Marie Curie

Care and support through terminal illness

Creating a death literate society

The importance of boosting understanding and awareness of death, dying and bereavement in Northern Ireland

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Introduction

With an aging population and growing palliative care needs, more and more people in Northern Ireland are being impacted by death, dying and bereavement with each passing year.

For understandable reasons, many people here don't like to think about death and would rather put any talk of it on the long finger until it can no longer be avoided. But what impact does this have?

How are our end of life and bereavement experiences affected if we have little awareness or knowledge of the practical matters of death and dying? What happens when someone close to us is diagnosed with a terminal health condition and we don't know very much about the care they need and how it is accessed? What are the consequences for the care we receive when we're dying if we haven't ever discussed our end of life wishes with our loved ones or clinicians? **Put another way, what are the impacts of 'death illiteracy'?**

Death literacy concerns the knowledge, skills and awareness of issues concerning death, dying, end of life care and bereavement. It is about understanding these issues and having the ability to put that knowledge into practice – not only for own benefit, but to support those within the wider community who are impacted by death and dying as well.

Death literacy is, perhaps, an unfamiliar concept in Northern Ireland, but a crucial one that will significantly impact the end of life and bereavement experiences of every person who lives and dies here. This report examines the importance and impact of death literacy and – based on new survey data – provides a snapshot assessment of levels of death literacy in Northern Ireland.

It shows that there are important gaps in death literacy among the local population, with too many people unprepared for the end of life and unaware of where and when they can access support when they're impacted by death, dying and bereavement.

Finally, the report provides recommendations that we believe can help address Northern Ireland's death literacy problem in the months and years ahead.

Death literacy is a growing area of study and scholarship around the world, but there is a lack of robust evidence that is specific to Northern Ireland. Given the enormous impact that death illiteracy can have, this situation needs to be addressed. We hope this report can play a small role in bridging that evidence gap, and maybe even spark a renewed interest in the subject among local policymakers and health and social care leaders.

Methodology

This report is based primarily on a survey of public attitudes to death and dying in Northern Ireland, carried out in 2021 and designed by a research partnership of Marie Curie; the School of Psychology, Queen's University Belfast; and the Marie Curie Palliative Care Research Centre and Division of Population Medicine, Cardiff University.

The survey was completed by 506 adults in Northern Ireland. The same survey was also conducted in England, Scotland and Wales, offering the opportunity to compare findings across these jurisdictions.[1]

Context

What is death literacy and why is it important?

Death literacy is commonly described as a set of knowledge and skills that make it possible to gain access to, understand and make informed choices about end of life and death care options. Populations with high levels of death literacy will have context-specific knowledge about the 'death system' where they live and the ability to put that knowledge into practice [2] [3]– both for their own benefit and to support those within the wider community who are impacted by death and dying.

'Death systems' are defined as the means by which death and dying are understood, regulated and managed in a society. They include and involve several components – including **people** (e.g. health and social care practitioners, funeral workers, religious leaders), **places** (e.g. hospitals, hospices, mortuaries, cemeteries), **times** (e.g. death anniversaries and remembrance days), **symbols and rituals** (e.g. last prayers) and more. [4]

Much like health literacy is about a person's ability to understand and use information to make decisions about their health, [5] death literacy enables people to engage, in an informed way, with issues of death, dying and bereavement.

When this death-related knowledge and awareness is delivered and facilitated through the community and other actors such as schools, workplaces, churches and more, this can be understood as a public health or health promotion approach – helping to change attitudes, behaviours and experiences of death, dying and bereavement in different populations. [6] [7] (see pages 11 and 14).

Researchers define a number of specific features or components that characterise death literacy. While they are grouped in other ways elsewhere, in this report, we combine them under the themes of *death knowledge and death skills.*

Death knowledge

This component of death literacy includes factual knowledge and understanding of the death system and the dying process, including what palliative and end of life care involves and who provides it. For example, a person with high levels of death literacy may be familiar with key palliative and end of life care terms/phrases and know how these services are accessed by patients and their loved ones.

Death knowledge also covers knowledge of end of life planning processes (e.g. advance care plans, wills, funerals etc.); what could be called 'death administration' – for example, how a death certificate is obtained; and community-level knowledge, such as awareness of the sources of support available for groups like end of life carers and bereaved people in the places they live.

Death skills

Death skills refers to the confidence and ability to talk about death, dying, and bereavement with others. This may include conversations with family, friends or health and social care professionals about issues like end of life wishes and planning, and experiences of loss and grief. [8]

Though there is some degree of overlap between elements of *death knowledge* and *death skills*, increased levels of knowledge can increase the confidence and ability to discuss issues of death and dying.

Why does death literacy matter?

While it may be a relatively unheard-of concept among the general population in Northern Ireland, death literacy is incredibly important.

Knowledge and understanding of palliative care impacts on access to quality care for dying people. [9] Robust knowledge of these services, and the range of other supports available, is therefore key to ensuring households and families impacted by terminal illnesses are able to access care and support when and where they need it.

Even in the best of circumstances, navigating Northern Ireland's complex Health and Social Care system is difficult – this difficulty will only be compounded if people at the end of life are unable to make informed decisions based on a strong understanding of the available services and how they're accessed.

When we acquire *death knowledge* and skills, it allows a whole-community approach to supporting those who are experiencing death, dying and bereavement. This may help to take some of the burden off end of life carers – many of whom face exhaustion, burnout and declining health and wellbeing as a result of their caring role.[10]

In death literate communities, people can talk openly about death and dying. This helps to increase engagement with palliative care services [11] and also leads people to feel more capable of sharing their end of life wishes. Such agency around a person's end of life wishes is a benefit in its own right and reduces the distress facing their loved ones, who would otherwise be left to make decisions on their behalf. [12] It can also avert potential conflict between different health professionals, family members and care agencies. [13]

Failure to have these conversations during the routine days of living results in decisions being made in times of declining health or crisis, affecting the quality and range of care and support available to patients and their loved ones; and impacting on people's ability to die where or how they would wish. [6]

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The Department of Health's Advance Care Planning Policy document reinforces these ideas, highlighting the wide range of benefits when people have meaningful conversations about end of life wishes, including: an enhanced quality of life; peace of mind, giving people the opportunity to put their affairs in order; easing caregiver concerns and clarifying a person's wishes at the end of life for those closest to them. [14]

While there are many factors and interventions necessary to encourage end of life discussions and advance care planning, high levels of death literacy are a crucial facilitator/driver.

In the bereavement phase, good levels of death literacy are also critical to ensuring newly bereaved people can identify their grief and seek out relevant information and support to help them manage it. As a consequence, they may avoid some of the complications sometimes associated with the grieving process, such as depression and wider mental ill-health. [15] In this sense, death literacy can help increase collective wellbeing and resilience among bereaved people.[8] Understanding the death process and knowing what to expect may also ease bereavement experiences.

The issue of death literacy among children and young people is strongly debated, even though experiencing death is an inescapable reality for many of them. Up to date statistics are hard to find, but it is estimated that around 1,500 children under the age of 18 in Northern Ireland were bereaved of a parent in 2015, [16] and this figure doesn't cover the many more who are bereaved of siblings, grandparents and other loved ones each year.

Evidence suggests that some children have a desire for access to information and education about death and recognise the importance of this – including in helping them to prepare for the experience of personal bereavement. [17]

In a VotesForSchools poll, run in collaboration with the UK Commission on Bereavement in 2022, 58% of 7-11 year old students across the UK, and 38% of 12-16 year old students, said that coping with loss and bereavement should be taught at school. [18]

Despite this, many children and young people do not have the opportunity to talk or learn about death and dying, whether that is in school or other settings. Researchers argue that this may be doing them harm – fostering confusion and ignorance about death, [13] stifling understanding of grief and the natural responses to it, and even creating obstacles to receiving meaningful bereavement support when they experience the loss of a loved one.[19]

Knowledge and understanding of the issues associated with death, dying and bereavement has the potential to significantly shape end of life experiences for everyone in Northern Ireland. The next chapter of this report analyses new survey data to provide a snapshot of death literacy levels among the local population.


Philip Hardman/Marie Curie

Levels of death literacy in Northern Ireland

Our survey on public attitudes to death and dying in Northern Ireland offers unique insights into levels of death literacy among the local population. With the same survey having been carried out in England, Scotland and Wales, we are also able to compare local levels of death literacy with those across the UK, helping to identify both strengths and areas for improvement in Northern Ireland.

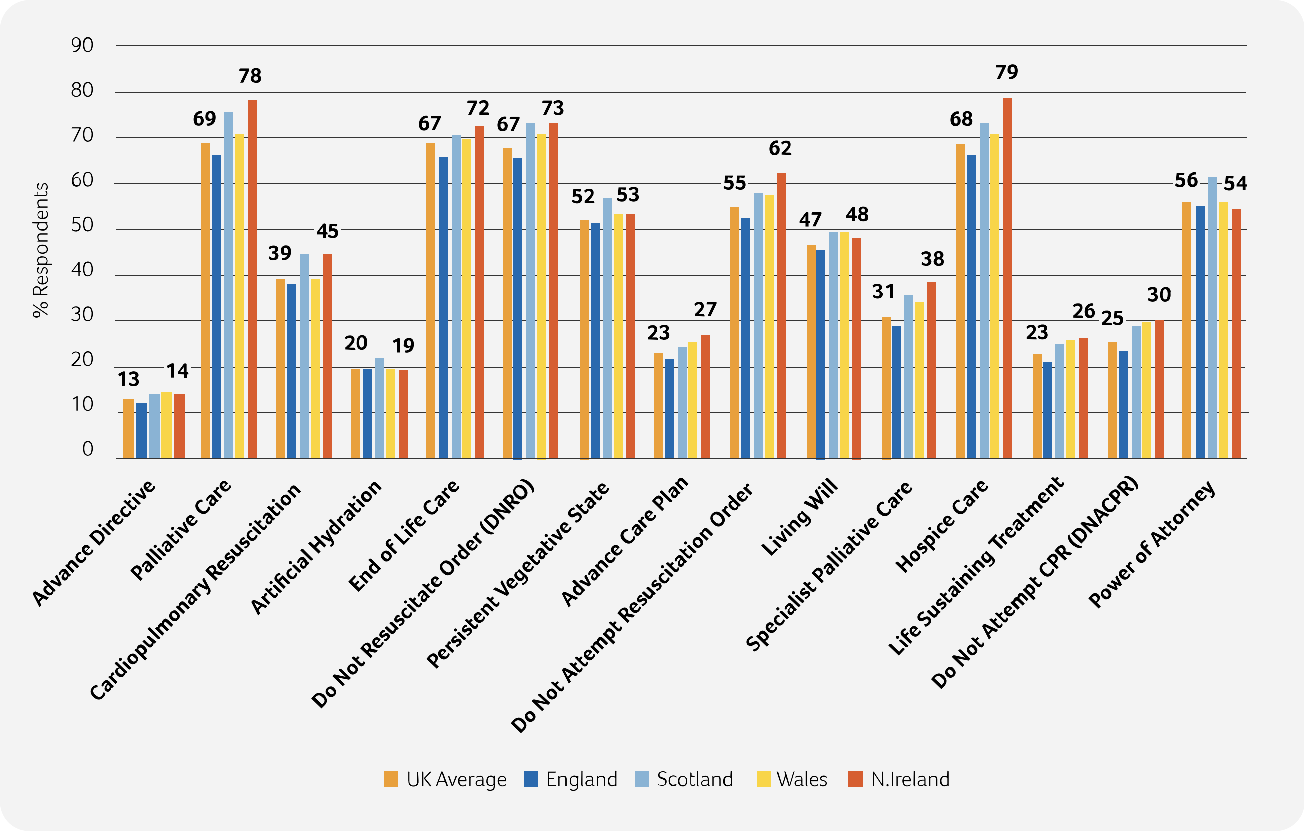
This chapter is divided into three primary sections, examining: i) Familiarity with key palliative and end of life care terms; ii) Talking to others about death, dying and bereavement; and iii) Finding support and information in the context of death, dying and bereavement.

Familiarity with key palliative and end of life care terms

Awareness and understanding of the core elements of palliative and end of life care is central to the knowledge element of death literacy. Our survey presented a number of relevant terms and asked respondents if they were familiar with them.

As Chart 1 illustrates, respondents in Northern Ireland performed favourably compared to their peers across the UK – with higher familiarity with 13 out of the 15 terms in NI compared to the UK average. Across the four individual jurisdictions, respondents in Northern Ireland had the same or higher levels of familiarity with 11 out of the 15 terms.

Chart 1 Which palliative and end of life care terms are you familiar with?



That being said, the local results are still cause for concern. Less than 50% of people in Northern Ireland were familiar with over half (8 out of 15) of the terms – and in some cases, recognition was even lower still.

Less familiarity with specialist terms like 'artificial hydration' and 'life sustaining treatment' was to be expected, but more than one in five people were not familiar even with more common terminology like 'palliative', 'end of life' and 'hospice care'. Given that these services make up core parts of the care and support that people will need when living with terminal illnesses, the lack of awareness of them among such large proportions of the public is very worrying.

The results for advance care planning (ACP) were even worse, with 73% of people unfamiliar with that term, and low levels of recognition of some of the documentation and processes involved. For example, 86% were unfamiliar with 'advance directive', over half (52%) were unfamiliar with 'living will' and 46% were unfamiliar with 'power of attorney'. People in Northern Ireland were less familiar with these latter two terms than their peers in Scotland and Wales by a range of 1-7%.

The impact of this is, arguably, illustrated when we asked people whether they had undertaken any activity in relation to advance care planning (Chart 2). Only a minority reported having done so, while a sizeable group responded negatively to the idea of ever engaging with the process in the future. This included 22% who said they would not, or did not intend, to speak to a doctor or nurse about their end of life wishes.

We may reasonably conclude that these trends are explained, at least partially, by a lack of awareness of advance care planning and its benefits – fundamentally an issue of death literacy (other contributing causes linked to death literacy are discussed in the next sections).

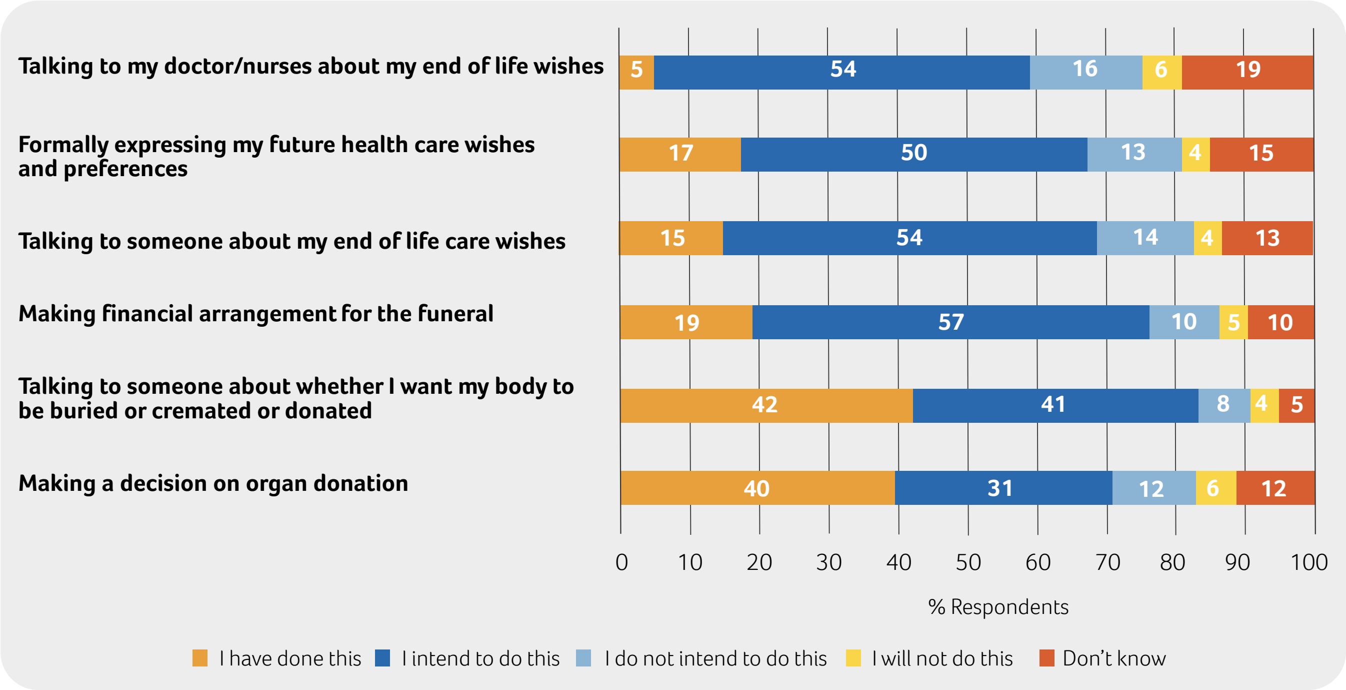
1 in 5

people in Northern Ireland were unfamiliar with the terms 'palliative care', 'end of life care' and 'hospice care'.

73%

of people in Northern Ireland were unfamiliar with the term 'advance care planning'.

Chart 2 Select an option to express your position on the following statements



Finally, it is worth highlighting the low levels of familiarity with terms related to resuscitation. More than one in four people in our survey were unfamiliar with the term ‘Do Not Resuscitate Order’ (DNRO), nearly 40% were unfamiliar with ‘Do Not Attempt Resuscitation’ (DNAR), and less than a third were familiar with ‘Do Not Attempt Cardiopulmonary Resuscitation’ (DNACPR).

Decisions about resuscitation may be among the most important any of us can make about the way we would like to die. They help to prevent inappropriate interventions at the end of life – ensuring the person’s last hours or days are spent as peacefully as possible [20] and avoiding added distress to families and loved ones. Raising greater awareness of these vital components of end of life planning ought to be a priority for health and social care stakeholders.

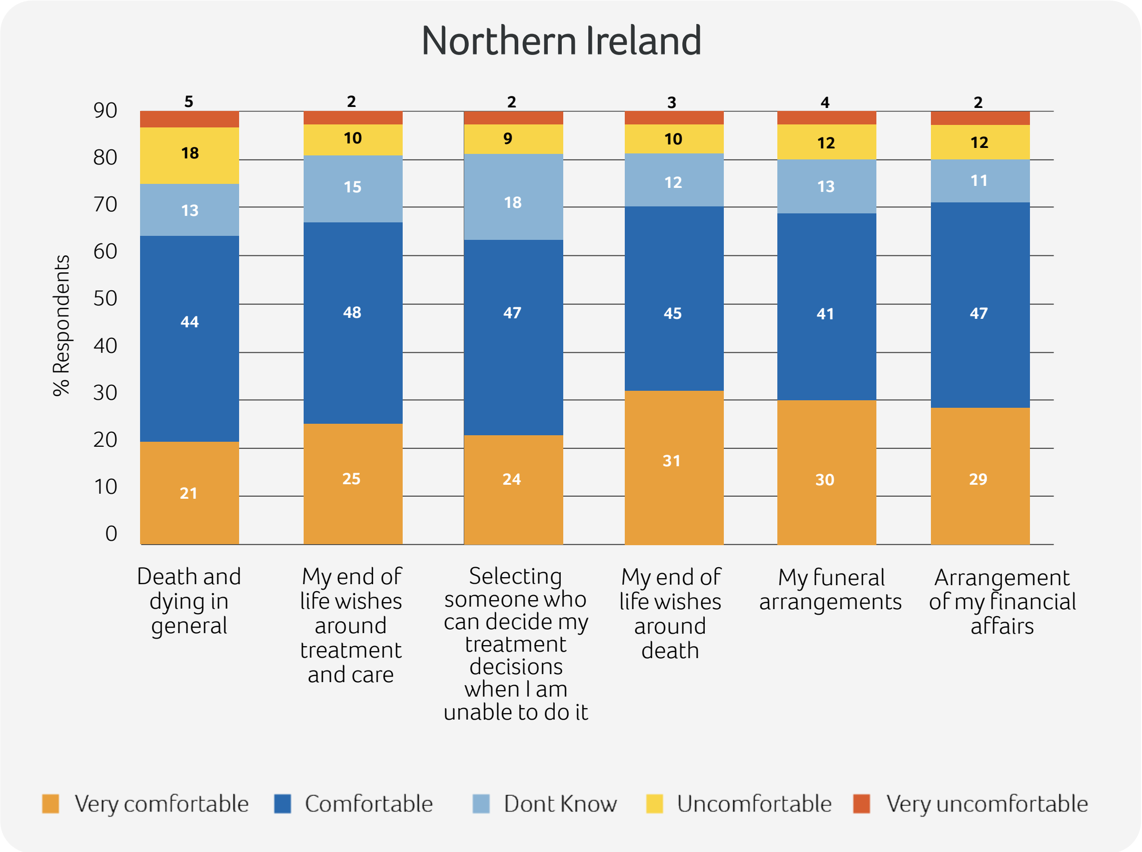
Talking to others about death, dying and bereavement

As highlighted in page 4, the willingness and ability to talk openly about matters of death, dying and bereavement is one of the central skills of a death literate population. When we asked how much Northern Ireland, as a society, talks about death and dying, 11% answered ‘too much’ – the highest proportion in the UK (3% more than in Wales, 2% more than in England and 8% more than in Scotland).

Our survey also specifically examined people’s willingness to talk about these issues with two groups – their friends and family and their doctors and nurses.

Nearly two-thirds (65%) of people said they were comfortable/very comfortable talking to their friends and family about death and dying in general, with 73% saying the same about their end of life treatment and care wishes. Slightly more (76%) said they were comfortable/very comfortable talking about their end of life wishes around death (Chart 3).

Chart 3 How comfortable would you feel discussing the following topics with your family and friends?



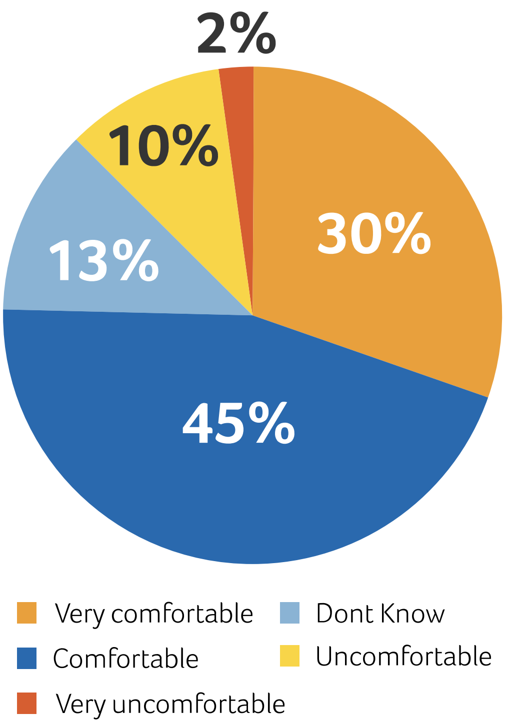
These trends are welcomed, but when we analyse the number of negative responses to these questions, it casts the results in a more worrying light.

In Northern Ireland, nearly one in four people (23%) said they were uncomfortable/very uncomfortable talking about death and dying in general with their friends and family – 5% higher than the UK average and between 5-7% higher than each individual jurisdiction (Chart 4*). Compared to the UK average, the number of people selecting uncomfortable/very uncomfortable was higher in Northern Ireland for every item in this question – suggesting that, of all the jurisdictions in the UK, we have the biggest problem with talking about death and dying within social settings.

People's willingness to talk specifically about their end of life wishes with their doctors and nurses were more similar across the UK. In NI, 76% of people said they would be comfortable/very comfortable to have those discussions (Chart 5) – which was only slightly higher than the UK average (74%) and the proportion in England (73%) and Wales (75%).

The proportion of those selecting uncomfortable/very uncomfortable was broadly similar across the UK as well, although slightly higher in Northern Ireland than the overall average (12% vs 10%) – meaning that roughly one in eight people here would not be comfortable talking about their end of life wishes with their doctor or nurse.

Chart 5 How comfortable would you feel discussing your end of life wishes with your doctors and nurses?



23%

of people in Northern Ireland said they were uncomfortable talking about death and dying with their friends and family.

Finding support and information in the context of death, dying and bereavement

As we have seen, someone with high levels of death literacy will have context-specific knowledge about the death system where they live and, crucially, *the ability to put that knowledge into practice.* [2] Our survey assessed this knowledge-into-practice element in relation to two key areas – planning ahead for the end of life and accessing bereavement support when someone dies (Chart 6).

The results are, again, very concerning. Nearly a third (30%) of people in Northern Ireland disagreed/strongly disagreed with the statement 'I know where to find information on how to plan in advance for my care at the end of life'.

30%

of people in Northern Ireland don't know where to find information on advance care planning.

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*See end of report (p18-19) for Chart 4

Public health approaches to palliative care

Public health approaches to palliative and end of life care seek to promote public openness around death, dying and loss; tackle the stigma that can surround these issues; and empower people, families and communities to draw on their own resources and community supports to adapt and cope with death and dying.[A]

There are a number of core tenants at the heart of these approaches, including community development, death education and partnership working between societal stakeholders such as schools, workplaces, churches and more.[B]

These approaches also help to extend the reach of end of life and bereavement services by engaging wider populations beyond those who are actively dying and their loved ones.

Examples of public health approaches in practice:

- The Cheshire Living Well, Dying Well programme delivered training to people in public-facing roles to engage their service users around issues of life, age, death and loss. The programme also delivered bereavement and grief training for students at the University of Chester.[C]

- St. Christopher's Hospice, London, developed programmes to raise awareness of dying and bereavement with local schools. Groups of students aged 9-16 visited the hospice and had the opportunity to talk to staff and patients about terminal illness and bereavement, helping to reduce anxiety and foster confidence in engaging with these issues.[D]

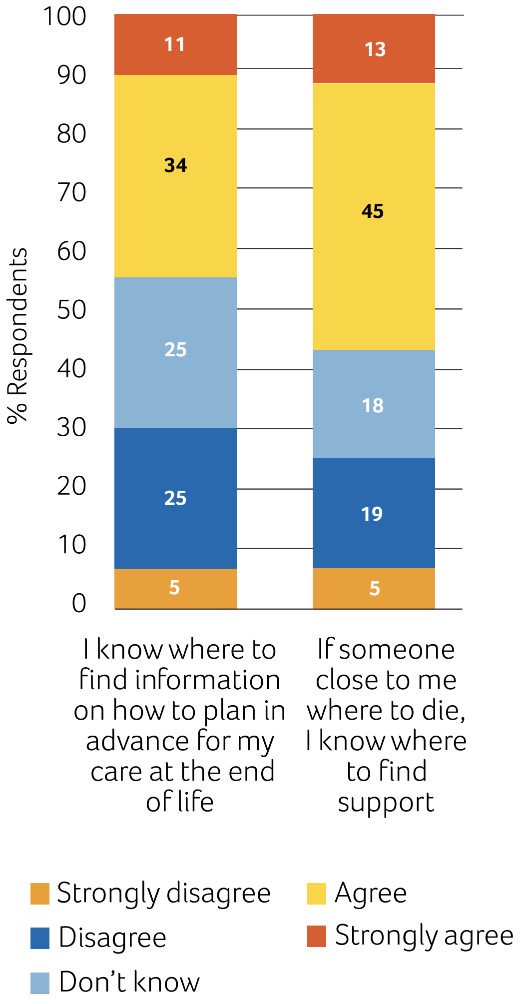
[A] Paul, S and Sallnow, L (2013). Public health approaches to end of life care in the UK: An online survey of palliative care services. BMJ Supportive & Palliative Care, 3 (2).

[B] Public Health Palliative Care International.

[C] Abel, J et al (2016). Each community is prepared to help: Community development in end of life care.

[D] Kelleher, A (2013). Compassionate communities: End of life care as everyone's responsibility. QJM, 106 (12)

Chart 6 To what extent do you agree or disagree with the following statements about the availability of information or services regarding end of life care?



When those who selected 'don't know' are added to this, it means over half (55%) of people failed to provide an affirmative answer to the question.

Local survey respondents performed slightly better in this question than the UK average, with 46% of people in Northern Ireland saying they agreed/strongly agreed that they knew where to find information on advance care planning, compared to 44% across the UK as a whole. Rates were the same in Scotland (46%) and higher in Wales (47%).

Our findings still suggest, however, that more than a decade after the Department of Health's Living Matters, Dying Matters Strategy highlighted the importance of accessible information to support meaningful future end of life care planning in Northern Ireland [21], too many people still do not know where to find this information.

Regarding bereavement support, nearly a quarter (24%) of people in Northern Ireland disagreed/strongly disagreed with the statement 'if someone close to me were to die, I know where to find support'. When the 'don't knows' are added, this means over 40% of people did not provide an affirmative answer to the question.

As above, there are some positives to take, as the proportion of people who selected agree/strongly agree to this question was slightly higher in Northern Ireland (58%) than the UK average (54%) and the four jurisdictions individually (England 53%, Scotland 54%, Wales 56%).

However, outperforming a low benchmark is not a cause for celebration. With evidence suggesting that those who receive insufficient bereavement support are more likely to experience a worsening of physical and mental health, [22] there is clearly a lot of work to do to ensure more people in Northern Ireland are aware of the bereavement support available where they live.

Time is running out to tackle Northern Ireland's death literacy problem

Our survey findings show that there are numerous important gaps in Northern Ireland's death literacy levels. Demographic trends here suggest there has never been a more important time to begin addressing them.

Like many of our neighbours, Northern Ireland's population is ageing rapidly, with growing numbers of people living longer with multiple chronic or terminal health conditions and complex needs. During the period 2010/11-2020/21, the number of people on Northern Ireland's Palliative Care Register doubled, [23] while deaths from cancer, chronic lower respiratory diseases and dementia alone increased by 10%, 17% and a staggering 65% respectively. [24]

Looking to the future, demand for palliative care is expected to grow by over 30% by 2040, [25] with the number of people dying each year growing by nearly a fifth during this time. [26]

In this context, it is imperative that death literacy is given much greater prominence on the agendas of policymakers and health and social care leaders. Failure to tackle the death illiteracy that exists in large parts of Northern Ireland's population will have serious consequences for the end of life experience of thousands of local people in the years ahead.

Philip Hardman/Marie Curie

Recommendations for policymakers and health and social care leaders

This report has shown that, while Northern Ireland is not an entirely death illiterate society, some sections of the population could benefit from greater understanding and awareness of key issues related to death, dying and bereavement. At present, there are too many people unprepared for the end of life and reluctant to discuss or plan for it. Others are comfortable talking about these topics, but are unaware of where and when they can access support when they need it.

These are critical challenges to overcome. The following recommendations, while by no means exhaustive, can help policymakers and health and social care leaders to begin addressing Northern Ireland's death literacy gaps:

- As part of a public health approach to palliative care, the Department of Health should commission an **action plan for promoting death literacy** across Northern Ireland. This should utilise co-design/co-production models involving all stakeholders and sectors with a role to play in raising awareness and understanding of issues of death, dying and bereavement (e.g. workplaces, religious groups, community organisations, schools etc. – see international examples on page 14). Funding should be attached to the action plan to ensure these stakeholders have the resources and capacity they need to play a full role in meeting its objectives. Development of the action plan would, ideally, be a dedicated workstream under a new **palliative care strategy for Northern Ireland.**

- Death education programmes should be included in relevant parts of the school curriculum in Northern Ireland, as part of a life-course approach to teaching children and young people about death, dying and bereavement. These programmes should be designed by the Departments of Health and Education and the Council for the Curriculum, Examinations and Assessment (CCEA), following international evidence and best practice.

- The Department of Health's new **Advance Care Planning Policy** should be finalised as a priority in the next Assembly mandate, with any required funding provided in full.

- Modules/courses on promoting death literacy among patients and their loved ones should be part of **training and Continuing Professional Development** for relevant health and social care disciplines. This should include nursing, Allied Health Professions, social work and more.

- A benchmarking exercise should be carried out to assess the accessibility and quality of information materials on core death literacy issues in every statutory health and social care setting in Northern Ireland. Where they are not available already, **information packs** covering key themes – including details on palliative and end of life care services, the importance of discussing death and dying with loved ones and signposting to bereavement support – should be distributed.

- **Further research** should be commissioned to explore death literacy challenges in Northern Ireland and design the evidence-based interventions required to address them. This should include a specific research focus on if/how public health interventions can improve death literacy.

- A representative **annual survey** should be carried out to measure progress and monitor trends on death literacy levels among the Northern Ireland population.

Developing death literacy: International examples

Death literacy among young people: Calvary Health Care Bethlehem schools project, Australia

In 2015 an immersion programme in palliative care was developed at Calvary Health Care Bethlehem, a public hospital specialising in palliative care and neurology, for Year 10 students at a girl's college in Oakleigh, Australia. The students interviewed a range of healthcare staff and spent time with patients. These activities supplied visual and narrative material for the development of a DVD resource, which was used as part of classroom death education sessions. A project evaluation found that:

- Most participants developed a new or deeper understanding of death and palliative care.

- Almost half of the participants described a decreased fear of death.

- Nearly half of the participants reported increased feelings of confidence in talking about death, dying, palliative care, grief and loss.

- Some described being able to speak for the first time about end of life issues with family and friends, while others spoke about being able to have these conversations more easily or with greater confidence. [27]

Death literacy through digital resources: Dying2Learn mass online course

In 2016, clinical and academic palliative care experts from Australia developed and launched a global online course aiming to foster community death conversations and build awareness of palliative care and other issues of death and dying. The course content explored themes including how care practices for dying people have changed over time, the role of medicine in how we die and how society engages with death. Participants from around the world accessed videos and articles on these subjects, completed online activities and interacted with each other via discussion boards.

An evaluation of the project found that mean scores on death competence – which includes many of the key death knowledge and skills themes set out in page 4 above – increased between the beginning and end of the course, with participants perceiving themselves to be better prepared to cope with the occurrence of death in their lives. The course was beneficial for all participants regardless of whether they had previously experienced a personal bereavement. [28]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Contributors and acknowledgments

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Philip Hardman/Marie Curie

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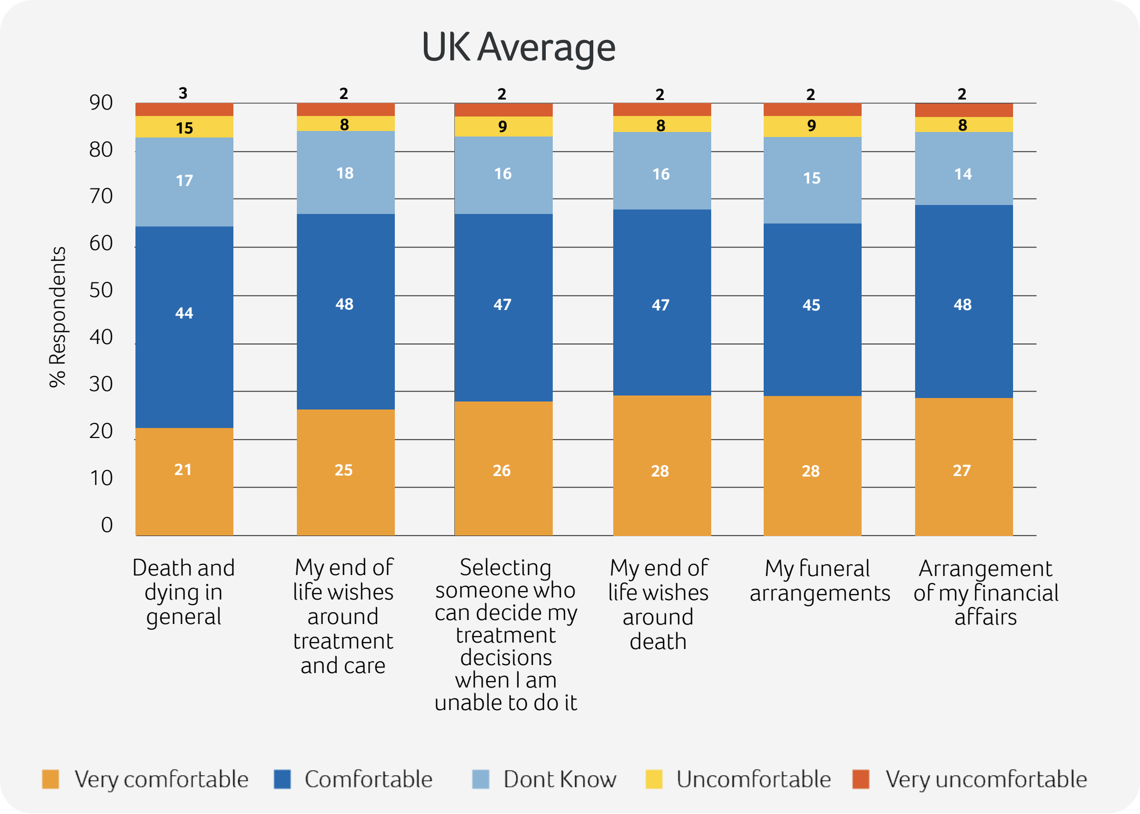
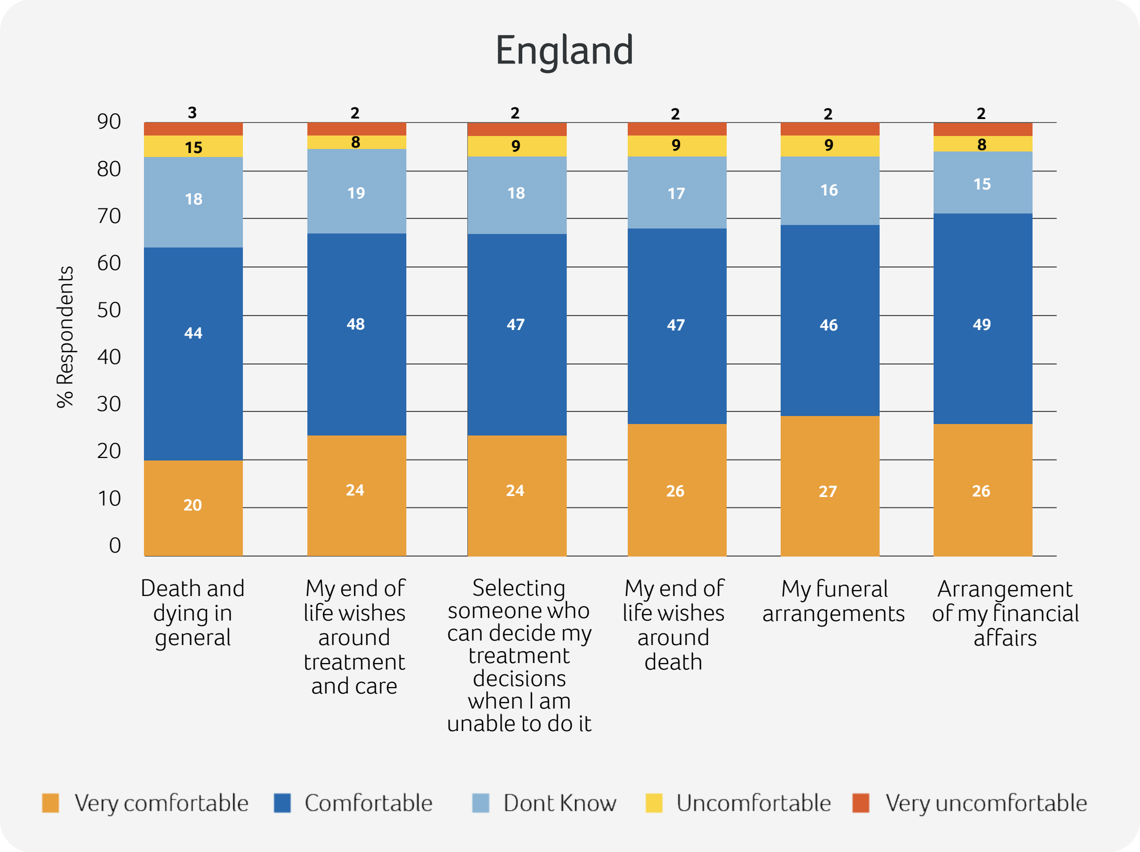
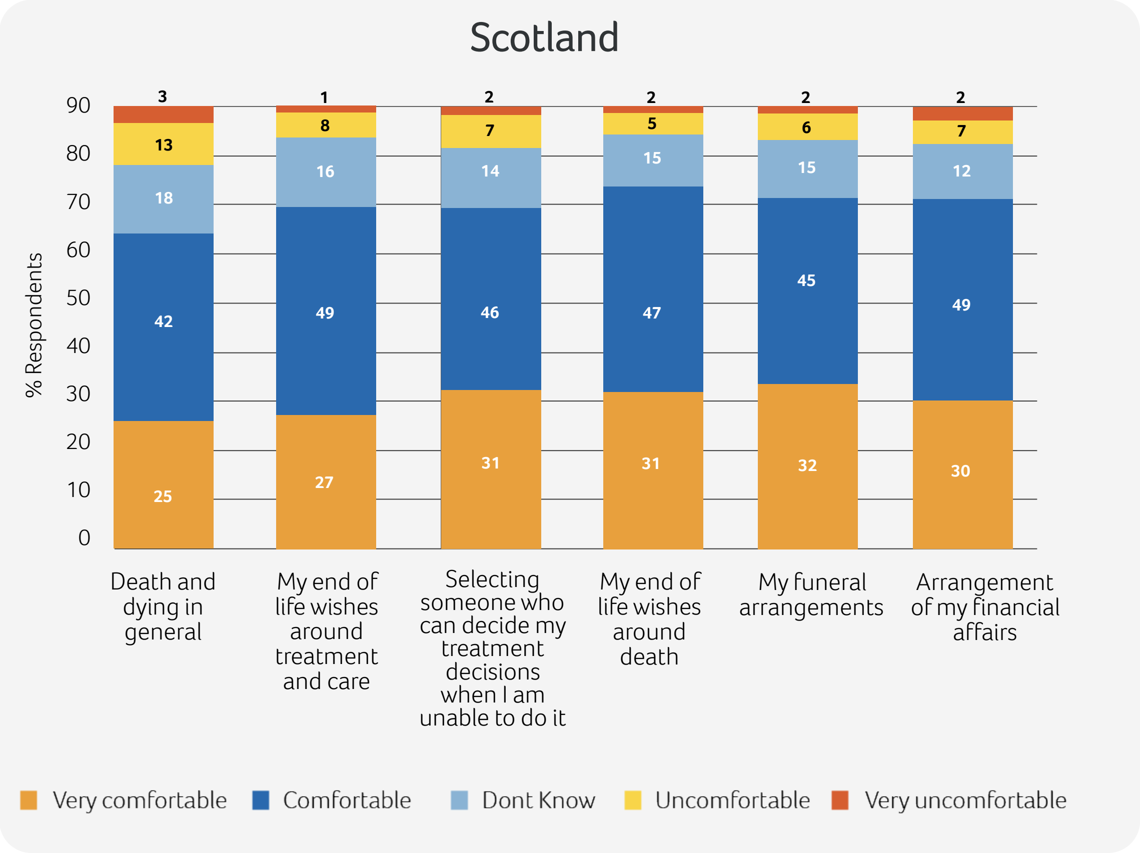
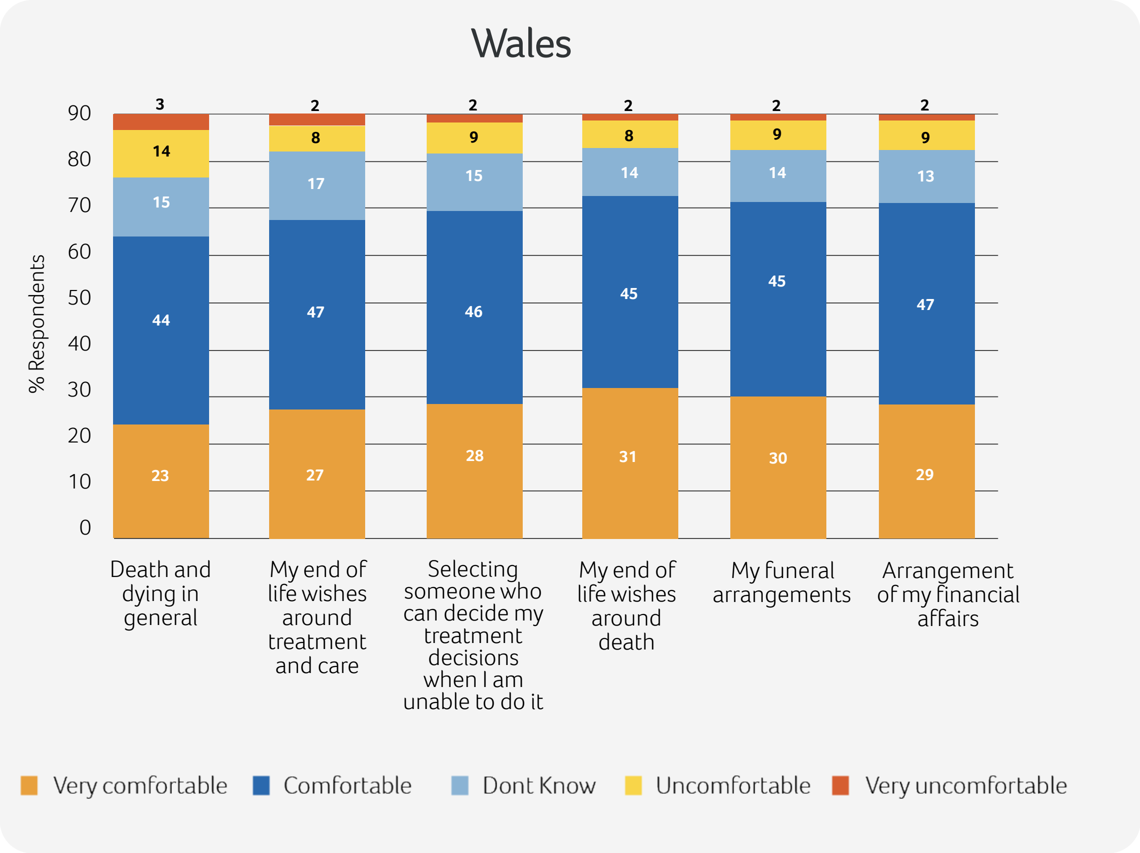
Chart 4 How comfortable would you feel discussing the following topics with your family and friends?






Scotland
% Respondents
0
10
20
30
40
50
60
70
80
90
Death and dying in general
25
42
18
13
3
My end of life wishes around treatment and care
27
49
16
8
1
Selecting someone who can decide my treatment decisions when I am unable to do it
31
46
14
7
2
My end of life wishes around death
31
47
15
5
2
My funeral arrangements
32
45
15
6
2
Arrangement of my financial affairs
30
49
12
7
2
Very comfortable
Comfortable
Dont Know
Uncomfortable
Very uncomfortable


Wales
% Respondents
0
10
20
30
40
50
60
70
80
90
Death and dying in general
23
44
15
14
3
My end of life wishes around treatment and care
27
47
17
8
2
Selecting someone who can decide my treatment decisions when I am unable to do it
28
46
15
9
2
My end of life wishes around death
31
45
14
8
2
My funeral arrangements
30
45
14
9
2
Arrangement of my financial affairs
29
47
13
9
2
Very comfortable
Comfortable
Dont Know
Uncomfortable
Very uncomfortable

For more information contact:

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