Telling It Like It Is:
Experiences of Older People at End of Life
2025

The Alliance of Age Sector NGOs

Age & Opportunity

ACTIVE RETIREMENT IRELAND

COPE Galway

third age

Irish Senior Citizens Parliament

Irish Hospice Foundation

THE ALZHEIMER SOCIETY of IRELAND

ALONE

Community Foundation Ireland

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Foreword

The Alliance of Age Sector NGOs works with a diversity of older people living across Ireland. ‘Experiences of Older People at End of Life’ is the third edition in the Alliance’s ‘Telling It Like It Is’ series. Previous editions have explored the lived experience of older people through the pandemic and the nature and impacts of ageism in an Irish context.

A key element of ageing well is dying well. Death, of course, can be a confronting subject, but the more we talk about it, plan for it, and actively invest in the very often practical supports and actions that have been proven to make a difference, the easier it can be to deal with when the time comes, both for the person and their loved ones.

‘Experiences of Older People at End of Life' identifies eleven recommended actions that can be taken so that Ireland can deliver on the best end-of-life and bereavement care, for all. The recommendations presented are evidence based and informed by the collective experience of the eight member organisations working to support older people.

Numerous commitments relevant to ageing and dying well have been set out in key Government policies and strategies such as the National Positive Ageing Strategy (2013), the National Adult Palliative Care Policy (2024), and the Programme for Government, Securing Ireland’s Future (2025).

The voice and lived experience of older people must be heard by those responsible for policy implementation. We are calling on decision makers to respond to the findings, reflections and recommendations gathered in this report.

The Alliance continues to call for the establishment of an Independent Commissioner for Ageing and Older People - similar to that which is in place in both Northern Ireland and Wales. An Independent Commissioner would help ensure that Ireland’s various policy commitments relevant to older people are meaningfully implemented and monitored.

Everyone deserves a positive end-of-life experience. In order for Ireland to truly achieve excellence at end of life, access to the supports that are proven to most shape this positive experience should be available to all.

The Alliance of Age Sector NGOs

A word from our partner, Community Foundation Ireland

Equality for all in thriving communities is the mission of Community Foundation Ireland. It is a mission which informs and drives all our work with community partners, philanthropists and supporters.

Our ambition is to be at the forefront of change; to nurture communities where everyone is respected, to empower generations where everyone is heard, and to overcome systematic and societal barriers to equality and fairness.

Death, it has been said, is the ultimate equalizer – the idea that it comes to us all - regardless of wealth, status, or power.

This latest Age Alliance report in the 'Telling It Like It Is' series reminds us that although death is a universal experience, it is also unique to each of us and may depend on factors such as where you live, the setting in which you die and the range and quality of supports that are available to you.

Everyone deserves equal rights and opportunities, in death as in life. In Ireland, as in all Western countries, most people will die in older age.

This Age Alliance report spotlights a range of practical actions that can make a real difference to the end-of-life and bereavement experience for older people. We must ensure dignified and equal access to end-of-life and bereavement care and address the systemic inequities highlighted in this report.

As a Foundation which believes in Equality for All we are proud philanthropic partners of the Alliance of Age Sector NGOs and welcome the publication of this report. It should be studied and acted upon by all policymakers.

An ageing Ireland is something that we all have a stake in. We all want to age well. We will all want to die well. As a country, we must strive to become an Ireland that supports people to live as well as possible for as long as possible and then be enabled to have a 'good' death, whatever that may mean to each person.

Pursuing the recommendations proposed by the Age Alliance in this report will ensure that Ireland continues to work towards the best end-of-life and bereavement care, for all.

Denise Charlton
Chief Executive, Community Foundation Ireland

Who is The Alliance of Age Sector NGOs?

The Alliance of Age Sector NGOs (the Alliance) represents the collective thinking of eight significant NGOs working in the age sector. As individual entities, we provide vital services and programmes for older people, support older people to contribute to and participate in community life and advocate for better policies, services and supports for older people at national and local level.

Together, we collaborate to seek action on specific issues that make older people's lives unnecessarily difficult. We work together to ensure Ireland becomes a better place in which to grow older.

The Alliance is committed to collaborative leadership and the pooling of our capacity and resources to maximise our collective impact.

The eight member organisations are Active Retirement Ireland, Age & Opportunity, ALONE, The Alzheimer Society of Ireland, Irish Hospice Foundation, The Irish Senior Citizens Parliament, Third Age and Cope Galway.

Meetings are attended by the CEOs of the eight member organisations together with the Alliance's Independent Chair, Maurice O'Connell.

Background to this report

Approximately 35,000 people die each year in Ireland, leaving those close to them bereaved. As Ireland's population ages, we will see a projected increase of 68% in the total number of deaths over a 30 year period, from 2016-2046. Three out of four deaths currently are from an illness indicating a need for palliative care.[1]

It is often said that the Irish 'do death well', and the evidence internationally would appear to support this. For example, Ireland ranked fourth in the world in the 2015 Economist Quality of Death Index.[2]

However, we know that this experience is not equal for everyone, and there are gaps in the care received, for individuals and for loved ones, at this critical time.

Death comes to us all; however, we know that any issues relating to end-of-life care will disproportionately affect older people. People aged 65 and over account for more than four out of five (83%) of all deaths in Ireland, and more than a third (36%) of all deaths are people aged over 85 years[3].

Everyone deserves a positive end-of-life experience. For Ireland to truly achieve excellence at end of life, access to the supports that are proven to most shape this positive experience should be available to all.

The National End of Life Survey, published in 2024[4], was the first nationwide survey that asked bereaved relatives about their experience of the care provided to their loved one in their last months and days of life.

This survey represents a major milestone as the first of its kind on a national scale, however, it is not the first survey of bereaved relatives to be undertaken. In 2017, the Mater and St James's Hospitals undertook the Survey of Bereaved Relatives: Voices MaJam[5], which helped lay the foundation for this national project.

The purpose of the National End of Life Survey was to learn from people's experiences to improve the services provided both to people who are dying, and those who care for them. Between September and December 2022, 4,570 bereaved family members and friends completed the survey.[6]

A report of the survey findings was published by the National Care Experience team in HIQA in April 2024. However, there is more to explore from this valuable dataset, particularly in telling the story of the end-of-life experiences of older people.

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[1] National Adult Palliative Care Policy, Department of Health, 2024

[2] The 2015 Quality of Death Index, The Economist Intelligence Unit, 2015

[3] Vital Statistics Yearly Summary, Central Statistics Office, 2024,

[4] National End of Life Survey, 2024

[5] Survey of Bereaved Relatives: VOICES MaJam, 2017

[6] National End of Life Survey, 2024

About this report

This Telling It Like It Is report draws on findings from the National End of Life Survey, as well as the wider evidence-base on older people's experiences at end of life, to describe critical areas of importance to older people, and their families, facing death and bereavement.

All quotes used in this report come from respondents to the National End of Life Survey. Details provided alongside each quote reference the relationship of the person who died to the bereaved relative providing the quote (for example, father, wife etc.), the age of the person who died, the setting they died in (home, nursing home, hospital or hospice), and the county where they died.

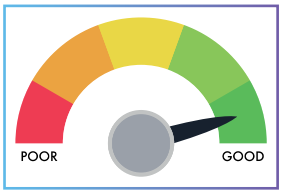
Where percentages are used, these have been rounded to the nearest full number.

The National End of Life Survey asked bereaved people about the end-of-life care provided to their loved ones at two distinct points in time – in the last three months of life and in the last two days of life. This report will focus on the experiences of people in the last three months of life.

New analysis of the National End of Life Survey data

Throughout the National End of Life Survey, respondents were asked to rate the care their loved ones received on a scale of 0-10 (with 0 indicating very poor care, and 10 indicating very good care).

For this report, further statistical analysis was carried out to understand which factors independently contribute to a higher or lower overall care rating on the 0-10 scales. This analysis allowed a measure of the impact of individual factors (for example: the experience of communication or having access to particular healthcare professionals) on the 0-10 score, while accounting for other participant characteristics which might also influence this score (e.g. where in the country the person lived).



This symbol is used throughout the report where findings relate to this further predictive analysis.

Profile of the people who died

Overall, there was good national representation in the survey, and a relatively even gender distribution of those who died 52% (n=2,266) were female and 48% (n=2,085) were male.

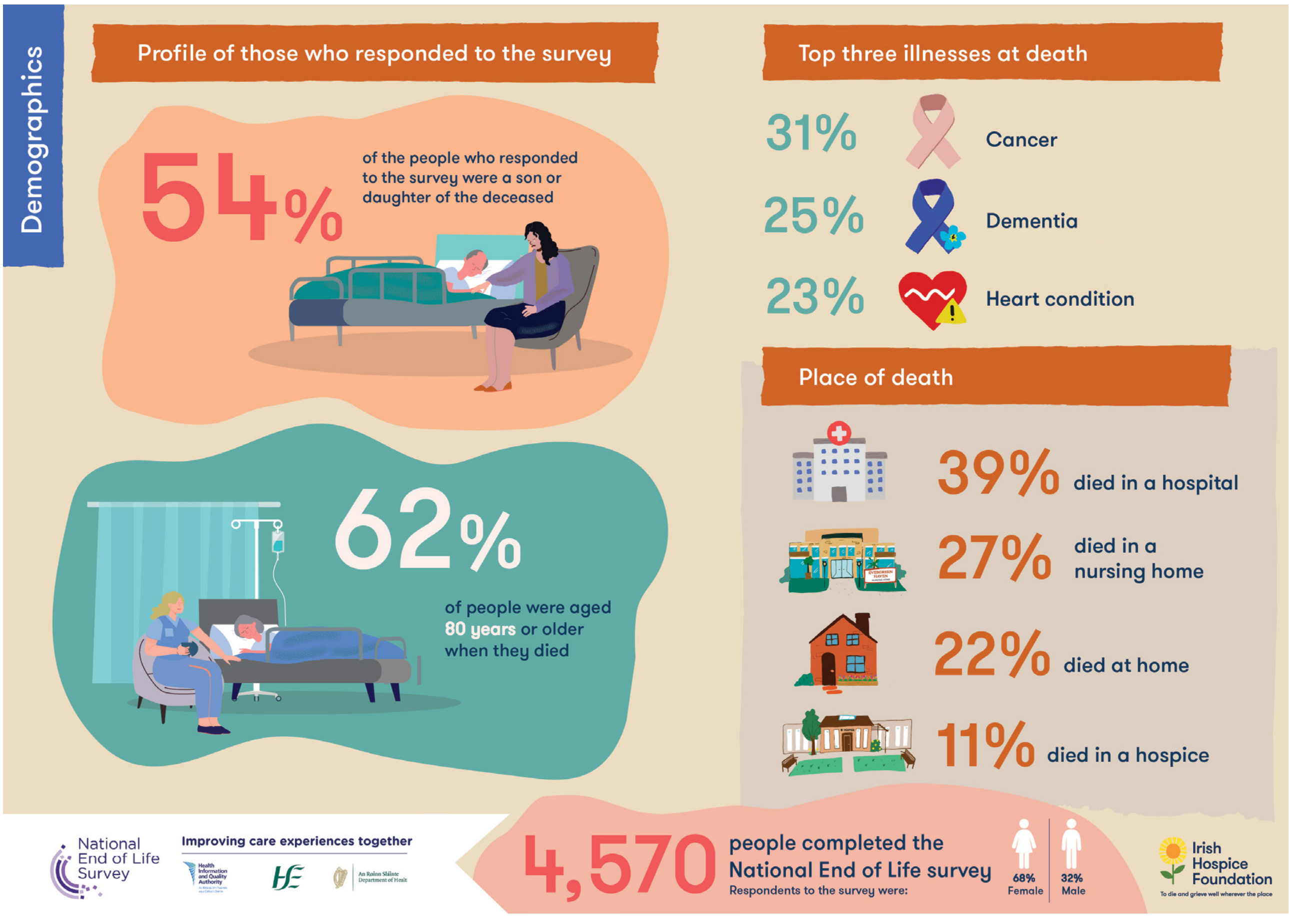


Figure 1. Summary of demographic characteristics of participants in the National End of Life Survey.

Most people included in the survey, were over 80 years of age when they died. Table 1 shows the ages of the people who died.

Table 1. Age profile of people who died

Age group	Number of participants	Percentage (%)
18-59 years	253	6%
60-69 years	441	10%
70-79 years	951	22%
80-89 years	1,634	38%
90+ years	1,026	24%

The three most commonly reported illnesses at death were cancer, dementia and heart conditions *(Figure 1)*. Other illnesses included lung conditions, influenza or pneumonia and a large number of survey participants identified the illness the person had at death as 'something else' (n=864).

Profile of bereaved family and friends

Of the family and friends who completed the survey, 68% (n=2,981) were female, 32% (n=1,390) were male, and 0.2% (n=10) responded 'Other' or 'Prefer not to say' for their gender.

The majority of respondents were either a daughter or son of the person who died *(Table 2)*.

Table 2. Relationship of person who completed the survey to the person who died

Relationship to the person who died	% of survey participants
Son/daughter	54%
Husband/wife/civil partner/partner	24%
Other relative	9%
Brother/sister	8%
Parent	2%
Friend/neighbour	1%
Other	3%

Key themes in the results

For this report, further analysis was carried out on the results from the National End of Life Survey data, through the lens of older peoples' experiences. The following four key themes were identified:

1. Communication at End of Life

2. Access to Key People and Timely Help

3. Care in the Community

4. Bereavement Support

1. Communication at End of Life

The majority of **older people in the survey were not told that they were likely to die.** There was a higher proportion of individuals not informed in the older age groups *(Figure 2)*, with fewer than one in five individuals over 90 years of age being told they were likely to die.

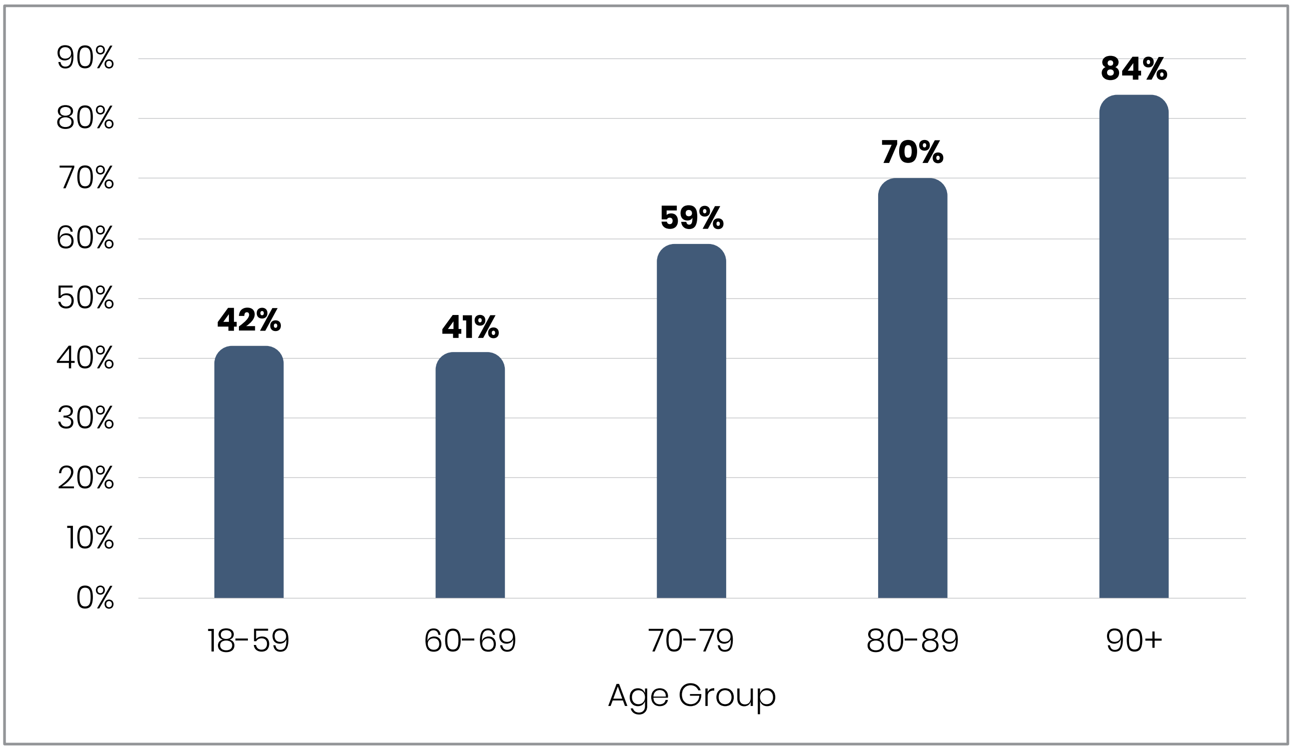


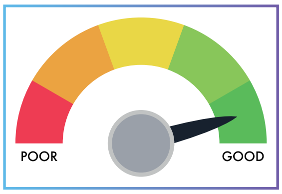
Figure 2. Percentage of people who were not told by a healthcare professional that they were likely to die, by age (n=2,991)

Family and friends also wanted to be kept informed about what to expect when their loved one was dying. For 29% of respondents, neither they nor their loved one who was dying, were told what to expect.

> The doctors' communication with family was poor. They did not advise us that my Dad was so ill and was at end of life and I feel they knew his prognosis and did not communicate this to us until the very end, which led to our family being in shock and not being able to say everything we wanted to say to our dad before he died.

Father, died aged 70-79, in Hospital, County Dublin

Of the 29% who were not told by healthcare professionals about **what they could expect** when their loved one was dying, 72% said that a discussion about this **would have been helpful.**



When healthcare staff took the time to **clearly explain someone's condition and care plans**, this led to significantly higher overall satisfaction ratings for the care and support received by relatives.

> The communication with medical staff was not what I would have expected there were mixed messages about my mother's prognosis. If I had truly understood how unwell she was I would have taken off more time from work to be with her.

Mother, died aged 70-79, in Hospital, County Dublin

There was also a clear **difference in whether individuals were told they were likely to die, according to which conditions they had.** For example, the vast majority (90%) of individuals with dementia were not told by a healthcare professional that they were likely to die, compared to around a third of individuals with cancer (35%) who were not told about this *(Figure 3)*.

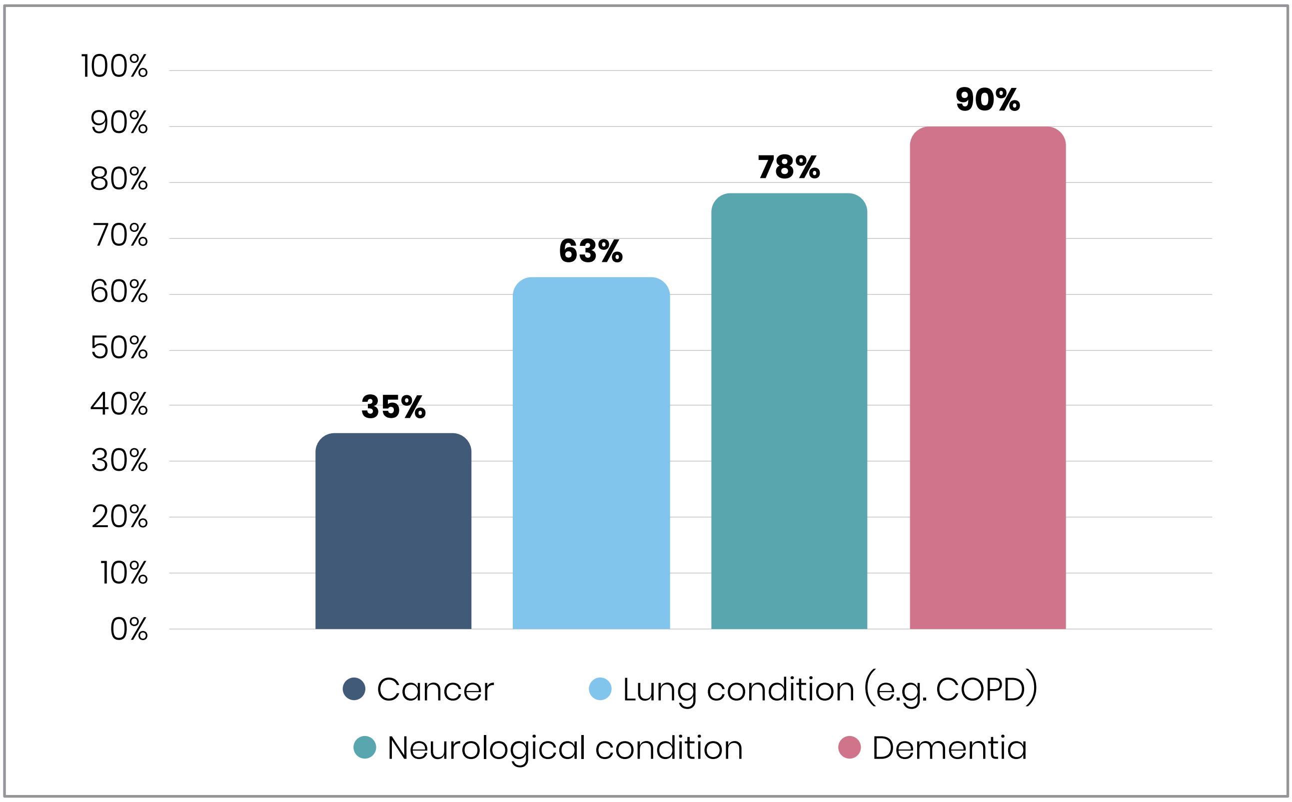


Figure 3. Proportion of people who were not told by a healthcare professional that they were likely to die, according to illness at death.

The proportion of respondents who stated that their relative or friend was **involved in the decisions about their care varied according to the setting** they were being cared for in. About half of those (52%) who died in hospital stated that their loved one was involved as much as they would have liked to be, compared to nearly 70% of people whose loved one died in a hospice setting *(Figure 4)*.

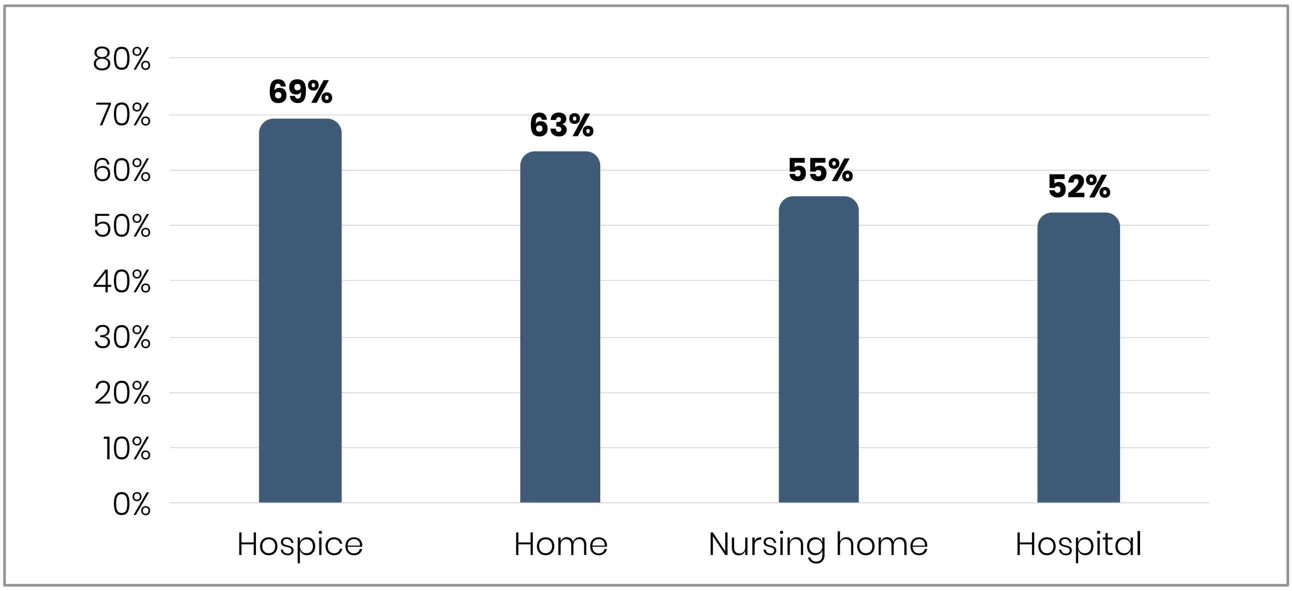


*Figure 4. Percentage of people who stated they were "**definitely**" involved as much as they wanted to be in decisions about their care, according to setting of death (n=3,582).*

I wonder if more conversations should happen in nursing homes and with older people services about decisions when medical treatment should/or should not be made. I was very clear on my father's wish regarding DNR but never had thought I would ever be deciding whether or not he should go to hospital for treatment...it would have helped to have thought about this and prepared in some way for what happened.

Father, died aged 90+, in a Nursing Home, County Wicklow

Family were asked to decide on potential resuscitation. The patient wasn't asked though he was fully competent. It should have been his decision once he was made aware of potential complications.

Father, died aged 80-89, in Hospital, County Louth

My father received excellent care during his final days... Every member of staff treated my father with utmost kindness and respect. He was involved in every aspect of his care and the final decision to withdraw active treatment was his.

Father, died aged 80-89, in Hospital, County Cork

The homecare and hospice care was fantastic. They treated my mam as the decision maker, they listened to what she wanted and they let us be her family.

Mother, died aged 80-89, in a Hospice, County Limerick

Why does communication matter at end of life?

Good communication is at the heart of end-of-life care. The Ombudsman report "A Good Death" into the complaints received to their office about end-of-life care notes that *"poor communication is a feature of almost every complaint sent to the Ombudsman."*[7] It also notes the reasons for this poor communication including insensitive tones, rushed messages, misunderstanding about what was said and what was heard and the medical terminology used.

The HSE National Healthcare Charter[8] pledges: *"We will involve you and your family and carers in decision making about your healthcare and will take account of your preferences and values."*

Aligned to this, the Quality Standards for End-of-Life Care in Hospitals[9] state that there should be *"timely, clear and sensitive communication with each person, as appropriate, in respect of a diagnosis that s/he may be approaching or at end of life."*

Internationally, a meta-analysis of 13 systematic reviews on the conditions for a good death (Zaman et. al, 2021)[10], found that the second most commonly cited condition for a death to be considered as good was *"effective communication and relationship with health-care providers."*

Similar to the findings in the National End of Life Survey, other research evidence also shows that whilst the majority of older adults would like the opportunity to discuss end-of-life care with a healthcare professional, only a minority are provided with the opportunity to have these conversations[11].

All older people living with a life limiting condition, including dementia, must be told of their illness and offered the opportunity to be involved in their end-of-life decision making and care. It is integral that a person who may have dementia is given a comprehensive diagnosis and tailored information, as set out in the Model of Care for Dementia in Ireland[12].

Advance care planning is another important aspect of communication at end of life. It can provide people with the opportunity to express their preferences at end of life and allows for these discussions to take place when care decisions are not imminent, or a crisis is occurring.

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[7] A Good Death, Office of the Ombudsman, 2014

[8] National Healthcare Charter, HSE, 2012

[9] Quality Standards for End-of-Life Care in Hospitals, Irish Hospice Foundation, 2010

[10] What would it take to die well? A systematic review of systematic reviews on the conditions for a good death, Zaman et al., Lancet Healthy Longevity, 2021

[11] Do the elderly have a voice? Advance care planning discussions with frail and older individuals: a systematic literature review and narrative synthesis, Sharp et al., British Journal of General Practice, 2013

[12] Model of Care for Dementia in Ireland, National Dementia Services, HSE, 2023.

The Assisted Decision-Making (Capacity) Act 2015 (ADMA)[13] establishes a legal framework in Ireland for supporting individuals who may need assistance in making decisions about their personal welfare, property, and affairs. The ADMA also enshrines people's right to make a legal Advance Healthcare Directive (AHD).

While advance care planning considers all end-of-life care needs an AHD is a legally binding document that allows a person to record their wishes about healthcare and medical treatment decisions in case they are unable to make these decisions at some time in the future.

Importantly an AHD should be registered in a place that can be easily accessed by all those involved in making decisions about a person's care. Currently, you do not have to notify the Decision Support Service[14] (DSS) that an AHD has been made. There is no centralised repository for healthcare professionals to reference or determine if an AHD has been made.

SUMMARY

EVERY OLDER PERSON HAS A RIGHT TO BE KEPT FULLY INFORMED WHEN APPROACHING END OF LIFE AND GIVEN THE OPPORTUNITY TO BE INVOLVED, AS MUCH AS THEY WOULD LIKE TO BE, IN HEALTHCARE DECISIONS AFFECTING THEM.

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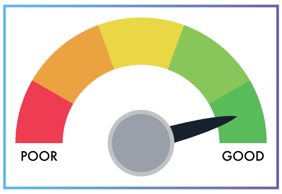
[13] Assisted Decision-Making (Capacity) Act 2015

[14] Decision Support Service website

2. Access to Key People and Timely Help

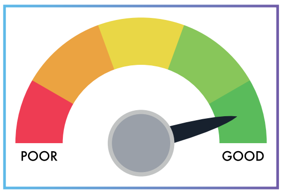


Analysis showed that having **confidence and trust in healthcare staff** was the number one factor that influenced overall ratings of quality of end-of-life care received across home, nursing home and hospital settings.

> *The last months of Dad's life were spent in (an) older persons residential facility. It was excellent and we are happy he got in there. We always had trust and confidence in the staff in how they looked after Dad, right to the end. We left after each visit with confidence that he was being well cared for. We had done everything to keep him at home for as long as possible.*
>
> Father, died aged 80-89, in a Nursing Home, County Tipperary

> Since my Mam has passed it continues to be very difficult for us, she is dearly missed. One comfort I do have at this very difficult time is knowing the standard of care provided to my Mam from all the staff in (hospital) was exceptional, they were so supportive and helpful to her, in particular during her time of palliative care...In the last week of my Mam's life I spent 24x7 by her bedside and nothing was too much trouble for the staff. Knowing that my Mam was not alone in the last stage of her life is a source of incredible comfort now and will be for many years to come.

Mother, died aged 60-69, in Hospital, County Dublin



Receiving help from healthcare staff as soon as it was needed was one of the most influential factors that impacted on the rating of overall quality of care across home, nursing home and hospital settings, as reported by participants.

> Staff dealt with my mother and us in a sympathetic way at all times and responded quickly to any requests. All necessary equipment was supplied in a timely way.

Mother, died aged 90+, at Home

> Staff were lovely but very overworked - at times Mam was waiting for help (we started coming in at lunch time to help her eat as she couldn't manage herself).

Mother, died aged 80-89, in Hospital, County Dublin

> *There was a delay in the doctor coming to see our mother which was stressful for the family. It was difficult on occasion to reach the palliative care nurse for pain relief for our mother. One day we had to wait all day for the nurse when our mother was particularly ill and holding nothing down.*

Mother, died aged 70-79, at Home, County Donegal

Those who received care at home were asked about their access to various supports. The lowest-scoring question related to the **availability of a GP to visit out of hours**, with 39% of respondents saying that the GP was not available to visit if their loved one required a home visit for help with urgent problems outside of normal working hours.

> During the week Monday to Friday 9am-5pm when my wife required help from the medical profession she was immediately looked after. At the weekend when she became ill she had to be admitted to hospital via A&E casualty dept, a very sick lady, which was a very stressful experience.

Wife, died aged 60-69, in a Hospice, County Dublin

There was notable **geographical variation in the availability of GPs to visit people outside of normal working hours** with urgent needs at end of life, as reported by survey participants *(Figure 5)*. Donegal was the best served county, with just 22% of people noting that a GP was not available to them out of hours, whereas in Westmeath, almost two thirds of people (64%) responded that a GP was not available to them out of hours.

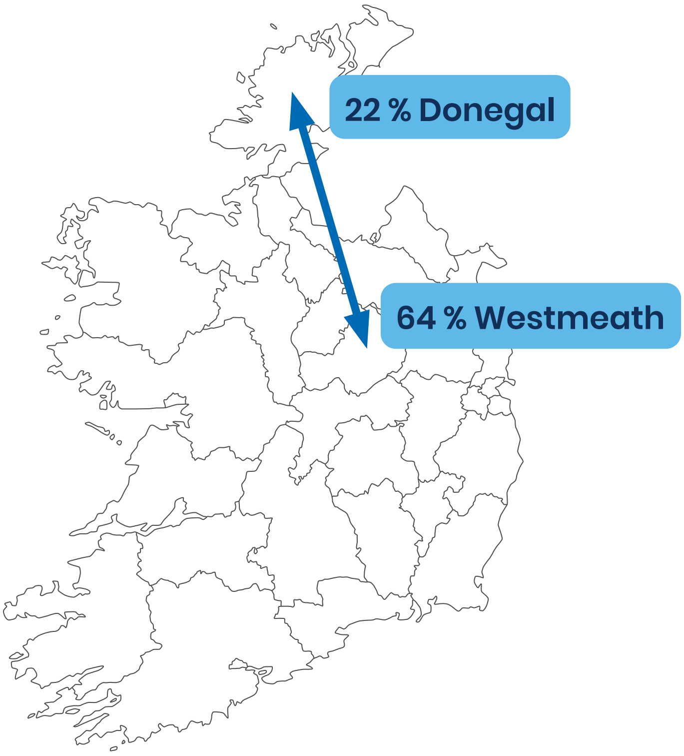


Figure 5. Geographical variation in the availability of a GP to help with urgent problems outside of normal working hours (out of hours). Values show the percentage of people reporting a GP was not available (n=1,439).

> There was absolutely no support to assist me in dealing with this during the hours of 6pm and 8am which was when support was absolutely and urgently needed for people who are remaining at home as per their wish…When I did receive the night time nursing support it was excellent and I could not emphasise that enough and is the one thing that I will always carry with me, with great gratitude for the care, support, professionalism and kindness of this person…

Husband, died aged 70-79, at Home, County Dublin

One in four people (24%) reported there was **not good coordination between the different services and staff** that cared for their loved one. Levels of satisfaction with co-ordination of care varied depending on the setting where the person died *(Figure 6)*.

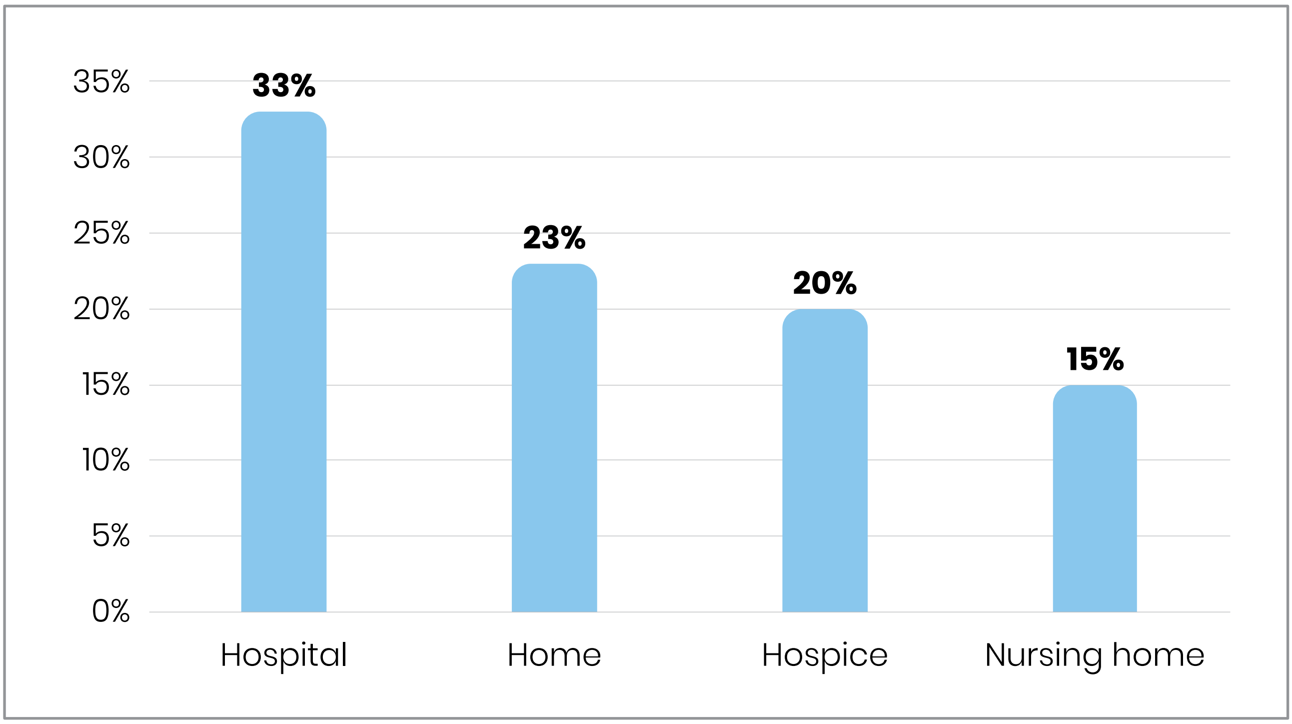


Figure 6. Percentage of respondents who felt there was poor coordination between the different services, according to setting (n=3,732).

> Co-ordination of various medical teams and communications with family - this seemed to be entirely lacking and most contact with doctors was because you bump into them as opposed to a formal way of getting information.

Mother, died aged 80-89, in Hospital, Leinster

> *My husband has three specialists involved in determining his condition… They badly needed to co-ordinate their treatment and care as I received contradictory information…. I had to go to hospital and try to find nurses to find out exactly what my husband's condition was and what if any treatment plan was being implemented. Hospitals need a system to keep family members informed instead of us trying to find out this information in bits and pieces. Remember a patient is more than a body part!*
>
> Husband, died aged 70-79, in Hospital, Munster

The survey showed that many **older people moved between care settings towards the end of life**, with more than half of all people spending at least some time in hospital within the last three months of life. While this survey does not allow for tracking of individual journeys through different settings, it is important that further research is conducted to understand what factors may make it more likely for older people to experience multiple settings of care at end of life and, where appropriate, the factors that may facilitate greater continuity of care, in line with the individual's wishes.

Why does access to key people and timely help matter at end of life?

Sláintecare is Ireland's health reform programme, focused on ensuring that healthcare services are timely, responsive, and patient-centred. Its guiding principles stress a patient-centred approach, with timely care available free at the point of delivery.[15]

Aligned to this, a key objective of the National Positive Ageing Strategy is to *"Promote the development and delivery of a continuum of high quality care services and supports that are responsive to the changing needs and preferences of people as they age and at end of life"*.[16] **Published more than 10 years ago, the Strategy has not had the investment or resourcing needed to deliver on its ambitions.**

People at end of life must have access to a reliable, trained and supportive healthcare team who work in close co-operation with each other. This often means access to responsive supports when needed, such as home carers that offer a family respite or 24-7 access to timely information, prescriptions or out-of-hours care. [17]

It is essential that the core primary care team (e.g. GPs and community nurses) have an understanding of their responsibilities when caring for a dying person in the community. Currently these types of services are not uniformly available and out-of-hours periods are particularly problematic. There is a need for these to be expanded upon to deliver people the right care, at the right time and in the right place, as is set out in Sláintecare.

A study by Irish Hospice Foundation into the experiences of people dying at home identified that poor access to care was a key barrier for them. Participants noted the gaps in continuous care, such as a lack of 24-hour support and weekend support exacerbated the pressures, anxieties, and strain that family/carers often feel.[18]

SUMMARY

THE AVAILABILITY OF KEY HEALTHCARE STAFF TO PROVIDE SUPPORT QUICKLY IN TIMES OF URGENT NEED IS ONE OF THE MOST INFLUENTIAL FACTORS DETERMINING OLDER PEOPLE'S OVERALL END-OF-LIFE EXPERIENCE. ACCESS TO THESE STAFF SHOULD BE UNIVERSAL, FOR EVERYONE WHO NEEDS IT.

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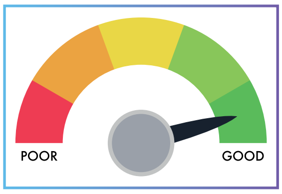
[15] Sláintecare, Department of Health, 2017

[16] National Positive Ageing Strategy, Department of Health, 2013

[17] Deaths at home during the Covid-19 pandemic and implications for patients and services, Nuffield Trust, 2023

[18] Dying Well at Home Report, Irish Hospice Foundation, 2023

3. Care in the Community



Having **access to key healthcare professionals**, for those being cared for at home, had a significant impact on people’s reported experiences.

The top five healthcare professionals that had the greatest positive impact on overall ratings of care for people at home, in order, were:

1) Community palliative care nurse
2) Occupational therapist
3) Public health nurse
4) Physiotherapist
5) Social worker

The proportion of people who had access to at least one of these five healthcare professionals, while they were being cared for at home, varied according to the individual’s age. **A lower proportion of people in the older age groups had access to one or more of these healthcare professionals** (*Figure 7*).

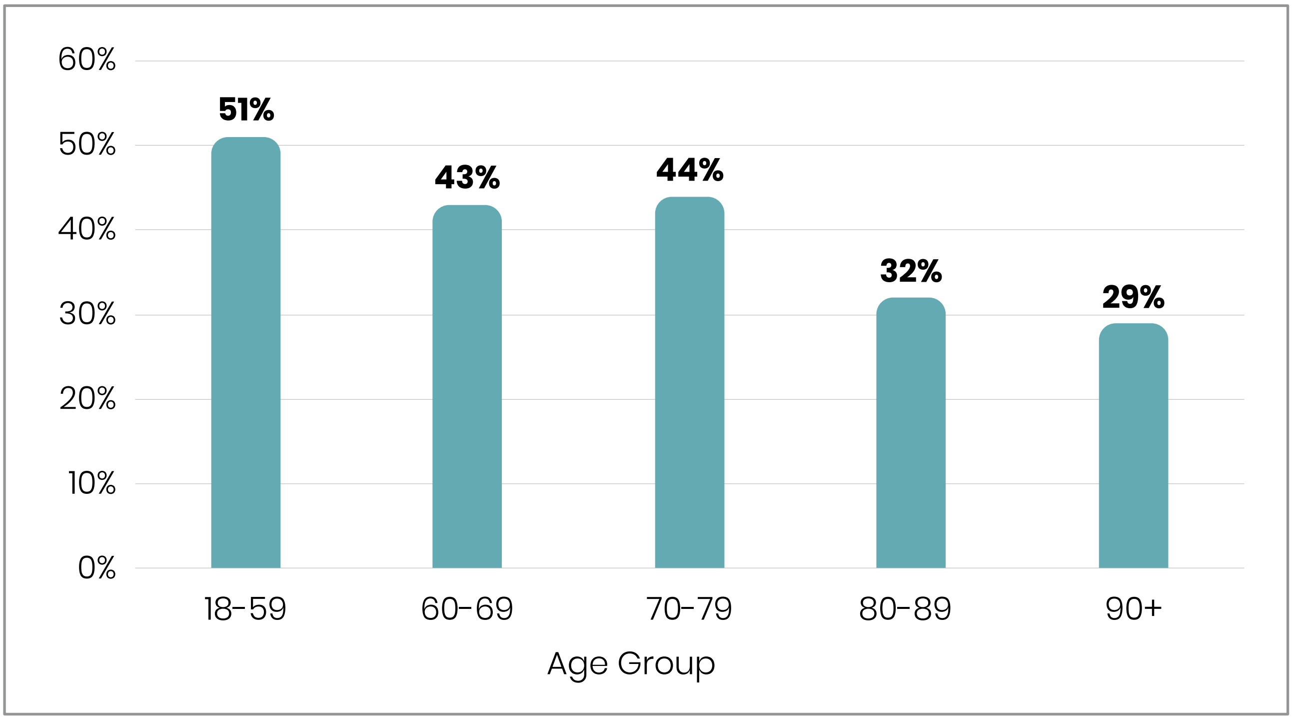


Figure 7. Percentage of people at home who had access to at least one of the five healthcare professionals in their last three months of life, by age (n=2,539).

The proportion of people who were cared for at home and had **access to at least one of these five healthcare professionals also varied according to the geographical location** of where the person lived. The greatest level of access to these services was reported in Cavan, with 57% of people at home having access to at least one of these five healthcare professionals. However, in Carlow, only 22% of people had access to at least one of these five healthcare professionals *(Figure 8)*. The mean average level of access across all counties was 38%.

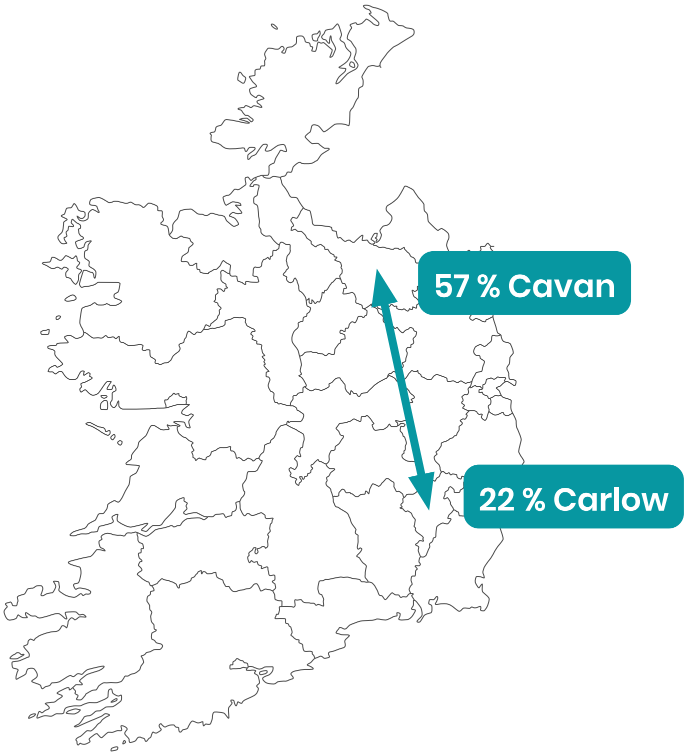


Figure 8. Geographical variation in access to key healthcare professionals in the community (n=2,595).

For participants whose loved one **died at home**, 99% responded that, on balance, they feel they **"died in the right place"**. It is not always medically, or practically, possible for someone to die at home and the best interests of the individual person must always be put first. However more can be done to empower older people to have their personal choice and wishes around place of death respected.

> The very best part was that we as a family were able to take care of our mother in her own home in which she had lived for 73 years. She was almost 97. Her dearest wish was to die at home even though her care was very complex… it was a wonderful accomplishment to complete the journey.

Mother, died aged 90+, at Home, County Mayo

> *My Dad's decision to end all treatment and go home to die was supported by the healthcare team, the palliative care team were sensitive to me but they helped me to understand Dad's decision…*
>
> *I never would have thought I could have helped nurse my Dad in his end days. I am so grateful for the palliative care services, for the public health nurses, for the daffodil nurses who helped make Dad's last week as comfortable as it could be. He died in his own bed, in a house he built fifty years ago, with Lyric FM playing and the windows open. Dad received exceptional care at a very difficult time.*
>
> Father, died aged 70-79, at Home, County Offaly

> She was single and lived alone. I took her to my home for nine months and looked after her until her death. A single person could easily get neglected in the system without an advocate for them.

Sister, died aged 80-89, at Home, County Kerry

Why does care in the community matter at end of life?

The Sláintecare vision of *"a universal health system accessible to all on the basis of need"* clearly champions integrated care. Prior to Sláintecare the need to shift towards service delivery in the community was well recognised in policy but development of acute and inpatient services continues to garner a large proportion of both resourcing and strategic planning focus.

Research, both in Ireland and internationally, consistently notes dying at home as the preferred place of death for the majority of people (approximately 74%).[19] Despite this, hospitals continue to be the place where the greatest proportion of people will die.[20] The reasons for this are wide and complex. As a person approaches end of life, preferences can change as health deteriorates, and needs grow, the realities of providing end-of-life care in the home can be challenging due to the limited resources of healthcare workers and the need for huge levels of investment in time and energy by family and carers.

The delivery of community and home care supports is facing ever increasing challenges. Although funding and hours of support provided through the home support scheme have increased in recent years, a statutory scheme has not yet been introduced. There is limited capacity within the existing overstretched primary care network. Waiting lists continue to grow for accessing community supports and there is an alarming number of people who have been assessed but remain without adequate, or indeed any, home supports.

According to analysis from the National Doctors Training and Planning, an additional 1,660 GPs will be needed by 2028 to meet demand[21]. To meet this demand, there is a need to increase the number of GP practice teams across the state, at an estimated cost of an additional €100m annually from 2026[22].

The Integrated Care Programme for Older Persons (ICPOP), which was established in 2016, aims to implement integrated services and care pathways for older adults with complex health and social care needs[23]. The ICPOP teams are multi-disciplinary and include physiotherapists, occupational therapists, social workers, pharmacists, speech and language therapists, geriatricians, and case managers. The multi-disciplinary approach means that those with complex needs are responded to quickly in order to keep them well at home and minimise hospital admissions.

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[19] Irish attitudes to death, dying and bereavement 2004-2014, J Weafer & Irish Hospice Foundation, 2014

[20] Dying and Death in Ireland: What Do We Routinely Measure, How Can We Improve?, S Matthews et al., 2021

[21] Demand for Medical Consultants and Specialists to 2028 and The Training Pipeline to Meet Demand, National Doctors Training & Planning, 2020

[22] Policy Options to Support Ageing Well at Home, Social Justice Ireland, 2026

[23] A practical guide to the local implementation of Integrated Care Programmes for Older Persons, HSE, 2017

Previous research has highlighted the enormous contributions that family and friends also make to supporting home-based care. A report from The Irish Longitudinal Study on Ageing (TILDA)[24] found that, in the last year of life, unpaid help from friend and family networks accounted for 42% of the total cost of care received. The report further highlighted that the levels of care received are not equitable across the older population. People who lived alone received less help with everyday activities, but this shortfall was not matched by increased use of formal healthcare services. As a result, older people living alone received less care on average.

SUMMARY

MANY OLDER PEOPLE WOULD LIKE TO BE CARED FOR AT HOME, WHEN POSSIBLE. KEY SUPPORTS AND ACCESS TO HEALTHCARE PROFESSIONALS THAT MAKE A SIGNIFICANT DIFFERENCE TO THEIR OVERALL EXPERIENCE OF CARE SHOULD BE MADE AVAILABLE, IN LINE WITH AN INDIVIDUAL'S WISHES.

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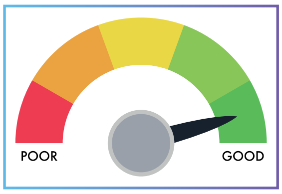
[24] End-of-life experience for older adults in Ireland: results from the Irish longitudinal study on ageing (TILDA). May et al., BMC Health Services Research, 2021

4. Bereavement Support



Respondents who **did <u>not</u> receive practical information** on what to do after their loved one's death, rated the quality of the care they received significantly lower.

The likelihood that the person was provided with this information varied across settings, with only half of those whose loved ones died in hospital reporting that they were 'definitely' given this information *(Figure 9)*.

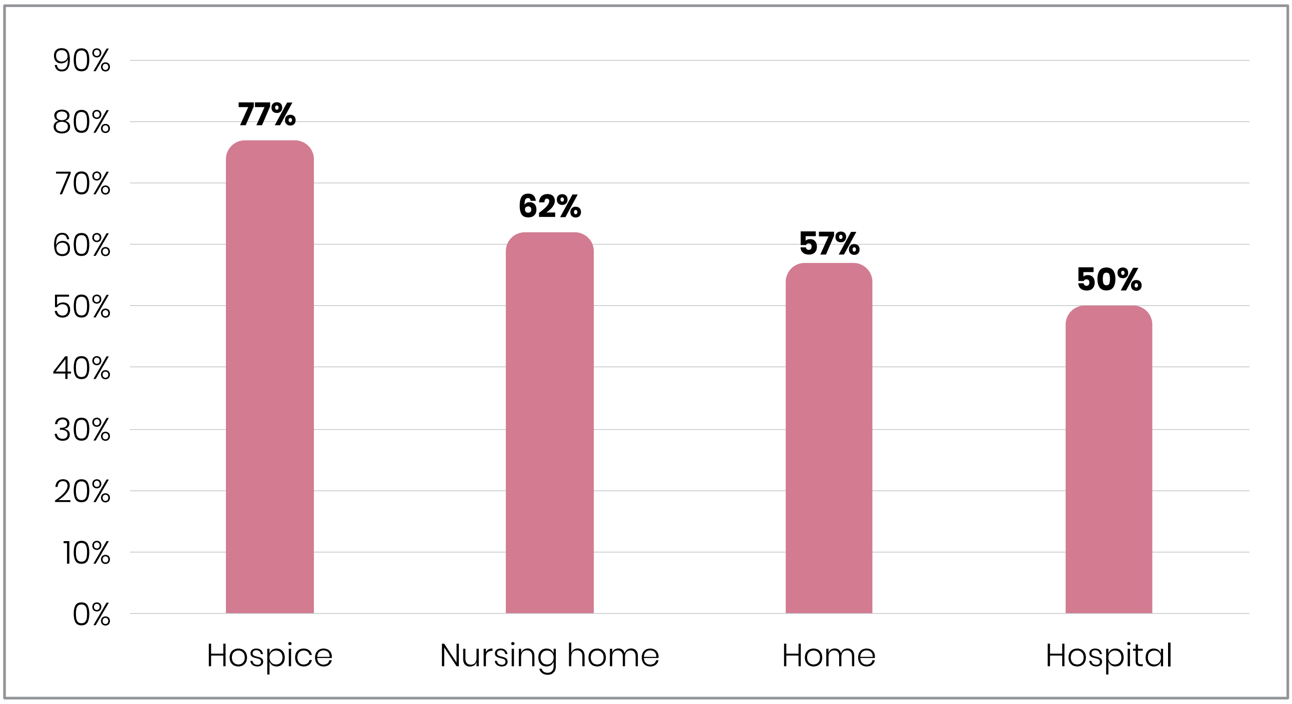


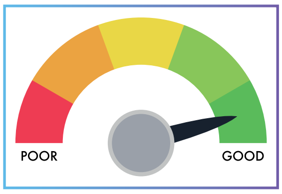
Figure 9. Proportion of bereaved participants who responded 'yes, definitely' when asked if they were provided with practical information from healthcare staff following their loved one's death, by setting (n=3,702).

> The staff in the nursing home were very supportive and took the time to help us with all the decisions, my mother's death was expected but happened quickly in the end which did not give us much time and we had to move quickly onto all the practical arrangements.

Mother, died aged 80-89, in a Nursing Home, County Kilkenny

> The hardest part is having gone from 100% support in the final 10 days to absolutely nothing after. Perhaps someone to check in? I am lucky I had family support, but for those that don't it must be very hard. To know: You need to register the death, you need to contact social welfare. You need to contact post office. You need to notify banks etc. etc. Some kind of fact sheet/check list for people would be a massive help and wouldn't be insensitive."

Mother, died aged 80-89, at Home, County Kerry



Relatives and friends who reported that **healthcare staff engaged with them in a sensitive manner following the death** of a loved one, reported higher ratings in the quality of overall care they received.

> *We were given ample notice when my relative's condition deteriorated and we had the opportunity to allow all family members to say their own farewells. The staff were kind and sensitive in how they dealt with our relative and they made the visiting family members very welcome and always provided us with a medical and emotional update.*

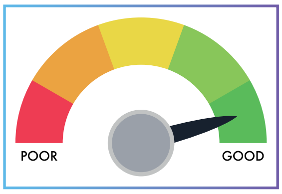
Father, died aged 80-89, in a Nursing Home, County Clare

> *From the moment the palliative care (home and hospice) teams started taking care of mum, they were 100% respectful, sensitive, professional, warm, generous with their time, emotionally and medically supportive. They were wonderful, so sincere in all their care, chats and actions. Thank you very much.*

Mother, died aged 70-79, in a Hospice, County Dublin

> Mum lived in the nursing home for 10 years. Two days after Mum died I returned to go through her belongings (I had brought bags/suitcase with me) to take home or dispose of. I was greeted by all her belongings being placed in black garbage bags. I appreciate a person was waiting for her bed but found this very upsetting. I would not have had a problem if they had placed her belongings in a box in storage room for me to go through. But black garbage bags after only two days! Very disrespectful and insensitive!

Mother, died aged 90+, in a Nursing Home, County Dublin



Access to a bereavement counsellor following a death also significantly improved ratings of overall care received by relatives and friends. Just 4% of respondents reported having received support from a bereavement counsellor.

> *I think families providing end-of-life care at home should receive support from a grief or palliative care counsellor at the onset of homecare and if necessary throughout the process as it can be a very emotive time and place strain on relationships.*

Mother, died aged 80-89, at Home, County Clare

Whilst not every bereaved person will need counselling, the relatively low uptake among the survey respondents may suggest a lack of awareness of what services are available to them. Equally it may suggest that access to these services was not available to them.

Why does bereavement support matter at end of life?

There were 35,477 deaths registered in 2022. For each death in Ireland up to 10 people are impacted, this includes adults and children[25]. This means that over 350,000 people are grieving the death of a loved one each year.

Yet despite the large numbers impacted, and the commonality of the experience among older people, bereavement remains relatively absent from formal policies in Ireland. There is only one brief mention of this issue in the National Positive Ageing Strategy.[26] It does not feature as an issue in overarching health strategies and when it is referenced, it is in the context of palliative care, mental health and suicide.

Bereavement care begins at the point of diagnosis and carries on through care at the time of death and as a follow-up with access to appropriate bereavement services. The National Adult Palliative Care Policy[27] notes the importance of providing bereavement support to help people cope with their family member's illness and their own experience of grief, loss, and bereavement.

Most older people will journey with someone who is dying at some point in their lives. A public health approach identifies their bereavement needs and maps out the appropriate informal, community, organised and professional responses which are needed. The Adult Bereavement Care Pyramid[28] notes that all bereaved people have needs; those needs include the need for compassion, for information and for the support of those around them. Others will require more support from their communities and peer support groups. For a small but significant proportion (nearly 10%),[29] their grief is extremely debilitating and will require more specialised support.

SUMMARY

ALL RELATIVES AND FRIENDS DESERVE TO BE KEPT WELL INFORMED AND COMMUNICATED WITH IN A SENSITIVE WAY AS THEIR LOVED ONE APPROACHES END OF LIFE. EVERYONE SHOULD BE PROVIDED WITH PRACTICAL INFORMATION ON WHAT TO DO FOLLOWING THE DEATH AND TO BE OFFERED BEREAVEMENT SUPPORT AND COUNSELLING, SHOULD THEY WANT IT.

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[25] Tracking the reach of COVID-19 kin loss with a bereavement multiplier applied to the USA, PNAS, 2020

[26] National Positive Ageing Strategy, Department of Health, 2013

[27] National Adult Palliative Care Policy, Department of Health, 2024,

[28] Adult Bereavement Care Pyramid: A National Framework, Irish Hospice Foundation, 2021

[29] Prevalence of prolonged grief disorder in adult bereavement: A systematic review and meta-analysis, Journal of Affective Disorders, 2017

Recommendations

Oversight & Accountability

Establish an Independent Commissioner for Ageing and Older People
Underpinning all of the following recommendations to improve the end-of-life experience for older people is the Alliance of Age Sector NGO's call for the establishment of an Independent Commissioner for Ageing and Older People.

The Commissioner would be directly accountable to the Oireachtas, with a mandate to promote and protect the interests and well-being of older people. This would mean that issues related to older people and ageing are kept to the fore of policy and decision-making to enable enhanced investment and accountability in the policies and services that support people to live and die well.

The establishment of an Independent Commissioner for Ageing and Older People would ensure:

- Older people are treated as equal partners in their own care.
- Oversight of the implementation of the recommendations outlined below to ensure fairness, swiftness, and accountability.
- Initiatives to enhance age-appropriate communication and delivery of services that are resourced and implemented.

The Alliance of Age Sector NGO's are calling for 11 recommended actions to improve the end-of-life experience for older people. The recommendations presented are based on a range of evidence: the findings from the National End of Life Survey, the collective experience of the eight member organisations in their work with older people, and the recommendations noted in our previous Telling It Like It Is series.

Training

1) **Ensure all those interacting with older people are provided with the training and resources to engage in honest conversations.**

   Targeted training should challenge assumptions that older people are not capable of or interested in participating in end-of-life discussions.

   - People need time when a person is at end of life. Time to be listened to, time to ask questions, time to be with the person and staff must ensure that people have an appropriate level of understanding of what is happening.

- Staff need to be resourced, supported and enabled to offer people this valuable time.
- Healthcare staff must know how to use everyday language, avoid medical jargon, and take time to ensure that people have understood what they have been told.
- If bad news has been given, healthcare staff should be enabled to have the time to check back with people in subsequent days to see if there are follow-up questions.

2) **Facilitate bereavement support to be offered proactively with particular attention paid to older bereaved people, who are at heightened risk of social isolation.**

- Health and social care professionals, across all care settings, should be provided with the training, time, and tools to enable them to signpost quickly and appropriately to support services that can provide practical information to people on what to do following a death.
- A cross-departmental, public health approach to bereavement should be adopted which identifies people's needs and maps out the appropriate informal, community, organised and professional responses which are needed.
- Communities should be empowered to provide responsive bereavement supports to older people, particularly those that are at risk of social isolation.
- As per the National Adult Palliative Care Policy, bereavement support should be considered an essential extension in the delivery of palliative care.
- All organisations, who have supported an older person who has died, should consider how they continue to support bereaved loved ones following the person's death.
- Investment is needed to enable health and social care professionals have access to bereavement support that acknowledges they themselves will have ongoing personal and professional grief to deal with in their workplace.

Support

3) **Guarantee access to out-of-hours GP and community nursing services for all older people, regardless of geography, finances, care setting or diagnosis.**

- As noted in the Programme for Government, additional support is needed for GP practices in rural areas and areas of increased need.

4) **Increase the number of GP practice teams in primary care services.**

There is a national shortage of GPs, resulting in longer waiting times for patients. Increased capacity will strengthen the delivery of community-based health services, ensuring timely access to care, reducing over-reliance on hospital services, and facilitating greater coordination of care.

5) **Commit to promptly achieving the strategic action outlined in the National Adult Palliative Care Policy – "*Enable people to stay in their preferred place of care as far as possible*".**
   - Urgently address key workforce shortfalls to enable all appropriate supports and necessary staffing to be put in place.
   - All older people being cared for at home should have equitable access to core community health professionals including palliative care nurses, occupational therapists, public health nurses, physiotherapists and social workers.

6) **Implement the Statutory Homecare Scheme which will enable people to stay in their own home for as long as possible, as per the Programme for Government.**

Awareness

7) **Promote greater awareness of information, resources and supports that involve older people in the decisions that impact on their health, wellbeing and recognises their will and preferences.**
   - Ongoing conversations around planning for future care decisions should be normalised as part of everyday interactions with health and social care professionals and not exclusively held within acute care settings (e.g. hospitals). Planning supports should be 'age-friendly' and tailored to the needs of the individual.
   - Initiatives that help broaden these conversations across society will help families to feel more prepared, involved and confident when the time comes to support an older person in making end-of-life care decisions.
   - Conversations and planning around potential future loss of capacity should be initiated/revisited at key times with older people e.g. at the time of a life-changing diagnosis.
   - Increase awareness and understanding of the Assisted Decision-Making (Capacity) Act 2015 (ADMA) which is the law that establishes a legal framework for supported decision-making in Ireland in important areas such as Enduring Power of Attorney and Advance Healthcare Directives (AHD).
   - The ADMA also enshrines people's right to make legal AHD. A Register of AHD is essential to ensure that citizens can be confident that their expressed wishes are accessible when needed and wherever the place. This is currently not available in Ireland. The Minister for Health has the power to make regulations to provide for this Register and should give serious consideration to doing so.

8) **Ensure free, accessible and age-friendly training and support opportunities are routinely made available to family carers.**
   - Training resources should focus on supporting loved ones to care for an older person who is approaching end of life, should incorporate elements of peer support, and should be age-friendly in content and design.

Research

9) **Prioritise research that directly involves the voice of older people at end of life in order to better understand their experiences.**

10) **Fund further research to understand the response needed in relation to coordination of services to ensure best-quality care is provided to those at end of life, particularly in the community.**

    - Further research is needed to explore the factors that can reduce unnecessary or avoidable hospital admissions and transfer between settings at end of life. Recognising that transfer to hospital can sometimes be in the best interest of the person.

11) **Repeat the National End of Life Survey**

    This will allow for the identification of important trends in older people's end-of-life experiences and the impact of quality improvement initiatives that have been implemented in response to the findings of the original survey.

Conclusion

The National End of Life Survey was the first time that, as a country, we had the opportunity to learn about bereaved family and friends' experiences at a national level of the care their loved one received in the last months and days of their life.

The Alliance undertook this deeper analysis of the findings from the National End of Life Survey to understand more specifically older people's experiences at end of life. The need for this further analysis is evidenced by the large majority of those aged over 80 who die in Ireland. In this Telling It Like It Is report the Alliance note a number of key themes and valuable insights from the national survey data that inform and influence our understanding of the older person's experience of end-of-life and bereavement care.

The respondents to the survey identified a desire for clear and consistent communication at end of life. A key finding is that people need support from healthcare professionals to navigate and understand the important conversations that take place when a person is nearing end of life. Families have a desire to know what to expect, and older people must be given an opportunity to be kept informed and an opportunity to be involved, as much as they would like, in healthcare decisions affecting them.

The survey found that confidence and trust in healthcare staff was the number one factor that influenced overall end-of-life care experiences, and this was across all settings.

Receiving support in a timely manner was another key factor for people. One of the biggest challenges people who were dying at home were faced with was the availability of a GP to visit out of hours and also the geographical variation in accessing a GP.

The survey asked about people's experiences of care in various settings. In many cases, people received care across more than one of these settings in the last months and days of their lives. The importance of close integration and coordination between these settings and the services that are provided, was noted as a key element contributing to positive experiences for people. Prioritising the factors that facilitate greater continuity of care, which are in line with a person's wishes, is an area that has the potential to significantly improve people's end-of-life care.

It is the express wish of many older people to be cared for and die at home. Access to the relevant healthcare professionals and key supports that play a role in enabling this to become a reality was a key feature of people's experiences at end of life. The findings suggest that the proportion of people who had access to these healthcare professionals, varied according to the individual's age and geographical location. Improving people's access to these healthcare professionals and supports must be a priority regardless of age, diagnosis or location.

Any focus on the experience of end-of-life care must also examine the impact on those who are left to grieve the death of their loved one. This report provides valuable information on the emotional impact of end of life on family and friends and their need for access to clear, understandable and timely information following a loved one's death. For some relatives and friends, they also identified a need for but difficulty accessing bereavement support and counselling, should they need it.

Dying, death and bereavement will affect us all at some point in our lives and as such the findings in this report inform so many facets of healthcare provision in Ireland. While there are many encouraging aspects regarding the care provided to older people at end of life, these findings must be used to give momentum to the recommendations noted by the Alliance. The recommendations highlight that dying, death and bereavement impact older people across a variety of aspects of life, not just in care settings. That is why an Independent Commissioner for Ageing and Older People would not only take account of the supports required to age well but also those supports that will be relevant to support people to die well.

This report provides valuable insights into the lived experience of the person who died and their families who loved and cared for them across the continuum of dying, death and bereavement. It is the responsibility of the Alliance to work as a collective to ensure we do all we can to learn from these experiences to improve the delivery of end-of-life and bereavement care for older people. This report provides us with information and recommendations that, as an Alliance, we will use to monitor and improve the delivery of end-of-life and bereavement care informed by older people's experiences.

Members of The Alliance of Age Sector NGOs

Active Retirement Ireland: Reach out to all older people to stop loneliness through friendship and support.
activeirl.ie

Age & Opportunity: Is the national organisation working to enhance wellbeing for older people through participation in sport and physical activity, arts and creative engagement, personal development, community collaboration and active citizenship.
ageandopportunity.ie

ALONE: Is a national organisation, whose aim is to transform ageing at home in Ireland. We support and empower older people to age happily and securely at home. We work with all older people, including those who are frail, lonely, homeless, living in poverty, or are facing other difficulties. We support them through these challenges by providing our services free of charge and working closely with everyone in the community.
alone.ie

COPE Galway: We understand, respect and respond to the needs of those who struggle with the challenges of homelessness and domestic abuse and we support older people towards healthy and active ageing.
copegalway.ie

Irish
Hospice
Foundation

Irish Hospice Foundation: Our mission is to work towards the best end-of-life and bereavement care for all.
hospicefoundation.ie

THE Alzheimer
SOCIETY OF IRELAND

The Alzheimer Society of Ireland: Our mission is to lead the growth of high-quality supports and services that meet the needs of people living with dementia and their families, carers and communities.
alzheimer.ie

Irish
Senior
Citizens
Parliament

The Irish Senior Citizens Parliament: Working to promote the voice of older people in policy development and decision-making.
seniors.ie

third age
Responding to the Opportunities
and Challenges of Ageing in Ireland

Third Age: We respond to the opportunities and challenges of ageing in Ireland by empowering older people, enabling them to live well, age better, stay connected, and support others in their community through our volunteer programmes.
thirdageireland.ie

Notes

Notes

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