (El-Jawahri et al., 2011; Kavalieratos et al., 2016; Gaertner 2017; Haun et al., 2017). This is in part because palliative interventions are, for a variety of reasons, not suited to the 'gold standard' randomised controlled trial, and may require more observational studies (Visser et al., 2015).

Using linked administrative data sets is an increasingly recognised method of improving end-of-life care (Davies et al., 2016; Maetens et al., 2016; Nwosu et al., 2018; Janssen et al., 2019). In addition, the use of patient-reported outcome measures (PROMs) in palliative-care provision – via patients or proxies, in the form of bereaved relatives – could, despite some limitations, help to improve system performance, enhance quality improvement and service delivery, and support the drive toward person-centred care. The results of the VOICES MaJam project (Ó Coimín et al., 2017) have shown how bereaved relatives' feedback can assist quality improvement in end-of-life care settings.

Policy Context in Ireland

The idea of wider determinants of health (specifically 'social determinants') informs Ireland's overarching health policy and governmental strategy, which are premised on a 'whole of society approach' (Department of Health 2013: 43-4). The new *Adult Palliative Care Services, Model of Care for Ireland*, published in 2019, explicitly promotes a public health

approach to palliative care, and, in this regard, 'views the community as an equal partner in the task of providing quality healthcare.' In common with the international initiatives previously listed, the vision here is the fostering of community care, and the model similarly (and very openly) makes family carers the focus of this policy (NCPPC 2019: 45-6). Bereavement support is incorporated into the new model, where the 'loss, grief and bereavement care pathway is a tiered one based on a public health model of bereavement support (NCPPC 2019: 87).'

The new model signals governmental commitment to a whole-of-society, public health approach to end-of-life care. At the same time, the politically multiparty Sláintecare plan announces the intended move to a population-based model for health-care planning, funding and resource allocation (Department of Health 2019: 16, 28, 53-4).

The *Health Service Capacity Review 2018*, which guides projections for health systems planning, notes the need for broader and better end-of-life care. Demographic changes, with more people living longer – including living alone in widowhood – and a documented rise in disability rates, guarantee an increase in the numbers of people living with life-limiting illnesses and in need of a degree of palliative and end-of-life care. It is on this basis that the capacity review recognises the need 'to increase palliative care services within hospitals (inpatient units and specialist beds), the community and in the home (Department of Health 2018: 75).' As importantly, the capacity review had in advance identified 'the impact of an enhanced palliative care service' as one of the 'non-demographic' variables important to assessment and projection of service capacity, but could not include it because of time constraints (Department of Health 2018: 90). The clear implication is that an improved service will positively affect throughput and improve overall system performance.

The capacity review's recognition of the need for more community palliative-care provision dovetails with Sláintecare's intended reorientation of health care, from the acute to the community setting, and the Adult Palliative Care Services, Model of Care for Ireland's view of the community as an equal partner. At the same time, it urges the need for more investment in acute and specialist inpatient end-of-life care. This would require, in addition to staffing costs to meet projected demand, capital budgeting for adequate settings for end-of-life care provision.

In reviewing the successes and shortcomings of palliative-care policy in Ireland since the *Report of the National Advisory Committee on Palliative Care* in 2001, May et al. note that 'policy initiatives in a relatively new field of healthcare face a trade-off between ambition and feasibility' (2014: 1) and highlight the fact that the implementation of a palliative-care policy, though buoyed by political support, was particularly hampered by the inability to adequately estimate capital costs. Eventually, the recession of 2008 made the building of required inpatient units unrealisable. The lack of inpatient units is one of the main drivers of inequalities in access, which is itself identified as a barrier to the implementation of a palliative-care policy (May et al., 2013).

A 2011 study on the place of death in Ireland of those with colorectal cancer noted the dearth of hospice deaths, particularly in the Midlands, where there are currently no inpatient beds, concluding, 'Where hospice deaths are uncommon [...] it probably reflects the lack of supply rather than lack of demand for such services. The observed increase in nursing home deaths in areas without hospices suggests that these facilities are compensating somewhat for the lack of hospices (Ó Céilleachair et al., 2011: 95).'

Hospice discharge data from Hospital In-Patient Enquiry (HIPE) over the five years from 2013 to 2017, broken down by county of residence, shows an average of seven Westmeath residents, and only 0.8 Longford residents, 1.2 Offaly residents and 1.2 Laois residents annually discharged from acute settings to hospices. By contrast, Cavan averages just over 17 residents discharged to hospice, and

Leitrim, despite its low population, 16 hospice discharges, showing the effect of the availability of facilities in Sligo. The study by Brick et al., in its examination of the preferred place of death, noted that the availability of a specialist inpatient hospice unit influenced preference, particularly as this changed close to death. In the Midwest, where patients were aware of the comparatively developed hospice service, the proportion expressing a preference to die in hospice rose to 31% in the last week of life (2015: 116-17).

Similarly, Weafer's polling data on preferences for place of death show clear trends toward preference for a hospice where people know it is available and are aware of the service and level of care that it provides: '[People's] preference for care during end-of-life was also influenced by their experience of care given to loved ones. For example, while 27% of respondents would like to be cared for in a hospice in the final days of life, this figure increased to 52% for people whose loved one had died in a hospice (Weafer 2014: 24).' All this research demonstrates that inequity in access to hospice care has a real impact on the expectations and experience of patients, and that if policy is to be realised, community engagement and support of carers – which suffices for the majority – must be supplemented by specialist services in hospital and hospice settings.

Finally, the landscape of end-of-life care will be significantly impacted by the Assisted Decision-Making (Capacity) Act 2015, scheduled to be fully commenced by 2020. The act will redefine capacity in Irish law and regulate advance health-care directives (AHDs). Successful reorientation of the relevant sections of the health system under the act may require significant resourcing in terms of staff training and will likely see a series of test legal cases to determine guidelines on issues like deprivation of liberty.

Future Direction

A public health approach to palliative care remains, despite the explicit statement in the 2019 model of care, something undeveloped in Ireland, and something of which the scope and exact nature is unclear. Collaboration among

multiple stakeholders is necessary to advance an understanding of how (and whether) such an approach will best serve systems for end-of-life care and bereavement support – how it might underpin initiatives that are feasible, sustainable, scalable and transferable. Here are some of the IHF's hopes for the future in this regard.

1. Resource the delivery of policy

Recent policy developments in end-of-life care are encouraging, but they need resourcing to be realised. The 2017 national palliative care framework, *Palliative Care Services: Three Year Development Framework (2017 – 2019)*, recommends that the staffing levels in all existing specialist palliative-care inpatient units, community services, and Model 3 and Model 4 acute hospitals should be brought up to the levels recommended in the 2001 *Report of the National Advisory Committee on Palliative Care*, and the number of consultants in palliative medicine should be brought up to the level recommended in the 2003 Hanly report, all within the lifetime of the framework (HSE 2017). The need for multidisciplinary teams for specialist palliative-care provision is reiterated in the *National Cancer Strategy 2017–2026*, which recommends full specialist teams, including psycho-oncologists, in national cancer centres and training for all oncology staff in identification and assessment of patients with palliative needs (Department of Health 2017: 96-7). To deliver on the recommendations in these and other policy documents, such as the *Adult Palliative Care Services, Model of Care for Ireland (2019)* and the *Health Service Capacity Review 2018*, requires investment, not only in adequate staffing, but also in capital stock, particularly specialist inpatient units. Sláintecare recommends ring-fenced palliative-care funding.

2. Support for carers

As mentioned, the commitment to a public health approach to palliative care in recent Irish policy immediately narrows its focus to the support of family carers. If the resources of the community are to be marshalled to support end-of-life care, carers and family members require training, as well as integrated 'soft' supports, such as information provision. Greater awareness of the

realities of life-limiting illnesses and what to expect in its terminal stages, training for carers, adequate bereavement supports, and platforms for information provision on supports and services, including advance planning, would all drive engagement between professionals and the community.

3. Bereavement supports embedded in end-of-life care

Kellehear identified bereavement as the neglected aspect of end-of-life care. This is despite the fact that, of the varying strands, the study of bereavement impacts and support has perhaps proved the most amenable to population health approaches (particularly in the work of Samar Aoun). Bereavement was previously included as a 'phase of illness' in the palliative-care continuum in the Australian National Subacute and Non-acute Patient (AN-SNAP) classification, bringing the family carer or relative into the trajectory of treatment. Though it has since been removed, it was noted that 'although there are no longer any AN-SNAP classes for the bereavement phase, this remains an important component of palliative care, including that provided to paediatric patients and their families and carers (AHSRI 2015: 14).' Full embedding of appropriate bereavement care into end-of-life care planning could serve to inform and improve both areas.

4. Involvement of specialist palliative care

One likely reason for the lack of engagement from public health professionals is that palliative care is seen as a specialised area, and something that does not fit well with population health approaches. For a good foundation, a public health approach requires buy-in from and promotion by those professionals involved in the provision of specialist palliative care. If this is not secured, another form of asymmetry or disconnection will hamper integrated approaches to care.

5. Involvement of public health professionals

As noted, one of the major points in Whitelaw's and Clark's critical assessment of the state of public health approaches to palliative care is the clear 'asymmetry', whereby palliative-care professionals show enthusiasm for a public

health approach while public health officials and professionals seem reluctant to integrate end-of-life care into their practice or planning. A briefing from the UK's Housing Learning and Improvement Network on facilitating home deaths notes, 'Public health's role is to protect and improve health and wellbeing and reduce health inequalities, and as such has been identified by NHS England as a key strategic partner in the delivery of high quality end of life care (Housing Learning and Improvement Network 2016: 5).' Involvement from public health professionals and bodies such as the Institute of Public Health in Ireland could help provide a conceptual and practical foundation for implementation of a public health approach to end-of-life care in Ireland.

6. Data linkages and outcome measures

In a discussion following a presentation to the Oireachtas Committee on the Future of Healthcare in September 2016, the economist Stephen Kinsella reported giving the grand rounds lecture in University Hospital Limerick, saying,

*'I asked the doctors present, if I gave them the money to hire the people lost between 2008 and today, what they would do with it. I asked whether they would hire more nurses or more people like them. They said they would put all of the money, every single penny, into ICT systems.'*¹

This anecdote is telling. The current linkage of health data sets in Ireland is, to say the least, not optimal. To accomplish better planning and delivery of care with a population-based funding model requires better linkage and use of available data.

The review of May et al. continually notes that the lack of an evidence base in what is the comparatively fledgling field of palliative care makes it more difficult to secure funding in a competitive environment. They write, 'The evidence base to allocate funding [related to the last year of life] optimally does not exist,' and note that cost projections for palliative-care capacity excluded capital costs. They conclude, 'The Irish experience emphasises the importance of ensuring priority is given to feasibility and evidence in compiling

¹ https://www.oireachtas.ie/en/debates/debate/committee_on_the_future_of_healthcare/2016-09-14/2/

a plan. Palliative care remains a relatively new field with limited capacity for rapid expansion and challenges in competing for resources with more established areas of a health care system (May et al., 2014: 7).'

Generally, end-of-life care, of which palliative care is a core element, requires more research and better use of available Irish routine data. Better linkages between data sets such as the Hospital In-Patient Enquiry (HIPE), the Specialist Palliative Care Minimum Data Set, the Healthcare Pricing Office Diagnosis-Related Group costings and the National Cancer Registry could drive improvements in the design and delivery of care.

A register of advance healthcare directives will similarly be required for adequate implementation of the provisions of Section 8 of the Assisted Decision-Making (Capacity) Act, which requires further ICT investment. Finally, what are conspicuously lacking in end-of-life care are patient outcome measures. Feedback from patients with life-limiting illnesses and the use of surveys with bereaved relatives should be integrated into end-of-life care provision.

Conclusion: 'Eating the Elephant'

'How do you eat an elephant?' the old joke asks. 'One piece at a time.' As clichéd as it sounds, defining the parameters and substance of a public health approach to dying, death and bereavement is something that must be done one step at a time, fitted to existing health systems while advocating for change, where appropriate. At the core of care of the dying and bereaved, palliative care itself is still, comparatively speaking, an emerging area, and, internationally, attempts to define a public health approach have not resulted in sustainable and transferable programmes, while some might now be characterised as false starts.

To enshrine a health promotion and population health-based approach in Ireland requires collaborative, inclusive work among various stakeholders: medical professionals, policymakers, academics and advocates. It requires that all parties be clear-eyed and frank about what does and does not work.

Any programme that relies on public engagement must assess the resources required for it to become sustainable, whether these resources are professional or voluntary. In a public address, Allan Kellehear reminded those present that sustainability is 'the final and only test' of public health programmes, and that 'if [public health practitioners] are needed, then you are providing a service, not implementing public health (Smith 2019).'

To repeat our point: any programme and broader approach must, beyond its impact, be feasible, sustainable, scalable and transferable, and ensuring this requires the buy-in of multiple parties and acceptance that it must be done 'one piece at a time'.

Appendix 1: A Definition of a Public Health Approach to Palliative Care

An Innovation Lab workshop on defining a public health approach to palliative care, held in Belfast in May 2019, agreed, in a release in October, the following definition:

A public health approach to palliative care recognises the role of society and community in enabling and supporting people living with life-limiting conditions, and those important to them, to live well with flexible, holistic and person-centred care based on positive and collaborative partnership.

A public health approach to palliative care will involve working collaboratively to:

- increase awareness, understanding and discussion around palliative care through education and information;
- create and enhance networks across communities and sectors to support people living with a life-limiting illness and those important to them; and
- encourage people to think about and plan for their future physical, emotional, social, financial and spiritual needs.

Appendix 2: IHF Programmes and the Pillars of the Ottawa Charter

The suite of programmes developed by the Irish Hospice Foundation, including extensive programmes of public engagement and education and collaborations with the health-care system and policymakers, were developed in response to needs as they emerged in Ireland. They were not designed consciously within a public health or health promotion framework, but they fit comfortably within the pillars and actions of the Ottawa Charter. That initiatives may fit organically within a public health framework should encourage cooperation among different stakeholders to scope the potential for a targeted, multifaceted approach with greater conceptual clarity.

Developing Personal Skills
<ul style="list-style-type: none"> • <i>Think Ahead</i>
Strengthening Community Action
<ul style="list-style-type: none"> • Café Conversations • Palliative Care for All • Carers' supports
Creating Supportive Environments
<ul style="list-style-type: none"> • Forum on End of Life • Grief at Work • The Irish Childhood Bereavement Network
Engaging with Health Services
<ul style="list-style-type: none"> • Hospice-Friendly Hospitals • Design & Dignity • Final Journeys: End-of-life care delivery training for hospital staff • Compassionate End Of Life (CEOL) programme for nursing homes • Nurses for Night Care
Building Healthy Public Policy
<ul style="list-style-type: none"> • The Irish Childhood Bereavement Network • Bereavement • Children's Palliative Care

Appendix 3: The People's Charter on Dying, Death and Bereavement in Ireland

The People's Charter on Dying, Death and Bereavement in Ireland.

The Irish Hospice Foundation asked the people of Ireland what is needed
for a good death and for healthy grieving.

3,000 people say

I want to live and die in an Ireland where:

- Death is talked about and not hidden away.
- I can prepare for what lies ahead.
- I can get relief from pain, no matter where I am being cared for or what condition I have.
- I am treated as an individual and my wishes, choices and beliefs are respected.
- I, and the people who care for me, can get the practical services and support that we need.
- I can get information to understand what is happening to me.
- There is the support to help me cope with worries or distress.
- I can die, surrounded by people I love, in a calm and comfortable place. In my home, if at all possible.
- I am supported to stay in control of my own decisions.
- My dignity is respected and maintained to the end of my life, and after my death.



For the people who matter to me, I want an Ireland where:

- People understand grief and do not avoid thinking or talking about it.
- Family and friends are supported during a loved one's illness and after their death.
- People get space and time to grieve, talk and remember.

Help us by rolling out the charter in your community, workplace, family or organisation.

Learn more at hospicefoundation.ie/haveyoursay

Your Life Your Death Your Say #haveyoursayirl



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