

Dying Well At Home Focus Group Report

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**Irish
Hospice
Foundation**

To die and grieve well wherever the place



Table of Contents

Acknowledgement	5
Executive Summary	6
Introduction	13
Background	14
Methodology	16
What the Research Tells Us	19
Discussion	55
Participants' Insights and Suggestions	57
Recommendations	58
Conclusion	60
Appendices	62
Invitation to participants	
Briefing document	
Participant consent form	
Questions	
Participants insights and suggestions	
Supplementary tables	
Glossary of Terms	



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Through the learnings gained and outlined in this report, we wish to raise awareness about the ongoing issues raised and work with our colleagues and stakeholders in non-governmental organisations and in the health sector to bridge some of the gaps in the provision of end-of-life care within the community. We will use the rich learnings gained to develop a programme that provides information, education and supports for people who wish to die home and for those who provide their care.

Executive Summary

Introduction

Research, both in Ireland and internationally, consistently demonstrates that home is the preferred place of death for the majority of people. Despite this, the realities of providing end-of-life care in the home can be challenging due to the limited resources of healthcare workers, untimely access to care, the increasing complexity of care and the investment of time and energy by family and carers.

Since 2021, Irish Hospice Foundation (IHF) has placed a stronger focus on end-of-life care and dying at home by examining previous research, conducting a literature review and evidence synthesis looking at policy, statistics and factors that enable or create barriers for people who wish to die at home. IHF are looking to develop a Dying Well at Home programme which aims to support people to die well at home if this is their wish and it is possible. IHF supports the delivery of end-of-life, palliative and bereavement care in all settings and at all levels across Ireland. By collaborating with people across the sector, we have established end-of-life programmes within both hospitals and long-stay residential care and nursing home settings.

To better understand the experience of dying at home in Ireland, IHF carried out qualitative research with key stakeholders between November 2021 and November 2022.

Focus groups and interviews were held with family and carer groups, healthcare professionals from a range of backgrounds and patients' advocacy groups. This report presents the findings of these discussions, to highlight the challenges of ensuring a good death at home and current gaps in the provision of end-of-life care.

The research questions that guided this work are:

1. What constitutes a good death?
2. What factors facilitate patients to have a good death at home in Ireland?
3. What factors prevent someone from dying at home in Ireland?
4. How has the Covid-19 pandemic affected end-of-life care at home in Ireland?

Methodology

Online focus group discussions were held with 49 individual participants, from 15 different organisations representing a wide variety of paid and unpaid end-of-life care providers in Ireland. Semi-structured discussions were recorded with participant consent, and thematic analysis was used by the research team to code participant responses. Responses were then categorised into common themes and subthemes across discussions, supported by participant quotes.

Results

A good death

A good death was described by participants as comfortable, calm and free from pain and suffering. A good death honoured the end-of-life wishes of the patient, allowing them to die with dignity in the place of their choosing, with those they wanted present.

A good death in the home was also one where families and carers were empowered to provide suitable care to patients; where medical professionals could support informal care; and where the medical and social needs of the patient were met promptly and responsively.

Enabling a good death

The factors that facilitated good end-of-life care at home were families being suitably informed and prepared for the realities of end-of-life care; access to specialist palliative services in complex cases; continuity and co-ordination of care across medical providers; timely access to care, especially for pain management; suitably resourced medical teams; and a supportive environment for care in the home.

Barriers to dying well at home

Participants reflected that, despite the tireless work of families, carers and medical teams, systemic gaps in the provision of end-of-life care in Ireland can lead to unmet patient wishes and traumatic deaths.

Barriers to care included:

1. Lack of co-ordination of medical teams, including incomplete referral and communication pathways.
2. Disparate and incomplete sources of information on end-of-life care.
3. Lack of 24-hour support.
4. Unequal access to palliative care services; understaffed and under-resourced medical teams.
5. Lack of integration with social services.

These issues were further exacerbated with respect to communities who already experience inequitable access to healthcare in Ireland, highlighting the lack of suitability of current services.

Addressing gaps in end-of-life care

Building on the wide range of professional and personal experiences of participants in providing end-of-life care in the home, the focus group discussions and interviews also discussed many opportunities to address current gaps in care provision and ensure greater support to patients, families, carers and health professionals.

Solutions presented included:

1. Nominated care coordinators to facilitate greater communication and continuity of care.
2. More accessible, realistic information for those considering home care.
3. Dedicated out-of-hours services for more responsive care.
4. Reform of prescription procedures to allow prompt pain management.
5. Further training and task shifting within palliative care teams.
6. Participants also highlighted the fundamental need for a strong health system in order to provide end-of-life care at home, including sufficiently resourced services and adequate staffing.
7. Participants also shared opportunities for greater holistic care through integration of health, social and community services.

For historically underserved communities, equitable access to health and social services will be foundational for developing and supporting appropriate end-of-life services.

Providing end-of-life care during Covid-19

The pandemic, as a mass destabilising event across society and the health sector, highlighted the fragility of the health system in Ireland, but also that radical change is possible when we are forced to move to adaptive and reactive ways of providing healthcare. For example, the increase in tele-medicine and electronic referrals was seen as a key positive. However, lockdowns also highlighted and intensified existing inequalities in care provision and deepened the isolation of families and carers.

Discussion

Despite the wide range of participants and supporting organisations included in the study, we saw consensus in the numerous ways the under-resourced and overburdened Irish health system created demonstrable harm for patients, families and carers trying to deliver a good death at home. We also heard success stories, where patients were supported to die with dignity and comfort in accordance with their wishes. However, these successes were often due to the tireless work of carers and healthcare workers in going above and beyond to provide the best possible care in spite of systemic failures of the health system. As the demand for opportunities to die at home continues to grow, this level of unsupported care will quickly become unsustainable for healthcare workers and carers.

To ensure an Ireland where everyone, regardless of background and socioeconomic status, can die in safety and comfort in the place of their choosing, we must renew our commitment to supporting professional and informal providers of end-of-life care.

Recommendations

To support people in Ireland to die well at home, Irish Hospice Foundation (IHF) will implement, lead and support on the recommendations. We will continue to conduct and be involved in research, advocacy and stakeholder engagement. We will align our work with the recommendations and framework of the new National Adult Palliative Care Policy (NAPCP, 2023). We will also use the important learnings of the National End of Life survey when released in 2024 to inform our work, along with other national data sets.

While the rich findings in this report acknowledge good experiences of people dying well at home, many of the findings have also identified huge gaps in services. The insights from the focus groups and interviews identified a need for signposting services, further research in a number of areas and advocacy to improve care for all.

IHF is committed to the next steps as outlined in the recommendations.

Next steps for IHF:

- 1. To scope and develop an Information and Support Line.** The report identified a need for signposting to services, a key theme in the study related to insufficient information and support for families and carers. We would envisage that the Information and Support Line will respond to enquiries and provide signposting to appropriate services. This resource when established will further inform IHF about current gaps in end-of-life information and services being experienced in the community.
- 2. Create an easily accessible map with information resources and current services for supporting end-of-life care.** The map will signpost care options for patients, families and carers.
- 3. Support and scope further research to identify the barriers and inform the development of resources and co-ordination required to better support dying well at home, all of which were prevalent themes in the study.**

Considerations for this research should include:

- A system mapping of what regional and local palliative and end-of-life supports are available for people in the community.
- Identify what gaps exist in services.
- Establish how individuals are referred and signposted to services.
- Explore the option for end-of-life co-ordinator roles in the community.

Recommendations

[Continued]

- 4. Conduct a review of existing resources and training with a view to making these accessible to the community.** Participants in the focus group discussions highlighted the need for more accessible, dedicated and educational end-of-life and bereavement resources and also the need to broaden the availability of standardised training support for carers and healthcare professionals. We would also seek to develop further information and educational resources through stakeholder engagement and partnership with service providers.
- 5. Identify best practice community-based end-of-life models of care, which are socially and culturally appropriate to address the specific barriers to care faced by underserved groups to support dying well within their communities.** The discussions identified that further research into the **health inequalities** faced by historically underserved communities is needed. This includes low socioeconomic status groups, migrants, Traveller communities, rural communities, disabled groups and people who are homeless.
- 6. Strengthen our advocacy for primary palliative care supports that help people remain in their community and die at home if this is their wish and is possible.** It will include advocating for continued improvements in home care and supports for family carers.

Introduction

Irish Hospice Foundation (IHF) supports the delivery of end-of-life, palliative and bereavement care in all settings and at all levels across Ireland. By collaborating with people across the sector and with the support of our key stakeholders, we have established end-of life programmes within both hospitals and long-stay residential care and nursing home settings.

Research conducted in Ireland and abroad has consistently shown that the majority of people want to die at home (Irish Hospice Foundation, 2021; Moriki et al., 2020; Vidal et al., 2020). However, there are multiple barriers that make having a good experience in end-of-life care in the home achievable for many people in Ireland.

In response to this need, IHF is developing a programme to support individuals who wish to die at home and for those who wish to care for them. This Dying Well at Home Programme will facilitate end-of-life care by collaborating with, supporting and working with patients, their families and the wide array of healthcare professionals who provide end-of-life and palliative care in the home. Since 2021, IHF has placed a stronger focus on end-of-life care and dying at home by examining previous research, supporting research on recent trends in place of death in Ireland, healthcare policy, statistics and factors that enable or create barriers for people who wish to die at home.

To inform the development of the Dying Well at Home Programme, between November 2021 and November 2022 IHF carried out a series of qualitative focus group discussions and interviews with carers, families and healthcare professionals to learn from and understand their experience of supporting patients to die at home if this is their wish and is medically possible.

Background

Previous research has shown that 74% of people in Ireland would want to die in their home (Enabling More People to Die at Home, Irish Hospice Foundation, 2014). However, in 2017 only 23% of individuals in Ireland had home deaths. This unmet need for end-of-life care in the home will increase as our population continues to age and grow. The number of at-home deaths in Ireland are expected to increase each year, with 8,444 deaths in the family home setting per year predicted by 2031, and over 12,000 home deaths expected by 2051 (assumptions based on static projections from CSO 2017 data). This growing gap in care has contributed to IHF's focus on better understanding the current experiences of those who provide and support home care.

Whilst not everyone can die at home, IHF believes that more can be done to enable greater choice about place of care as death approaches, to allow people to be cared for and to allow their preference to die at home if medically and practically possible.

Covid-19 has further strengthened IHF's belief that more can and should be done to enable people to live and die at home. Barriers to care during lockdowns and the rapid restructuring of health services in response to the pandemic have both highlighted some of the gaps in care provision and opportunities for meaningful systemic improvement of services.

A key priority of IHF's strategy since 2020 has been to focus on innovation in end-of-life and healthcare in the home setting, by establishing a new Dying Well at Home programme. This programme will draw on IHF's existing palliative care programmes, including Hospice Friendly Hospitals programme, Caru (a continuous learning programme, supporting care and compassion at end-of-life in nursing homes) and the Nurses for Night Care service, in order to develop best practices and policies for end-of-life care in the home.

To inform the development of the Dying Well at Home Programme, IHF conducted a series of focus group discussions with key stakeholders including members of the community who had experienced and provided support for people who chose to die at home. Focus group discussions included family and carers of those who died at home; advocates for groups with life-limiting conditions; healthcare workers for marginalised groups, such as homeless communities and Traveller communities; and healthcare workers from multiple arms of the health service who have experience in providing care for those who die at home. This report outlines the rationale, methods and findings from these focus group discussions and interviews.

The research questions that guided this work are:

1. What constitutes a good death?
2. What factors facilitate patients to have a good death at home in Ireland?
3. What factors prevent someone from dying at home in Ireland?
4. How has the Covid-19 pandemic affected end-of-life care at home in Ireland?

A note on participants' provision of care

Throughout this report, we share the personal experiences of family members and carers in providing informal, unpaid care to patients. Alongside this we share the professional experiences of healthcare workers in providing formal care. However, it is important to note that healthcare workers also drew on their personal experiences in providing unpaid care to family members. Similarly, healthcare workers often must work beyond the scope of their role, sometimes unpaid, in order to cover gaps in the healthcare provision.

The experiences shared by formal and informal carers in these focus group discussions were complimentary and provide a more complete view of the combination of paid and unpaid work that is fundamental to the current functioning of the Irish medical system. For this reason, and to ensure anonymity of respondents, this report where possible will not delineate whether observations shared came from informal or formal workers.

Providing care for a loved one at end-of-life is a common but underreported experience for people in Ireland. Promoting honest, open and supportive conversations about experiences of dying, death and bereavement in Ireland is a central goal of Irish Hospice Foundation.

Methodology

To better understand the experience of end-of-life care in the home in Ireland, IHF carried out a series of semi-structured focus group discussions with key stakeholders from November 2021 until November 2022. These focus group discussions and interviews aimed to gather an in-depth understanding from individuals, groups, organisations and services about their experiences and views surrounding home-based end-of-life care. IHF also sought to listen and learn from people's experiences and insights in relation to home-based end-of-life care during the pandemic.

Participants

An initial mapping exercise was carried out by the research team to identify points of end-of-life care provision and advocacy in Ireland. IHF then reached out to prospective groups directly through our programmes (e.g., Nurse for Night Care) and our wider networks and partners (e.g., Primary Palliative Care Steering Committee, Care Alliance Ireland, Family Carers Ireland, Neurological Association of Ireland) and other non-governmental partners (e.g., All Ireland Institute of Hospice and Palliative Care, Irish Heart Foundation) to invite them to participate in the focus group discussions (Appendix 1). IHF also shared an open call for participants on our website and through social media platforms. Prospective participating groups and organisations were sent a briefing document describing the scope and goals of the research (Appendix 2) and asked to invite/identify individuals to attend the focus group discussions and interviews. All prospective participating individuals were then sent an invitation, as well as the briefing document. Prospective participants were also provided with the opportunity to talk to IHF staff if they had questions on the study methods or goals. Finally, informed consent was obtained from each participant who participated in the sessions (Appendix 3).

The final sample included 49 individual participants across 15 different participating organisations, representing a wide variety of paid and unpaid end-of-life care providers in Ireland. Organisations were split into focus group discussions and interviews according to topic where possible. Some organisations were split into multiple focus group discussions and interviews due to scheduling challenges. Similarly, some participants were only available for individual interviews with the research team. The list of focus group discussions, interviews and participants are presented below in Table 1. Informed consent was collected for all participants to be included in the study.

Table 1: Description of participants by focus group and interview

Focus group discussion	Participant organisation	Participants per organisation	Total participants per focus group discussion/interview
1	The Alzheimer Society of Ireland	3	5
	Progressive Supranuclear Palsy Association	2	
2	Care Alliance Ireland	2	4
	Family Carers	2	
3	Public Health and Community Nurses	3	3
4	Practice Nurses	2	2
5	Irish Cancer Society Night Nurses (1)	3	3
6	Irish Cancer Society Night Nurses (2)	5	5
7	Community Pharmacists through the Irish Pharmacy Union	5	5
8	Specialist Palliative Care Community Nurses	9	9
9	Traveller Mental Health Services	1	2
	Traveller Primary Healthcare Project	1	
10	Members of Voices4Care	4	4
11	Primary Palliative Care Steering Committee members (1)	3	3
Interviews	Primary Palliative Care Steering Committee member (2)	1	1
	Family Carers Ireland	1	1
	Homeless services staff representative (residential)	1	1
	Homeless services staff representative (clinical)	1	1
		Total	49

Data collection and storage

Focus group discussions were conducted through video calls, via Zoom, due to Covid-19 restrictions and geographic spread of participants (Table 2). Each session was recorded for later analysis with the express consent of participants. Focus group discussions and interviews lasted 60 to 90 minutes, with semi-structured discussions, following the interview guide included in Appendix 4. All recordings were stored confidentially and deleted on completion of this report. The information provided in this report has been anonymised to protect the identity of participants and respect confidentiality.

Table 2: Participants by community healthcare organisation

CHO	Regions	Number	%
CHO 1	Donegal, Sligo, Leitrim, Cavan and Monaghan	4	8.2%
CHO 2	Galway, Roscommon and Mayo	3	6.1%
CHO 3	Limerick, Clare and North Tipperary	3	6.1%
CHO 4	Kerry and Cork	4	8.2%
CHO 5	South Tipperary, Carlow, Kilkenny, Waterford and Wexford	3	6.1%
CHO 6	Wicklow and Dublin South East	5	10.2%
CHO 7	Kildare, West Wicklow, Dublin West, Dublin South City, and Dublin South West	10	20.4%
CHO 8	Laois, Offaly, Longford, Westmeath, Louth and Meath	7	14.3%
CHO 9	Dublin North, Dublin North Central and Dublin North West	10	20.4%

Data analysis

The research team used thematic analysis to review and analyse the focus group recordings. All focus group discussions and interviews were initially analysed separately by three team members for initial emergent themes. Researchers then categorised the discussion into themes and sub-themes together, based on the research questions, merging their initial findings. Recordings were subsequently reviewed for selection of appropriate quotes for the themes and sub-themes.

What the Research Tells Us

Results

Thematic analysis

From our thematic analysis, we categorised our findings into six global themes based on the initial research questions:

1. Conceptualising a good death.
2. Enabling a good death at home.
3. Barriers to dying well at home.
4. Future resources for dying well at home.
5. Effects of Covid-19 on providing palliative care at home.
6. Other themes.

Observations for each global theme were then categorised into organising themes where possible, representing different facets in end-of-life care provision. An overview of the global themes and organising themes is presented in Table 3.

Table 3: Global themes and organising themes

Global themes	Conceptualising a good death	Enabling a good death at home	Barriers to dying well at home	Future resources for dying well at home	Effects of Covid-19 on providing home palliative care	Other themes
Organising themes	End-of-life wishes fulfilled	Appropriate support for family and carers	Insufficient information and support for families and carers	Information and education resources for families, carers and patients	Negative effects	The role of housing in dying well at home
	Patients, families and carers are suitably informed	Specific forms of palliative care	Inadequate access to care	Education and training for healthcare workers		Building community for care providers
	Patients, families and carers have good access to care	Good access to care	Poor co-ordination of care	Dedicated palliative care	Positive effects	The Irish health system
	Patients, families and carers have ongoing, sustained support	Co-ordination of care	Insufficient resources to provide care	Essential resources (staffing, hours)		
	Patients receive individualised, appropriate care	Other factors	Care is unsuitable for individual or community	Other resources /supports		
		Lack of other social support	Tools and services			


1. Conceptualising a good death

There was broad consensus amongst groups on what constitutes a “good death”. The sub-themes that emerged were fulfilment of end-of-life wishes; practical information for family/carers on providing end-of-life care; continuity of support for patients, families and carers; and access to individualised, appropriate care (Supplementary Table 1, ‘Themes associated with conceptualising a good death’, page 70).


Fulfilment of end-of-life wishes

Participants described a good death as ultimately fulfilling the patient’s end-of-life wishes supporting them to remain in their home; to be able die pain free, with dignity in a comfortable, calm environment; to die in the place of their choosing; and to be surrounded by the people they wanted present.

“...we had a lovely few weeks before he died, it was lovely. He had everybody that he wanted in around the house, it was a great death.”



“When somebody’s prepared, it’s much easier, because they have expressed their wishes, the family have to feel comfortable that they have the support and that they can ask questions.”



“When [end-of-life home care] works, families are often so relieved, and they can’t believe that they did it. There’s a sense of satisfaction that they gave their loved one their wish.”

Participants highlighted the importance of involving patients in shared decision-making on end-of-life treatments, but also giving patients opportunities to discuss their experience of their palliative care/end-of-life journey, as this can be missed during routine consultations with GPs and other primary healthcare providers.

“[It’s important to have] the opportunity as well to hear their story, because sometimes there isn’t time in the hospital for them to actually explain how things have been for them on the journey, and sometimes, we’re the first person to actually hear the full story...[You have to] listen with an ear to let them know you understand where they are at, so that they will feel that they are actually understood and the trust will grow between you.”

Part of a good death for patients included not feeling like they or their care is a burden to their family/carer, and that carers and families would be adequately supported and empowered to provide care.

For those working with people living in homeless accommodation, they said the ability for service users to die in privacy was essential for a good death.

For those providing services and support to members of the Traveller community, they observed that from a cultural perspective no death was considered a good death. However, they described the importance of family and community members being able to prepare and say goodbye to the person who is dying and how this can be difficult and the impact it can have on grieving processes when death comes unexpectedly, suddenly or through suicide.

“I don’t think any death is a good one but....cancer, even though it’s a painful death, it’s a good one. It gives you a chance to prepare yourself and talk with your family...I’ve seen where people don’t wake up due to a massive heart attack, and the family is left in limbo. They didn’t get a chance to say goodbye or anything.”

“[In a good death,] people are afforded the dignity to die with family or friends around them and to ensure that there is no pain or as little as possible. Part of that is to die in the privacy of a single room.”



Clear communication between family/carers, patients and healthcare teams

A good death was also conceptualised as including open, compassionate and informative discussions between patients, their family/carers and healthcare teams, specifically in clarity about division of roles and expert advice on care provision, such as pain relief.

Participants also mentioned the need for identified points of contact to support families, so they are secure in their support.

“I think sometimes they need help in identifying who does what. They may never have had any interface with healthcare services, and suddenly they have the [public health nurses, specialist palliative care, community intervention team and night nurses], and they can be quite bothered about who does what.”

“Information is really important, and that it’s left in the home so when everybody goes away when they’re sitting down and maybe having their cup of tea, they can read it and say, ‘Right – that’s who that person is to access.’”

Access to responsive, appropriate and individualised care

A good death was described as one where the patient’s individual medical needs were met. Specifically, most groups highlighted the importance of a patient’s freedom from pain and suffering.

Throughout all the group sessions, participants cited an expectation for good management of pain and other symptoms by the healthcare system. Access to specialist and responsive care was also listed as a key component of a good death, in particular disease-specific care, support for complex deaths and care appropriate for the severity of illness. Access to suitably complex care as needed was also mentioned, with references to holistic support and access to psychological support for patients, as well as families and carers. Patients and families need reassurance that they will be cared for.

“Everybody’s afraid that they are in pain, and they’re all worried about how it will be at the end, that they’ll be gasping for air. You just have to reassure them that we will do our best to help them and that there’s medication there to relieve those symptoms. They just want to have somebody around them, that they are not on their own.”



2. Enabling a good death at home

Participants reflected on factors that would enable a good death. Sub-themes were categorised as suitably informed family/carers, specialist palliative care, good access to care, co-ordination of care and supportive environment (Supplementary Table 2, ‘Themes associated with conceptualising a good death at home’, page 71).

“We were lucky enough to get the Night Care Nurse for both my parents in the last couple of days...The Nurse was amazing; she wrote us out a list of what to do in the morning when he died. You know, leave the bed switched on, cancel the carer, step by step – that was gold. We didn’t have to think; we just followed her list.”





Suitably informed families and carers

Participants reflected that facilitating a good death at home was dependent on adequate timely information and support for family/carers. Family/carers can facilitate a good death when they are provided with support, adequately informed on end-of-life care, understand their role in relation to healthcare teams, understand the stages of dying and understand the worst-case scenarios of dying at home.

“In the weeks coming up to end of life, we have to have a foundation that’s solid so that people have knowledge, and the counselling is already happening, and we’ve got sustained relationships with carers and care providers. That’s got to be part of a programme to support people to die at home.”

When this information is shared with families through the expertise of care providers, participants voiced that they felt empowered to provide end-of-life care. Being more informed allowed them to feel less anxious and fearful about how to provide quality care. This was further supported by realistic expectation setting by healthcare teams.

“It’s about having the support. [Family and carers] want the person to come home, but obviously there’s an element of fear about their ability to care for them adequately at home. [It’s important] having that home support and access to home support.”

Specialist palliative care services

Specialist Palliative Care Services were seen as key enablers of a good death at home, both in terms of specialist medical teams and specialist resources such as hospital beds that can be used within home settings. Of note was the importance of being able to access a range of healthcare professionals such as Night Nurses, Public Health Nurses, as well as Occupational Therapists for providing and supporting home-based end-of-life care.

Good access to care

Dying well at home was linked to timely delivery of medical care. This included immediacy of support when needed, such as home carers and a standard of 24-hour access to services when possible. Good access also covered steps taken during care planning to prevent discontinuity of care, such as providing stop-gap care before a patient’s home care package is enacted by their health team and planning just in case prescriptions for out-of-hours care. Further, linking family/carers to pastoral or counselling services for anticipatory grief was seen as an aspect of good access to care that was described by participants.

“Nurses on the ground prioritise that, if that family needs help, and there isn’t a home package in, sometimes we might just have to facilitate that gap before a home care package comes in. We might also get our own healthcare assistant ... for some time before a full home care package comes in. Also liaising with the family to get a rota going, we would very much be advocates for that for families ... because a lot of them want to do that.”

Co-ordination of care

Participants reflected on the multidisciplinary skills needed to facilitate a good death at home and highlighted the need for close co-ordination of family/carers and different arms of the health system.

“The home help service [supports dying at home]. When we mention the GPs and the PHNs, they’re both services that are stretched, no more than our own in the community, and having a good home help service going in to help with personal care can really reduce anxiety, help the family to maintain and manage the person in the absence of GPs, or PHNs or SPC coming in.”

Participants highlighted the importance of a singular end-of-life care coordinator, to support the initiation of care needs within the home, such as the processes for getting necessary equipment and also to ensure continuity of care and prompt follow-up.

“The key there for me would be phone numbers so that I could actually contact the person who discharged that patient, or the team, so I could contact them during the night if we ran into difficulties.”

It was also mentioned that the coordinator role would create unity in health messaging between various healthcare teams/members supporting a patient, and in clarifying the rota of care between healthcare teams and family/carers. Good co-ordination of care was also seen as a means for reducing stress on families and also preventing overlap or bureaucracy between healthcare teams.

Supportive environment

Participants noted having strong existing support structures in place and positive dynamic, such as family, friends and carers working together, are foundational for good end-of-life care.

“I would feel the enablers are the support structures that are around the family or a particular circumstance that allow [the patient] to be at home. Whether it’s right down to your carers, PHN, Night Nurse, GP, palliative care team, it all allows it to develop as it should.”

Other aspects enabling a good death included preserving a sense of familiarity and comfort in the home, and not making homes into ‘mini hospitals’.

“I think something as simple as trying to keep the room as un-hospital-like as possible [is important] because you have a hospital bed there for starters, so it can quite quickly become very foreign and unhomelike, [so it’s important to have] little things like their own sheets, duvet, radio, music, keep it as normal as possible.”



3. Barriers to dying well at home

The discussion of barriers to dying well at home were in-depth across all focus group discussions and interviews, drawing on participants’ personal and professional experiences. They included practitioners’ observations of gaps in care provision, family/carers’ experiences of being unable to access support and marginalised groups’ experiences that barriers to home care reflected their wider general experiences of exclusion from the health service.

The sub-themes for barriers to dying well at home were (Supplementary Table 3, ‘Themes associated with barriers to dying well at home’, page 72).

1. Insufficient support for families and carers.
2. Inadequate access to care.
3. Poor co-ordination of care.
4. Insufficient resources to provide care.
5. Unsuitable standard of care for individuals or communities, and lack of other social supports.

Insufficient support for family and carers

Participants identified how a lack of sufficient support and information for family/carers impeded patients dying well at home. Family/carers faced deficits in knowledge and skills, which exacerbated the difficulty in providing suitable home care. Often mentioned were lack of knowledge of essential skills for home care, such as bed changing and manual handling. Similarly, lack of adequate information on end-of-life care made the difficulties of providing home care even more stressful. Families and carers were often unaware of existing support and services available to them.

“The other thing from a family carer’s perspective is that sometimes people don’t know their rights and entitlements...that they have a right, by law, to take carer’s leave and that type of thing if they are caring for somebody who is terminally unwell.”

“When I happened to mention it in passing to a nurse [how expensive medicine was] she said, because he’s terminally ill, he’s entitled to a medical card...It didn’t come up in conversation before that and, of course, I didn’t know to ask.”

Confusion about disease/symptom progression, a lack of 24-hour care support, poor understanding of short-term vs long-term home care, fear of patients being hospitalised and lack of support and knowledge around traumatic deaths were all mentioned as aspects that made providing home-based end-of-life care challenging and frightening. Time spent trying to find information or get support often detracted from the time families and carers spent providing care.

“Because there is no access to 24-hour care, some patients are ending up in A&E inappropriately.”

“I suppose the challenge is that families are on the phone a lot when things change, and they start to chase services and support. They’re calling you, the PHN, home care team, whoever, it’s always key person, a son or a daughter, they’re not with their dad or their mam during this time when they’re fighting for services.”

It was also mentioned that family/carers had high expectations of the support that would be available for home-based end-of-life care provision compared to the realities of local resources. Also highlighted was the lack of support for family/carers, such as emotional and psychological support. Not being able to take breaks from caring was frequently mentioned as a contributing factor towards family/carers experiencing burn-out.

For the Traveller community, it was noted there was a lack of information and understanding about end-of-life services.

It was observed that fears about death prevented the Traveller community from participating in advance care planning.

“[The] majority of the Traveller community don’t even make a will, they wouldn’t have life insurance, some of them wouldn’t even know about it. Some people are afraid to talk about it [death] in case it brings it on.”

Inadequate access to care

Poor access to care was identified as a key barrier to dying well at home. Participants noted the gaps in continuous care, such as a lack of 24-hour support and weekend support, as exacerbating the pressures, anxieties and strain that family/carers often feel. Multiple participants referred to medical services and teams not answering phones and being uncontactable. Lack of access to GPs prevented timely updating of patients’ prescriptions, which in turn prevented suitable pain and symptom management for patients with increasing needs.

Similarly, delays in access to necessary equipment for home-based end-of-life care prevented or delayed the ability for family/carers to set up a suitable and safe environment at home to care for patients.

“We seemed to run into a crisis late on Fridays or a Bank Holiday weekend, and you are left with very limited backup support. It’s all left on you, as a carer...there was no co-ordination of services. It’s very frustrating. To have a parent in severe pain, and trying to get the meds right and stuff, if there could be quicker access to supports – timely phone support from a palliative doctor/nurse, it would ease the carer’s burden and the distress of their loved one.”

“It took 10 days for the bed to arrive, sometimes the length of time it takes to get equipment can be prohibitive...sometimes the equipment provision is just not fast enough.”

“I sometimes wish that there was a catheter pack brought when the syringe box comes because a lot of people do end up having catheterisation, sometimes there’s a delay, which can cause discomfort.”

Lack of access to, and knowledge of, terminally ill medical cards also prevented access to primary care.

“Where there is an initial diagnosis, several things should follow on immediately from that. The first thing...everyone should have a [terminally ill] medical card. We found...we didn’t have a medical card, and, because of that, there were certain things that we couldn’t avail of.”

It was also observed that poor access to palliative care services has been worsening.

“I’m noticing that to get hold of palliative services is becoming increasingly difficult for families and where typically a year or two ago they may have had access earlier on, families I am talking to at the minute, where closer to end stage, they are not having access to SPC that we would hope they would have at that point.”

Participants mentioned different drivers of poor access to care. Staffing issues were seen as leading to lack of access to Public Health Nurses. In other discussions, reduced access to nurses was linked to the introduction of the home care package, which was seen as codifying limited hours of support. Family/carers were reported as rationing their allotment of night care to try and manage the home care demands on them. While the home care package is vital, it seems to have replaced the specific nurses-led care, which was noted as a gap that needs to be filled.

“Before there were home care packages, the nurse always prioritised the person at end of life, and it was a daily call, you went out every morning for at least an hour and did full care...when home care packages came in, the nurses stood back, and the carers went in. I do think that’s a gap...the nurse is removed and there is more disjointed care then.”

Poor access to services throughout rural communities was highlighted by participants, as was the lack of equitable access to all mainstream health services for homeless populations.

“I don’t know what it’s like in your area, but it’s so hard to get specialist services now or in touch with palliative care to get the pain relief increased as rapidly as you might need it. Some days if [patients have] taken a big deterioration and then the more distressed with pain the patient is, the more pressure, stress and worry is on the family.”

Finally, it was observed that families may initially commit to providing home based end-of-life care due to the lack of alternative routes to access care at end of life.

Poor co-ordination of care

Poor co-ordination of health services was identified by all focus group discussions and interviews as a barrier to sufficient end-of-life care at home. Families/carers were often unable to navigate referral pathways between services, with healthcare workers reflecting on health cases being lost due to incomplete referrals between different health teams and settings.

The inconsistent triage of end-of-life cases was seen as compounding poor co-ordination between services, with some participants reflecting only the most severe end-of-life cases received access to services. Other participants noted that the rapid discharge policy of the HSE prevented handover of patient cases between services.

Similarly, the poor co-ordination of care was reported to have led to poor responsiveness within care planning. One example mentioned was the difficulty in taking end-of-life patients off prescriptions of preventative medicines they may have previously been advised to take. It was also observed that there was a lack of shared responsibility between health teams for patient health plans and outcomes.

“With the [non-malignant illnesses], it’s more unpredictable if anything, the pathway of medications can be more difficult. Sometimes there isn’t enough written down on the directives, so you have to contact whoever the team was. There can be a lot of time wasted trying to get in contact with the discharge team.”

“It’s probably down to resources. It’s only when someone is actively dying, and I’ve had experience with both my mam and dad, that palliative care kicks in. I knew a month or two before my dad died that he was going downhill. I asked our GP about it, and our GP was great, and she said he wasn’t eligible for palliative care because he wasn’t actively dying. I think if I would have had been linked in, even a couple of weeks prior to that, with a palliative care team, he wouldn’t have suffered the way he did, and I wouldn’t have suffered watching it.”



Insufficient resources to provide care

Healthcare workers, family/carers and members of marginalised communities all reflected on the lack of sufficient resources within the health system to provide adequate end-of-life care at home. Participants reflected on the absence of vital services, such as the lack of paediatric palliative care and specialised care in general.

“[With the lack of] paediatric, we are missing a huge opportunity with our beautiful children who are dying at home, and sometimes they don’t die at home because nurses are scared; home care teams are scared, that is not good enough...[Ireland is] a teeny tiny country, we do (SPC) palliative care better than anything else, but in this area, I do think we fail and I do think we can do something about it.”

Lack of palliative care options was reported as leading to a reliance on nursing homes for community based end-of-life care, due to lack of alternative services. This was particularly problematic in terms of homeless populations, as nursing homes were seen as inappropriate for meeting the complex needs of patients coming from residential homeless services.

“Certainly, in the residential [homeless accommodation] home, all of them wanted to die, but we were not equipped to look after them when they were coming to end of life. All of them had written those wishes down, but we had no nursing staff, no GP input, no one to come out after hours, so inevitably they couldn’t die at home.”

Similarly, a lack of clinical staff working within homeless accommodation led to the health needs of residents being managed (as best as possible, for as long as possible) by social care workers, who have insufficient capacity and skills to provide palliative care.

“Because of the funding that goes into [residential homeless accommodation services], what’s hired is not compatible with what someone needs from a healthcare supportive piece. The way that funding for homeless services is set up is that you’re hiring project workers or key workers who are hired not to actually provide physical care but to provide social care. Stuff like working towards completing housing applications, a medical care application, a hostel if someone has lost their hostel because of behaviour. So, the staff in hostels, they’re not even trained in patient manual handling.”

Staffing problems was an issue mentioned by all groups as a barrier to home-based end-of-life care. GP practices were described as understaffed. Palliative care in the GP setting was also seen as underfunded, with current support grants to GPs for palliative care making little impact.

Other missing resources included lack of psychological support for care staff, and lack of clinical and financial support for family/carers in adapting homes for end-of-life care. Another issue highlighted was the inconsistent selection of medicines in pharmacies, limiting the fulfilment of prescriptions, especially in rural areas.

Through sharing their experiences from working in different parts of the country, participants also reflected on the vast differences in the standard, quality and availability of care in different regions, and the need for greater consistency of care.

“In terms of resources, I suppose what we would see is it’s very different in the different areas, so (for example) in Dublin, the SPC is much more difficult to get than what we’re seeing in maybe Tipperary and Cork.”

“I just wish we had a plan in place across the board where everybody had the same standard, the same sliding sheets [for manoeuvring patients] were in every household as opposed to knowing if I go to a different county, they won’t have them.”

Unsuitable care for individuals and communities

Issues in access to palliative care and insufficient resources were compounded for communities with complex needs and ongoing exclusion from health and social services.

Homeless communities were identified as having complex needs, stemming from the prevalence of chronic mental and physical health conditions, addiction and trauma. As such, services such as nursing homes were seen as unsuitable for managing their end-of-life care needs. Homeless populations can often be transient, which further leads to a discontinuity of care. A general lack of ground-floor accommodation options in homeless facilities was also noted as a barrier towards palliative care being able to take place within homeless accommodation settings due to accessibility issues.

The dependent relationship that long-term homeless clients living in homeless accommodation can often have with social care staff within services was discussed as often mirroring the relationship that non-homeless people may have with their family/carers. People living in homeless services may look to social care staff members for support and guidance in making decisions about their health and end-of-life care wishes, and social care staff may not be equipped to support these types of decision-making conversations because of a lack of training/awareness about community-based end-of-life care options for people living in homeless settings. Similarly, the inadequate understanding and training surrounding the unique and complex health needs of people experiencing homelessness was also noted to be a factor which contributes to the exclusion of homeless communities within mainstream primary healthcare services.

For Traveller communities, participants mentioned that there was often insufficient space within mobile homes to be able to provide home-based end-of-life care. Similarly, it was noted that there is a lack of facilities at halting sites to support dying at home, and a lack of stability for continuity of care. The lack of basic services at halting sites was a continued problem, and one medical staff were often unaware of, such as lack of access to clean water, electricity, washing facilities and postal service.

“Within the Traveller community, family is a huge thing, as faith is and community and that would be a huge gathering around where the family member might want to die at home but can’t die at home and then the family have to go to the hospice or the hospital and then that separates them. It should be a personal thing.”

End-of-life care for members of the Traveller community was also bound by ongoing issues of lack of cultural awareness from healthcare staff. Community members were often reliant on building relationships with individual healthcare staff to improve access to care. However, this would be reset any time there was change of personnel and the relationship was lost. This was an issue also due to the lack of health fluency within the Traveller community, which prevented individuals from being able to negotiate with health services for necessary care. One example given of this was the negotiation for fulfilment of repeat prescriptions.

Despite the complexity in providing end-of-life care in the home to Travellers, specialist workers within the Traveller community reaffirmed the need for accessible and suitable home services.

“Some [Travellers] in the last couple of days get really frightened and they’d rather kind of be away, in a different environment from the family looking and having these memories that they were in that room when they died...but there should be something put in place to give them the option if they do choose to die at home.”

Other groups included those with degenerative disorders, who were unable to have their complex needs met by the health service. In the case of dementia patients, it was observed that people with chronic conditions who had a history of poor access to standard healthcare often assumed that home care by extension would be unachievable.

“It’s down to options as well. It’s down to healthcare professionals and what their opinion and view of palliative care is as well. I had a case where the only option that was given to the person with dementia who was at end of life and their family by a healthcare professional was a nursing home - to put them into a nursing home. The family came back to me, we got involved in palliative care services, and the person got to die at home. Even though they had a great support network and family, they needed the support and encouragement to know that they could look for other options so that it didn’t have to have two weeks in a nursing home and go through the whole ordeal of Fair Deal and all of that. It’s down to options.”

It was also observed that there are large inequalities in standard of care received based on socioeconomic status. Issues were compounded for non-native English speakers due to lack of language support within the health system. Poor accessibility to suitable services in general led to inappropriate hospitalisation.

Lack of other social support

The ability of family/carers to support loved ones to die well at home was impeded by the lack of integration of health, social and financial support. Carers reported being unable to go back to work immediately after caring for a loved who died and relying on social welfare to survive. However, carers experienced reduced social support, exacerbated by delays in receiving social welfare. Complications in social support only further undermined the work of carers in providing care at home. One family carer reflected on not disclosing the gap in support to their patient so as not to burden them.

“I told [loved one] that the money’s come in...that was bothering [my loved one]. It’s not something that should be bothering someone at the end of their life – is their loved one getting anything?”

Poor integration of services also prevented holistic care, with lack of timely communication between hospitals and community services.

4. Future resources for dying well at home

Participants were asked what future resources could be put in place to better ensure that patients were supported to die well at home. The sub-themes that emerged were improved information resources for carers and patients, further training for healthcare workers on end-of-life care, dedicated palliative care resources, essential medical system resources and resources to improve communication (Supplementary Table 4, ‘Themes associated with future resources for end-of-life home care’, page 74). Additionally, participants suggested different forms of dissemination of information on palliative care options.

Information resources for carers and patients

All participants highlighted the importance of easily accessible and understandable information resources on end-of-life care, so that patients and carers could be empowered to make informed decision.

Participants mentioned the difficulties in integrating advice from multiple disparate sources and suggested step-by-step information guides for families and carers of all stages of end-of-life care and dying at home. A positive example of this was the Irish Cancer Society’s information on caring for someone at home. While the below suggested information may all appear online in some form, it is difficult to access due to its fragmented distribution between multiple national and international health organisations.

“There should be something in the community for somebody who’s going to be minding someone at home, even if it’s an hour tutorial or something online of how to handle somebody in bed, the position, what to look out for.”

“[There should be information on] oral care, eye care, hygiene in general, how to move a patient in the bed, if family want to do that type of thing.”



A step-by-step resource should include practical education on medical issues such as the use of morphine pumps and catheters, in part to destigmatise them, as well as frank and realistic discussion on the worst-case possibilities of illness progression and pain management. Participants observed that current information available did not prepare carers and patients for the worst eventualities of managing end-of-life care and led to a mismatch of expectations.

To support this, participants also suggested a platform or resource where carers and families could share their experiences of end-of-life care at home, both to inform future patients and carers, and to process their own experiences.

Timeliness of access to practical information was also important, and it was mentioned that families/carers needed to be suitably informed before patients were discharged to home care. There was also a need for non-medical advice on providing comfort for patients, whether that be physical, social or spiritual comfort. Similarly, resources and tools for emotional support for carers was highlighted as being important.

“[There could be] a toolkit for carers going into homes that could let them know that it’s okay to say certain things or help them to talk about death and dying and to engage them in a conversation if they want. People get nervous and try to avoid conversations about death and dying.”

“Sometimes people get so focused in on how they’re managing the medicines that they are losing sight of someone who may have only days or weeks left, we would try to get people to reach in to support service just to speak to someone from a pastoral or spiritual side.”

Stemming from the issue of poor referrals between health teams, and difficulty for patients and carers in navigating referral pathways, participants suggested the need for clear and understandable signposting of existing services and support for dying at home, as well how to access them. One example of this was Nurses for Nightcare, which participants reported was easily missed by carers who had never heard of the service. Similarly, there was a need for greater visibility and awareness of home care packages at end of life. Signposting of care was even more important for marginalised groups, who had more complex barriers to care to overcome and required dedicated resources.

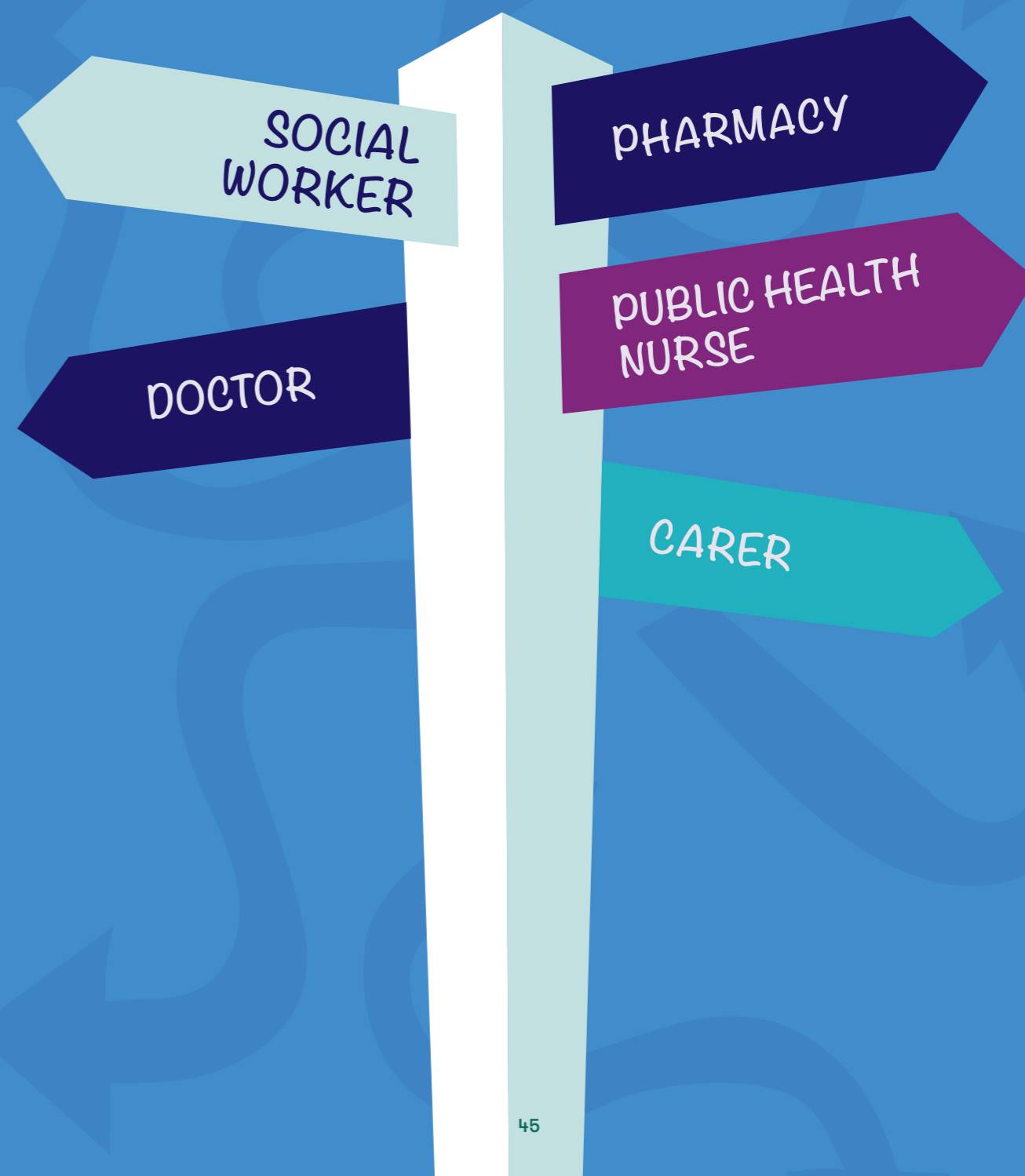
Finally, there was a need for specific guides on non-medical practicalities of home care, such as guides for renting or buying home medical equipment; guides on death arrangements, such as death certificates, removals, and funerals; and information of social support available for families and carers.



“It would be great to have a map, search for ‘support’ it is the things like the bed, where to get it, things like if you want an air mattress, where do you get it from? Hover on the map, where would you actually find these things?”



“A booklet would be very valuable, a signpost or somebody to signpost on where to go, what to do next, people don’t know how to access a death cert, have they a living alone allowance.”





Further training for healthcare workers

It was also discussed that although there is information online for healthcare workers on end-of-life care, an integrated resource was needed to improve accessibility. Alternately, participants suggested an information hub that would signpost resources available elsewhere on different topics, such as detailed information on different end-of-life conditions.

“As a night nurse minding non-malignant patients, we could well do with more education about different conditions, a day on MND, cardiac failure, renal failure or dementia, every night nurse is crying out for education and for study days.”

There was also an interest in making international models of end-of-life care available to healthcare teams, so that they could integrate best practices from other countries. Similarly, there was a need to facilitate sharing of experiences and information between practitioners, in order to overcome challenges and problems that arise during end-of-life care.

There was also a need for dedicated training for healthcare workers on working with marginalised communities. This was apparent in the case of rough sleepers, as often the standard end-of-life care suggested by healthcare teams was incompatible with the living conditions of rough sleepers. Finally, participants also suggested the development of a toolkit for managers of health teams, to support easier co-ordination of care.

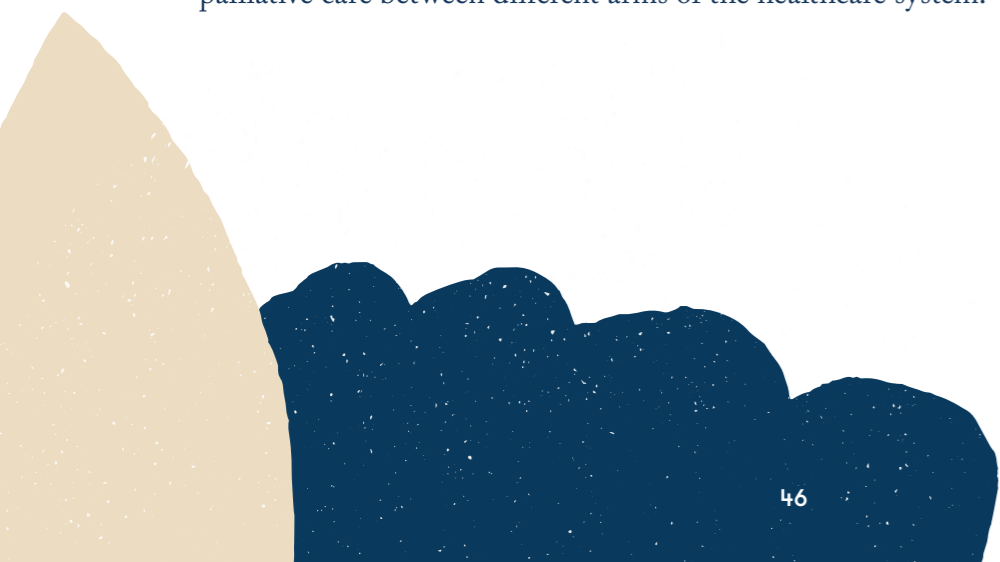
Dedicated palliative care resources

Participants identified the need for dedicated and integrated palliative care and suggested multiple different routes to achieve this. Participants suggested the expansion in access to specialist palliative care teams; access to psychological support as part of palliative care; and access to a continuous nursing contact for ongoing support.

Participants reflected on the ability of existing roles to fill gaps and highlighted these roles as in need of further investment and expansion.

Participants also suggested improvements of existing care, such as greater integration of GPs with nursing homes; training of healthcare assistants to provide palliative care; palliative care packages with a dedicated number of consultations with healthcare workers; and greater standardisation of palliative care between different arms of the healthcare system.

“A good public health nurse in the area really means a lot, occupational therapists and night nurses are really the huge thing for us. It’s a long time from 5pm in the evening to 9am the following morning, GPs are off... We do have a good support system here (local hospice) in that they can ring and speak to the Doctor on call. We can’t go out to them, but at least we can give a bit of support if they feel unwell... what’s the right thing to do, will they ring CareDoc to go see the patient? The home helps are fantastic, they really are.”



Essential medical system resources

Participants in the focus groups and interviews also reflected on the underlying pressures on the Irish health system which led to gaps in provision of end-of-life care. Participants identified staffing issues as a high priority, with a need for more staff at all levels and better retention of healthcare workers, including through better pay. They also identified a need for debriefing for healthcare workers, both for emotional processing and for reflecting on best care practices.

There was a need for an appointed contact liaison for patients in order to facilitate greater co-ordination between health services and to prevent referrals being lost. A right for patients to be seen in person was also suggested as a means of reducing barriers in access to care.

“[There’s a need for] a right to be seen in person, a right that a certain percentage of your consultations are in person.”

There was also a need for a blended model of care between health and social care, to ensure better functioning between state services and to support groups with complex social care needs, such as the homeless population.

“What we need really, would be a blended model, where you’ve got your social worker side of things for those who are not quite at end of life and then your health carers, who are doing the stuff like – changing pads after incontinence, supporting with facilitating showering or cleaning, supporting around things like if there’s peg feed involved. That kind of thing. I don’t think you’d ever bring that into the social care piece. It’s more about looking at a blended service.”

“As a sector we’re under resourced from a nursing perspective, so if palliative care could link in with some of the services and clinical teams that are working within the homeless sector, that would benefit the clients and staff in services.”



Improving communication

As well as information, participants in the focus groups identified multiple ways in which communication between families, carers and healthcare teams should be improved. There was a need for greater clarity between healthcare workers, patients, families and carers on expected timelines for end-of-life care. Similarly, there was a need for frank discussions between patients, families and healthcare on the severity of a patient's condition. There was also a need for different end-of-life care options for different home and housing situations.

There was a clear need for greater adoption and use of electronic records to ensure completeness of referral pathways, continuity of care, timely response and to prevent loss of vital information. As well as this was methods for alerts for healthcare workers.

“[We need] electronic health records, because it's not something we should be using pen and paper for, especially as it's so fluid.”

“[We need] an alert to let pharmacists know an important email has come through... Health mail is relatively new to pharmacists; some pharmacies are getting thousands of emails everyday so [alerts are needed] so that cases stand out as ones that needs action.”

To facilitate improved communication, participants suggested identifying a point of contact within family/carers who would be provided contact details for health teams and establishing a clear handover between discharge teams and home care, which would cover essential information such as drug prescriptions and care directives. It was also important for points of contact to lead on discussions of cessation of ancillary medicines at end of life.

“If you're suddenly going to need 4 or 5 more medicines for symptom control, practically being on 8 preventative tablets, it would be great if that was documented as part of a palliative review, that we are not really worried about prevention any more, we all about today's bread today and having a good day today and more likely to have a more planned day tomorrow... so while I would feel that much as adding medicine can often be delayed, stopping medicine doesn't seem to be given enough, it should be its own process.”

Participants also suggested the use of third parties to facilitate communication between patients, families, carers and healthcare teams, such as the provision of health service advocates for carers, or access to support through death doulas.

Participants highlighted the importance of advance care planning in facilitating clear communication between patients, families, carers and healthcare teams. Advance care plans needed to be clearly stored so they could be accessed and followed by families, carers and healthcare teams. Access to advance care plans was particularly important in the case of admittance to emergency services, to ensure end-of-life wishes are prioritised. Early advance care planning was also essential in the case of patients with degenerative and early onset life-limiting conditions.

Disseminating information

For disseminating information required for patients, families and carers to make informed decisions on dying at home, participants suggested multiple options. 24-hour support lines were suggested to cover current gaps in care provision, as well as greater opportunities for video calls with healthcare teams. Local maps of health and social services and for accessing equipment were suggested to improve access to care, particularly in rural and underserved regions.

While digital resources were seen as the most frequently used and the most helpful, participants also reflected that specialised information resources were necessary for groups with special needs. The provision of image-heavy resources is important for groups with literacy challenges. Similarly, for groups with low computer access or literacy, mobile-focused resources were suggested as a solution, such as text services or using WhatsApp networks.

5. Effects of Covid-19 on providing palliative care at home

We asked participants to reflect on their experiences of end-of-life care, and to discuss the multiple ways the Covid-19 pandemic impacted the experience of dying at home in Ireland, presented below (Supplementary Table 5, ‘Themes associated with Covid-19 and dying well at home’, page 76).

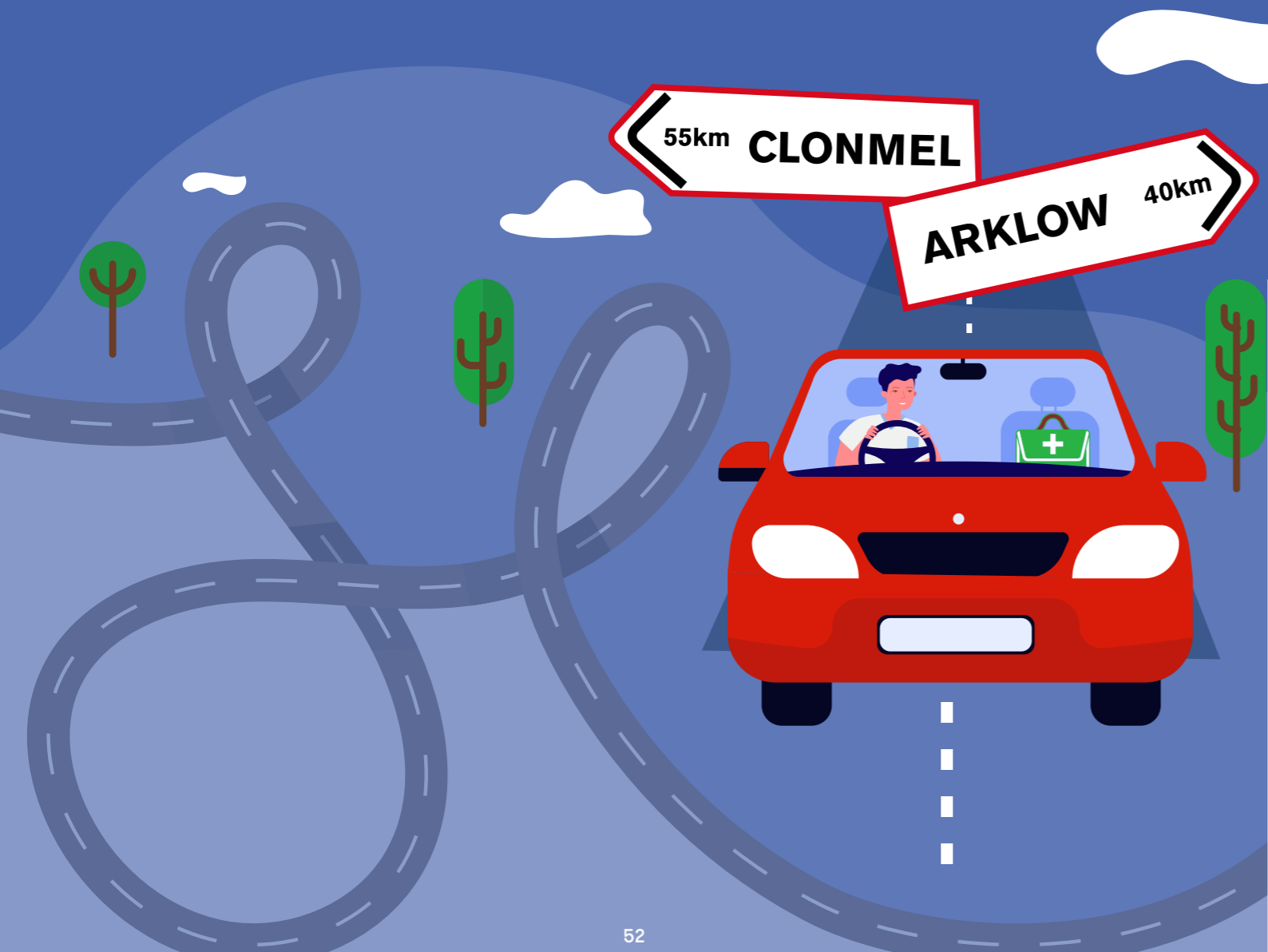
Participants reflected on the difficulties of providing end-of-life home care during the Covid-19 pandemic. Fear and confusion over social distancing guidelines often interrupted care, with carers instructed to pull out of homes where patients had tested positive for Covid-19, and families fearing outside carers would introduce Covid-19 to the home. Similarly, there was difficulty for healthcare staff in working in home conditions where families/carers were not complying with restrictions.

It was also noted that restrictions on access to hospitals were prevalent during the pandemic, with people with complex end-of-life needs unable to attend hospital for fear of contracting Covid-19. On the other hand, for patients in hospital, due to reduced visitation guidelines, families often were less aware of disease progression as they had less opportunities to see patients. Patients would die alone in hospital due to restrictions on visitors.

Covid-19 reduced access and quality to care, due to guidelines and shifting norms in response to restrictions. One participant reflected, that in their experience, nursing homes were excluded from specialist palliative care during covid and left behind, and families were given the option of patients staying in nursing homes or dying in hospitals. Another reflected the pandemic had made it acceptable to refuse provision of medical services to patients, and reduced obligation by the system for in-person care. The pressure on the health service exacerbated referral gaps, leading to an increased reliance on pharmacists to provide care, while specialist care such as occupational therapists or speech therapists were unable to see patients in person.

The pandemic also worsened health inequalities. Residents of homeless living facilities were reported to be restricted in their movements within residential homes during the pandemic, their needs unmet. Participants in differing geographical locations throughout Ireland also reported experiencing varying levels of support from services due to unequal funding, staffing and availability of services in different areas.

“[Healthcare] teams would say their resources are limited, they can often have a large geographical reach, sometimes it’s near the end when they get into families, so they haven’t had time to build that relationship. Sometimes there’s an hour’s distance between patients. There are long trips to be made and a lot of paperwork, which really holds things up.”



For members of the Traveller community, despite the community being designated as a priority group by the government for Covid-19 response, specialist workers who worked with the Traveller community throughout the pandemic were not designated as frontline workers and were stymied by restrictions.

There were also some perceived positive effects from Covid-19 on home care. Families and carers were glad that the pandemic prevented visitors to the house, as it lessened stress on family and patients.

“A lot of families seem to have got more quality time with their loved one because of the absence of large amount of visitors, I think that has been a positive, quite often before we could arrive at 11pm at night and the primary carer was making tea for everybody else that was sitting by the bed and hasn’t had the time themselves.”

The pandemic, through interrupting standard care, challenged ideas of what is possible. Healthcare teams had to become more flexible to provide care alongside restrictions, becoming more reactive, and gave care with less reliance on hospitals. There was an increased adoption of telemedicine, including video assessments and digital prescriptions, as well as somewhat better access to controlled drugs. Similarly, the pandemic normalised online access to funerals.

Despite this, it was observed that when tele medicine was not paired with in-person visits, that vital information could be missed.

“We were advised to try and assess people as much over the phone and do less patient face-to-face contact, I suppose then what we found was when you were ringing people over the phone, they were saying ‘Yeah, I’m not too bad, grand, grand, grand’, but then when you would go out to the house maybe after a couple of weeks, the GPs haven’t seen them, the public health nurses hasn’t seen them, we haven’t seen them, and they were in a crisis...we were missing things on the phone.”

One final reflection was that the isolation experienced by the general population during lockdowns contextualised the ongoing isolation experienced by carers when caring for a loved one at home.

6. Other themes

The role of housing in dying well at home

While not an explicit point of conversation, underlying all the discussions was the impact of the material realities of an individual’s accommodation and living situations on their ability to die at home, or support a home death for a loved one. Recurring concepts were the challenges of shared accommodation, the effects of lack of access to basic services, the lack

of support from the medical system for non-traditional forms of accommodation and the socioeconomic divide between those with homes that can readily support end-of-life care and those without.

Building community for care providers

While participants were largely drawn from larger organisations advocating for end-of-life care, the act of providing both informal and formal end-of-life care in Ireland is frequently isolated and isolating. Many participants reflected that engaging in these focus group discussions and interviews was the first time they had the opportunity to discuss the challenges of home care with other colleagues. There is a clear need and desire for more opportunities for knowledge sharing, peer support and building a community of practice for informal and formal care providers.

The Irish health system

Through the focus group discussions, participants also shared their thoughts on the existing state of the Irish healthcare system, and how it impacts carers, families and healthcare workers in their ability to help patients die in comfort and dignity at home (**Supplementary Table 5, 'Themes associated with Covid-19 and dying well at home', page 76**). As participants reflected on their own experiences of end-of-life care in Ireland, either as healthcare workers or as family and carers, the focus group discussions and interviews all moved to wider conversations on the challenges of the healthcare system in Ireland. Participants reflected that the health system is overstretched and under resourced, making it difficult to conceptualise it fully supporting individuals in dying well. The problems of the healthcare system will likely compound after Covid-19 as well, as deferred care in combination with Ireland's ageing population are setting up a healthcare crisis. Continued loss of staff further exacerbates issues, with one participant noting that previous healthcare assistants that retired from the role have yet to be replaced.

And for marginalised groups, the gaps in appropriate care only intensify their estrangement and alienation from the healthcare system. As observed by homeless services workers, there can be no hope of dying well at home as long as there is inequitable access to care in Ireland. For dying well at home to be realised, the differential health risks and social determinants of health for marginalised groups need to be mainstreamed into end-of-life care provision. For example, the need to account for high rates of trauma within the homeless population, or high rates of COPD and need for oxygen for residents of homeless residential services.

As noted by professionals working with and within the Traveller community, addressing inequalities within the political determinants of health, which members of the Traveller community are adversely impacted by (including housing, healthcare, and economic barriers, etc.), will always be at the root of any solution to improve their health outcomes.

This rings true when we try to envision a more inclusive health system for all groups in Ireland. Only then will we achieve equitable dignity in dying.

Discussion

From our 15 focus group discussions and interviews, across 49 participants, we heard from healthcare professionals from multiple disciplines, families and carers, and advocates. Participants spoke freely and shared a wealth of experience on their professional and personal experiences of end-of-life care in Ireland and dying at home. Despite the plurality of voices and the wide range of backgrounds, the focus group discussions and interviews consistently highlighted the important components of dying well at home and described in detail the current systemic issues in the Irish health system that lead to gaps in care for end-of-life care.

Strengths and limitations

A key strength of this research was the variety of voices and experiences included, representing a wide array of groups providing care in Ireland. However, the groups included are not a full representation of all groups affected by home care, and further work needs to be done to include the experiences of rural communities, economically deprived communities, migrant communities and disabled communities. Notably, our discussions focused on providers of formal and informal care. As such, it does not represent the direct experiences of those receiving care, which is an opportunity for future research.

For the purposes of this research, we did not delineate between palliative care for cancer vs. non-cancer illnesses. Historically, the provision of end-of-life services for those with cancer is far better developed in Ireland. While we did not investigate differences in care for cancer vs. non-cancer illnesses, this should be explored in future research.

Findings

An ideal death at home would be peaceful, calm and pain free, surrounded by the people you chose to be there. While it was noted that many people do die well at home, contrary to this, in many cases, findings through the 15 focus group sessions showed consistent barriers and difficulties for both the individual and those who care for them at home and also for the professionals providing care. Huge gaps were noted in our healthcare system, which were mainly around difficulties in knowing how and where to access appropriate care when most needed, delays in getting this care, resource issues and huge fears about what to do or how to cope out of regular provision care hours, outside the 9am - 5pm Monday to Friday working week. These issues often led to stressful situations for both healthcare professionals trying to contact each other through the different teams and for families/carers trying to access support, pain management and further help. These difficulties sometimes resulted in the person being cared for inappropriately been transferred to hospital or for families struggling to provide care in an unideal situation and not being able provide the appropriate care for their loved one. Participants also shared a wide range of possible solutions to make dying well at home in Ireland more holistic, more person focused and more equitable, which are listed in the recommendations section below.

Dying well at home in Ireland

Dying well at home means a dignified and comfortable death for the patient, free from pain.

In a well-functioning system, holistic care would be linked to psychological support services for patients, families, and carers, social support and to pastoral services.

In a well-functioning system, patients, families and carers would be sufficiently informed to face the challenges of end-of-life-care with confidence and free from anxiety. Patients, families and carers would have realistic expectations of the benefits and the wide array of challenges involved in providing end-of-life care at home. In a well-functioning system, healthcare teams would be sufficiently resourced to support families and carers in providing care, offering expert advice and timely response to challenges and complication. In a well-functioning system, social support for families and carers would be readily available and accessible, and sufficient to support the unpaid labour they do in caring for loved ones.

In a well-functioning system, holistic care would emerge through clear communication and collaboration between healthcare teams. Digital workflows and tools would be fully adopted to allow quick and precise referrals between services and allow responsive changes to care plans and prescriptions, such as pain management. Clear points of contact and 24-hour access to those points of contact would close gaps in provision of care, lessen inappropriate referrals and lessen anxiety and stress for both families and healthcare workers.

In a well-functioning system, there would be equitable provision of end-of-life care to everyone in Ireland. Rural communities would be well served by health and social services, with clear signposting of regional amenities. Marginalised groups would be able to readily access sensitive and appropriate care, responsive to their needs.

From the experiences of participants, we do not currently live in a well-functioning health system. In each group, individuals shared personal experiences of the health system failing patients, families and healthcare workers. The positive experiences that people had were often down to the hard work of individuals and healthcare teams going the extra mile to cover gaps in the system. However, as issues with the system continue to grow, this is unsustainable.

What is clear from the focus group discussions and interviews is that all these challenges are surmountable. Participants shared specific and actionable solutions which would improve not only end-of-life care in Ireland but the wider health system. Dying well at home is achievable with better information resources for patients, families, carers and healthcare workers; with greater communication and collaboration within the health system; with greater resourcing of healthcare services; with greater linkages to social services; and with lower barriers to care for marginalised groups.

Participants' Insights and Suggestions

Through meaningful, frank and honest discussions with the participants, the facilitators listened and noted the participants' ideas and suggestions and collaboratively explored further what types of support they felt were needed to be in place to support someone to die well at home. The participants were very engaged, invested and passionate, discussing many ways to improve the standard in the provision of holistic and quality end-of-life care in the home in Ireland. A brief list is summarised here and ways this could be achieved (the more detailed list is in Appendix 5).

Participants' ideas and suggestions covered many areas for improvements in care, such as:

1. Increase staffing across all multidisciplinary teams.
2. Improve access to specialist palliative services.
3. Increase access to all services 7 days a week.
4. Improve information for patients, families and carers.
5. Provide greater accessibility for end-of-life care.
6. Develop effective communication pathways between end-of-life services.
7. Electronic records (referrals/prescriptions).

The participants cited many ways this can be achieved:

1. Include Healthcare Assistants as part of the primary care teams.
2. A mapping out of health systems and signposting.
3. Increase services to provide a 7-day week service.
4. A digital portal with information resources for patients' families (entitlements and health information).
5. A liaison person on the community to coordinate end-of-life home care.
6. Training supports for carers and professionals and debriefing opportunities.
7. A platform to share experiences for patients, their carers and professionals.

Recommendations

To support people in Ireland to die well at home, Irish Hospice Foundation (IHF) will implement, lead and support on the recommendations. We will continue to conduct and be involved in research, advocacy and stakeholder engagement. We will align our work with the recommendations and framework of the new National Adult Palliative Care Policy (NAPCP, 2023). We will also use the important learnings of the National End of Life survey when released in 2024 to inform our work, along with other national data sets.

While the rich findings in this report acknowledge good experiences of people dying well at home, many of the findings have also identified huge gaps in services. The insights from the focus groups and interviews identified a need for signposting services, further research in a number of areas and advocacy to improve care for all.

IHF is committed to the next steps as outlined in the recommendations.

Next steps for IHF

1. To scope and develop an Information and Support Line. The report identified a need for signposting to services, a key theme in the study related to insufficient information and support for families and carers. We would envisage that the Information and Support Line will respond to enquiries and provide signposting to appropriate services. This resource, when established, will further inform IHF about current gaps in end-of-life information and services being experienced in the community.

2. Create an easily accessible map with information resources and current services for supporting end-of-life care. The map will signpost care options for patients, families and carers.

3. Support and scope further research to identify the barriers and inform the development of resources and co-ordination required to better support dying well at home, all of which were prevalent themes in the study.

Considerations for this research should include:

- A system mapping of what regional and local palliative and end-of-life supports are available for people in the community.
- Identify what gaps exist in services.
- Establish how individuals are referred and signposted to services.
- Explore the option for end-of-life co-ordinator roles in the community.

4. Conduct a review of existing resources and training with a view to making these accessible to the community. Participants in the focus group discussions highlighted the need for more accessible dedicated, educational end-of-life and bereavement resources and also the need to broaden the availability of standardised training support for carers and healthcare professionals. We would also seek to develop further information and educational resources through stakeholder engagement and partnership with service providers.

5. Identify best practice community-based end-of-life models of care that are socially and culturally appropriate to address the specific barriers to care faced by underserved groups to support dying well within their communities. The discussions identified that further research into the **health inequalities** faced by historically underserved communities is needed. This includes low socioeconomic status groups, migrants, Traveller communities, rural communities, disabled groups and people who are homeless.

6. Strengthen our advocacy for primary palliative care supports that help people remain in their community and die at home if this is their wish and is possible. It will include advocating for continued improvements in homecare and supports for family carers.

Conclusion

The startling inconsistencies in the provision of end-of-life care was very apparent throughout the sessions. The huge financial, psychological, physical and emotional pressures placed on both families, carers and healthcare professionals results from not only a lack of resources but system failure. This system failure impacts how healthcare teams interact and how people in the community can access appropriate services, leading to inappropriate care and treatment for people who wish to die at home. Care systems need to be mapped out clearly.

Information on how to access care must be transparent, inequity of services across all regions needs to be addressed. Strong discussions need to be had about the 9am – 5pm Monday to Friday care provision, people become ill and can become sicker at any time of day or night, the lack of services outside these hours is extremely frightening for people, a huge risk, and also a burden for the skeleton staff who are left to cover these hours.

Irish Hospices Foundation's new Dying Well at Home Programme will endeavour to work towards bridging some of the gaps in services by working with its partners to develop resources and supports. However, on a national level, a serious review is needed both systemically and functionally to enhance quality and good end-of-life care for people who wish to die in their own homes in the community.

Every death matters, and we only have one chance to get it right.

The aim of the HSE's Adult Palliative Care Services – Model of Care (2019) is that: *“Every person with a life-limiting or life-threatening condition can easily access a level of palliative care appropriate to their needs regardless of care setting or diagnosis in order to optimise quality of life.”*

IHF wish to collaborate with our stakeholders and work towards achieving this goal.



Appendices

Appendix 1 Invitation to participants

Dear xxx

As part of our work to support end-of-life and palliative care across Ireland, Irish Hospice Foundation (IHF) is beginning a process of cross-sectoral stakeholder consultations to hear from individuals, groups and services about their experiences and views on home based end-of-life care. We also wish to listen and learn from people's experiences and insights in relation to home based end-of-life care during the pandemic.

We are reaching out to you, as we know you have an important role in providing end-of-life care for people who wish to die at home, and their loved ones. We are keen to understand more about your experiences of supporting end-of-life care at home and what it means for the person, their families, and for the people caring for them.

As you may know, Irish Hospice Foundation supports the delivery of best practice end-of-life and palliative care within all settings and at all levels across Ireland. By collaborating with people across the sector, we have established end-of life programmes within both hospitals - the Hospital Friendly Hospice programme - and long-stay residential care settings (Nursing Homes) – the Compassionate End-of-Life (CEOL) programme. We are interested in expanding our work to support individuals who wish to die at home, their families, and the professionals who provide end-of-life and palliative care at home. To do this, we are developing our Dying Well at Home programme to complement IHF's existing Primary Palliative Care Programme and Nurses for Night Care service which are focused on the home setting.

People call us every week looking for advice and support on dying at home. Hence, we would be very grateful to have the opportunity to discuss with you how we can support them and also complement the work you do through our resources and our advocacy work. We are planning to meet individuals and groups via zoom over the next 6 weeks and it would be great to have XXXXXX in this consultation.

I would really appreciate it if you could contact me to let me know if you are interested in sharing your experiences and views with IHF. I would be more than happy to chat with you and to go through the process in more detail at any time.

With kind regards,

Marese

Appendix 2 Briefing document



Focus group discussions and interviews to inform the development of Irish Hospice Foundation's Dying Well at Home Programme.

We are looking forward to meeting you and hearing your views. Please see the following information about the programme and a brief outline of the focus group session.

Background

Irish Hospice Foundation supports the delivery of best practice end-of-life and palliative care within all settings and at all levels across Ireland. By collaborating with people across the sector, we have established end-of-life programmes within both hospitals - the Hospital Friendly Hospice programme - and long-stay residential care settings (Nursing Homes) – the Compassionate End-of-Life (CEOL) programme. We are interested in expanding our work to support people who wish to die at home, their families, and the professionals who provide end-of-life and palliative care at home. We want to learn more about how palliative care and end-of-life care across Ireland functions within different 'home' settings across Ireland.

We are reaching out to you, as we know you have an important role in providing end-of-life care for people who wish to die at home, and their loved ones. We are keen to understand more about your experiences of supporting end-of-life care for people who are homeless/housing insecure, what it means for the person, their families, and for the people caring for them.

Context

In 2017, 23% of Irish people died at home. If current death rates at home remain stable into the future, the number of people dying at home will increase due to the projected rise in population. Covid-19 has strengthened IHF's belief that more can and should be done to enable people to live and die at home if this is their wish. We believe that more can be done to enable greater choice about place of care as death approaches - to allow people to be cared for and, if possible, to die at home if this is their wish.

Briefing document (continued)

IHF receive enquiries regularly from people seeking advice and information about end-of life care at home. Hence, we would be very grateful to have the opportunity to explore discuss with you how we can best support them and also to help complement the work you do through our information supports, resources and advocacy work.

How you can contribute to the Dying Well at Home Programme

As part of our work to support end-of-life and palliative care across Ireland, Irish Hospice Foundation (IHF) is beginning a process of cross-sectoral stakeholder consultations to hear from individuals, groups and services about their experiences and views on home based end-of-life care. We also wish to listen and learn from people's experiences and insights in relation to home based end-of-life care during the pandemic.

This focus group session will provide an opportunity for people to share their views on what it is that makes it possible for someone to die well at home.

In preparation for the focus group, we are asking you to consider the following questions:

- What makes it possible for someone to die well at home?
- What are the barriers that prevent someone from dying at home if that is their wish and is appropriate?
- What have your experiences been, if any, of end-of-life care at home during the pandemic?

The focus group will run for approximately one and a half hours online, using Zoom, and will be facilitated by members of IHF's Healthcare and Research teams. The information from these focus group discussions and interviews will be treated confidentially. Points will be summarised and will not be attributed to any one individual.

The zoom sessions will be recorded for transcription notes to be gathered afterwards and once transcribed the recordings will be deleted.

For more information about the programme and about your participation please contact Marese Damery at marese.damery@hospicefoundation.ie or Nicole Forster at nicole.forster@hospicefoundation.ie or on 01 6793188.

Appendix 3

Participant consent form



Focus group discussions and interviews to inform the development of Irish Hospice Foundation's Dying Well @ Home Programme

Project title:

The development of Irish Hospice Foundation's Dying Well @ Home Programme

Declaration of the participant

I have read the Focus Group briefing document for this focus group and I understand the contents.	
I have had the opportunity to ask questions and all my questions have been answered to my satisfaction.	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason and without any negative consequences.	
I consent to taking part in the focus group	

Participant

Participant name:

Date:

Please return completed consent form to Marese Damery or Nicole Forster: marese.damery@hospicefoundation.ie or nicole.forster@hospicefoundation.ie in advance of the focus group session.

Appendix 4 Questions

Dying Well at Home & Reflections Project

Stakeholder Engagement meetings- Focus group discussions and interviews

Professional and personal experience.

Overall time 1.5 hours

Irish Hospice Foundation's vision is an Ireland where people experiencing dying, death and bereavement are provided with the care and support they need.
Every death Matters and we only have one chance to get it right.

Opening: 16 minutes

- Welcome and introductions. (3)
- Description of the Dying Well @ Home Programme, background and rationale. (5)
- Comment about Reflections process. (3)
- Set the scene with 2 Vignettes which can be referred to throughout discussions. (5)

Focus Group Question: 50 minutes.

Make sure to focus on before and now (COVID)

1. What does a good death mean to you? in one or two words (6)
2. In your experience, what is the main thing that the person who wishes to die at home tells you that they want and need? (10)

What about those who are caring for them: their family or carers?

- What makes that possible?
 - What makes that challenging?
3. When the experience seems to be working well for the person and their family at home, what are the enablers that are supporting them to have this positive experience? (8)
 4. Are there things that aren't available/possible now that you think would make a difference to:

- a. to your work
- b. to the end-of-life palliative experiences of people who wish to die at home,
- c. and their loved ones/carers?

What difference would it make if that/those were possible? (10)

5. Irish Hospice Foundation is planning to develop further resources with information and signposting on where to go for care and advice when supporting someone to die well at home (8)
 - Is this something you think is needed or would be of value, what resources do you feel will be helpful?
 - Who do you think we would need to involve to develop these?
6. Open to the group to have an open-ended discussion for (8)

Reflections questions: (20) min

- What has your experience been of end-of-life care at home during the pandemic?
 - o (If report challenges) Was that specific to the pandemic or were these issues ones you faced before the pandemic?
 - o (If report positives) What would be needed to keep that going into the future?
- Have your experiences during the pandemic revealed anything about what needs to change to support home based end-of-life care in Ireland?
- What about you? What supports (practical, emotional, other) do you need/think you would need to provide home based end-of-life care?

Close: 4 minutes

Appendix 5

Participants' insights and suggestions

Participants recommendations to improve end-of-life care at home:

- **Information on how to navigate and access supports and resources:**
 - Signposting/mapping out of health system referrals.
 - Mapping of local services and how to access them.
 - Entitlement information such as medical care, carers allowances.
 - Guides on progression of life limiting conditions.
 - Step by step guide for home care.
 - Realistic, including worst case scenarios.
 - Just in case prescriptions.
 - Platform/resource for carers/families to share experiences.
 - Repository for reselling/sharing medical equipment (beds etc).
 - Information on caring for the deceased at home and next steps.
 - Guides on pain management, opioid pump.
- **Dedicated palliative care services:**
 - Specialist palliative care teams 7 days a week.
 - Package of minimum number of consultations.
 - Toolkit for managers of healthcare teams.
 - Training of healthcare assistants in palliative care.
 - Basic training for lay people at home providing care.
 - Improvement in access and scope of GP palliative care grant.
- **Improved healthcare resources:**
 - Improved staffing capacity.
 - Debriefing opportunities for staff.
 - Platform/resource for staff to learn from each other and share experiences throughout different CHOs Nationally.
 - Training on specialised care for marginalised groups.

- **Improved communication/referrals:**
 - Care coordinator/point of contact.
 - Electronic records (referrals/prescriptions).
 - Contact number for care teams.
- **Improved continuity of care:**
 - Access to services at night and weekends.
 - Out of hours/24-hour support line.
- **Improved holistic care:**
 - Improved visibility/access to social support for carers.
 - Greater integration with social services.
 - Greater integration with community services.

Appendix 6
Supplementary tables

Supplementary Table 1: Themes associated with conceptualising a good death

Global theme Conceptualising a good death					
Organising themes	End-of-life wishes fulfilled	Patients, families and carers are suitably informed	Patients, families and carers have good access to care	Patients, families and carers have ongoing sustained support	Patients receive individualised, appropriate care
Basic themes	To die in a comfortable, calm environment	Patients, families and carers understand the role of palliative and healthcare teams	Patients, families and carers have access to psychological support	Patients, families, and carers have ongoing support from multidisciplinary teams	Patients' deaths are pain free, with no suffering
	To die in the place of their wishes				Patients receive disease-specific care
	To die in privacy	Patients, families and carers receive clear communication on pain relief	Patients, families and carers have access to equipment necessary for home care		End-of-life care is responsive to progression severity of illness
	To die with dignity				Patients receive holistic end-of-life care
	Patients are involved in decision making	Patients, families and carers receive expert medical advice	Open discussions between family, carers, patients and health teams		Patients receive appropriate symptom management
	Opportunity for patient to share their health journey				Patients, families and carers receive appropriate support during complex deaths
	Patient does not feel like a burden	Patients are surrounded by people they want present	No death is a good death		

Supplementary Table 2: Themes associated with enabling a good death at home

Global theme Enabling a good death at home					
Organising themes	Appropriate support for family and carers	Specific forms of palliative care	Good access to care	Co-ordination of care	Other factors
Basic themes	Families and carers are suitably informed, and not afraid of home care	Access to specialist palliative care	Immediacy of support	Palliative care coordinator	Efforts to keep a house feeling like a home
		Access to a hospital bed for home care	24-hour access to care	Positive family dynamics	Families and carers have previous experience of end-of-life care
	Families and carers understand their role in providing home care	Chronic disease management scheme which includes care planning	Pre-emptive linking of families and carers to pastoral or counselling services	Close relationship with GPs, facilitating adjusting of care	
					Families and carers feel empowered to provide home care
	Families and carers understand the stages of dying	Public Health Nurses	Occupational therapists	Continuity of care and follow-up	Unity in messaging to family and carers by different healthcare teams
	Families and carers have expectations of home care set by professionals				

Supplementary Table 3: Themes associated with barriers to dying well at home

Global theme Barriers to dying well at home				Global theme Barriers to dying well at home		
Organising themes	Insufficient information and support for families and carers	Inadequate access to care	Poor co-ordination of care	Insufficient resources to provide care	Care is unsuitable for individual or community	Lack of other social support
Basic themes	Lack of training of families and carers in specifics of home care	Lack of timely pain management support	Unclear referral pathways	Support needed for adapting the house	Carers sometimes shelter patients from reality of illness	Unable to go back to work after caring for a loved one
	Carers have little time for breaks, leading to burning out	Inadequate support once patient discharged	Only severe cases get timely care access	Reliance on nursing homes due to lack of other services	Insufficient care for homeless people living with chronic mental health conditions	Reduced social support as a carer
		Lack of access to public health nurses due to staffing	Referrals lost between services		End-of-life care difficult for groups in institutions	
	Patients try to minimize their experience to comfort families	Lack of weekend services	Poor triage of patients	Lack of psychological support for care staff	Poor knowledge by services of specific needs of community	Lack of timely communication between hospital and community social services
		Lack of 24-hour care	Rapid discharge policy in HSE affects care continuity		Lack of specialised care	
	Lack of emotional support for families and carers	Lack of timely change to prescriptions from GP	Difficulty stopping preventative medicines in palliative reviews	Resources not in place for homeless people to die in residential services	Lack of ground floor residential accommodation for homeless creates accessibility issues	Delays in social support payments
	Anxiety for families and carers around out of hours care	Delays in equipment			Unclear division of roles between health teams	
		Lack of support for traumatic deaths	Lack of equitable access to care	Lack of shared responsibility between health teams	Lack of language support for non-English speakers	Inappropriate hospitalisation due to lack of alternatives
	Family and carer fear of patient hospitalisation	Rationing of night care	Poor rural access to services		End-of-life care for homeless people managed by social care staff, with insufficient capacity and skills for healthcare	
		Poor understanding of short term vs. sustainable home care		Home care package reduces access to nurses		Patients with previous poor experience of care assume home care in unachievable
	Expectations by families and carers out of line with locally available resources	Limited hours of support within care package	Families and carers chose home care due to lack of alternative settings	Nursing homes inappropriate for homeless people's needs	Unaddressed complex needs of degenerative disorders	
		Lack of access to primary care teams for nursing home residents			No facilities to support dying at home on Traveller sites	
	Fear of death in the Traveller community prevents advance care planning	Lack of medical card prevented care access	Under-resourced paediatric support staff	GPs understaffed	No space in Traveller homes to support terminally ill	
					Traveller reliance on hospice and hospital	
					No support for carers in Traveller community	
		Palliative care grant underfunded and underused		Change of personnel leads to loss of relationship with services		
				Lack of health fluency to negotiate with health services for suitable services		
				Lack of cultural awareness training for health staff		
				Lack of basic services on Traveller sites		

Supplementary Table 4: Themes associated with future resources for end-of-life home care

Global theme Future resources for dying well at home				Global theme Future resources for dying well at home		
Organising themes	Information and education resources for families, carers and patients	Education and training for healthcare workers	Dedicated palliative care support for life-limiting conditions	Essential resources	Other resources/supports	Tools and services
Basic themes	Step-by-step information for families and carers	Signposting information for families and carers	More specialist palliative care teams	Greater co-ordination	Greater focus on community healthcare	24-hour advice line
	Greater visibility of existing services	Information on end-of-life conditions	Standardisation of care between health services	Contact liaison	Clarity between healthcare, patients and families on severity of condition	Toolkit for manager of health teams
	Realistic discussions on worst cases for illness progression and management	Training on working with rough sleepers	Continuous nursing contact	Timely access to equipment	Clarity between healthcare, patients and families on timelines for end-of-life care	Telemedicine
	On emotional support for carers	Information exchange between nurses	Healthcare assistants trained in palliative care	Blended model of health and social care	End-of-life care options for different home situations	Map of local services
	Non-medical advice on providing comfort at home	Adoption of international models of care	Dedicated package of care with minimum number of consultations	A right to be seen in person	Contact details available for health teams	Map for accessing equipment
	Education on morphine pumps		Greater integration of GPs within nursing homes	Debriefing for staff	Clear handover between discharge team and home care	Fully electronic records
	Signposting care for marginalized communities			More staffing	Identify point of contact within family/carers	Preference for digital resources
	Advance care planning			Better pay to retain nurses	Signposting to social care entitlements	Image-heavy resources for groups with literacy challenges
	Access to catheter materials				Prioritization of end-of-life wishes at point of emergency admittance	
	Shared experience of carers and families				Clear storage of advance care plans	
	Awareness raising for home care package				Early advance care planning for degenerative disorders	Mobile-focused resources (text services) for groups reliant on phones
	Guide for renting/buying equipment				Health service advocate for carers	
	Death arrangements				Advice for family/carers on managing visitors	
	Available social support					

Supplementary Table 5: Themes associated with Covid-19 and dying well at home

Global theme Effects of Covid-19 on providing palliative care at home		
Organising themes	Negative effects	Positive effects
Basic themes	Carers pulled out of homes when patients were tested for Covid-19	Prevented visitors to the home, less stress for families and patients
	Families feared outsider coming into the home	Less reliance on hospitals
	Residents restricted in homeless facilities	Greater flexibility in health teams, reactive
	Families and carers felt little capacity to live with future lockdowns	Challenged ideas of what is possible in care provision
	Families less aware of disease progression due to inability to see patients regularly	Improved access to controlled drugs
	Difficulty challenging non-compliance with restrictions	Increased access to telemedicine
	Patients with complex needs unable to be admitted to hospital	Online access to funerals
	Interruption of grief rituals	Contextualised the ongoing isolation of carers
	Worse hospital experience	
	Nursing homes excluded from specialist palliative care services	
	Became acceptable to refuse provision of medical services	
	Reduced obligation for in-person care	
	Patients died alone	
	Increased reliance on community pharmacists	
	Families had more capacity to be present for care	
	Referral gaps exacerbated	
	Families given choice of nursing home treatment or patients dying in hospital	
	No access to occupational or speech therapists	
	Traveller support workers not designated as frontline workers	

Supplementary Table 6: Themes associated with covid-19 and dying well at home

Global theme Other themes	
Basic themes	Current health system is too overstretched and under-resourced to give people a good death
	Inappropriate referral of immune compromised patients to hospital emergency department by GP during out of hours
	Greater access to care without delays would help families' and carers' anxiety
	Need to conceptualise homeless residential services as home care setting
	Advance care planning became irrelevant due to fast disease progression
	Dying well at home is not achievable when there is ongoing unequitable access to care
	Homeless population require trauma informed services
	Previous healthcare assistants retired from the profession and haven't been replaced
	After Covid-19, deferred care and an aging population are setting up a health crisis
	When we don't provide suitable end-of-life care, we create traumatic situations for patients, families, carers and healthcare workers
	Ongoing challenges in shifting palliative care to the community
	Addressing the cultural, social and economic barriers for the Traveller community must always be the basis of any healthcare solutions

Appendix 7

Glossary of terms

Advance Care Planning

Advance care planning is the process of discussing end-of-life care with someone who works in healthcare and/or a member of your family/friends.

Anticipatory Grief

Grieving a future loss.¹

Carer

A carer is anyone, who looks after a family member, partner or friend who needs help because of their illness and cannot cope without their support. The care that carers provide is unpaid. The relationships that carers have with people they are caring for are diverse, complex and unique and should not be assumed.

End-of-life Care

Care designed to meet the physical, spiritual, social, practical, and psychological needs of patients and caregivers experiencing life limiting illness at end of life.

Family

“Family” in this report means any person(s) who plays a significant role in an individual’s life. This may include a person(s) not biologically or legally related to the individual.²

General Practice Nurse

A General Practice Nurse is a registered general nurse who works with a General Practitioner (GP). General Practice Nurses are privately employed by the GP. They provide holistic nursing care to patients of the GP surgery.³

Hospice

A hospice is a unit where the main activity is providing specialist palliative care. Other services are developed around these units such as in-patient care, day care, community palliative care, out-patient care and bereavement services.

Just in Case Prescriptions

Also known as ‘anticipatory medicines’, these are medicines that are given ‘just in case’ you may need them. These may be medicines to manage pain or other symptoms if you need it, especially during the night or at the weekend.

Life-Limiting Illness

An incurable condition that will shorten a person’s life, though they may continue to live active lives for many years.

Palliative Care

Palliative care is an approach that improves the quality of life of people facing the problems associated with life-limiting illness and supports their families. The palliative care approach focuses on the prevention and relief of suffering by means of assessing and treating pain and other physical, psychosocial or spiritual problems.⁴

Primary Palliative Care

Holistic (whole person) approach to care for people who have advancing life-limiting conditions who are living at home. It includes improving quality of life through managing symptoms, and addressing psychological, social and spiritual issues.

Public Health Nurse

Public Health Nurses (PHN) work within a defined geographical area, providing care that is preventative and curative through a range of services tailored to the needs of the individual, including nursing care in the home and palliative care of the terminally ill.⁵

Quality of Life

An individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.⁶

Community Registered General Nurse

Community Registered General Nurses (CRGNs) work alongside the PHN. The primary focus of the CRGN is on individual patients and care of the older person. The CRGN works closely with the PHN to assess plan and implement nursing care and works in the home and clinic environment.⁷

Respite

Temporary care given by healthcare providers to allow family caregivers time to rest.

Specialist Palliative Care

Specialist Palliative Care (SPC) services have an important role in supporting other healthcare providers in hospital, residential care and community settings to meet the palliative care needs of persons with life-limiting conditions and their families. When a person’s palliative care needs are anticipated to become or are more complex and difficult to manage, access to SPC services is required.⁸

Voices4Care

A forum established to learn from people’s personal experiences of palliative care and to inform and influence palliative care on the island of Ireland.⁹

1. <https://hospicefoundation.ie/i-need-help/i-want-to-think-ahead-old/facing-a-coming-loss/>

2. <https://www.thehrfoundation.org/professional-resources/lgbtq--inclusive-definitions-of-family>

3. <https://www.hse.ie/eng/services/list/2/primarycare/generalpracticenursing/>

4. <https://www.hse.ie/eng/about/who/cspd/ncps/palliative-care/>

5. <https://www.hse.ie/eng/services/list/1/lho/dublinse/public-health-nursing/>

6. <https://www.who.int/tools/whoqol>

7. <https://healthservice.hse.ie/about-us/onmsd/onmsd/specific-programmes/phn-community-registered-general-nurses.html>

8. <https://www.hse.ie/eng/about/who/cspd/ncps/palliative-care/resources/referring/>

9. <https://online.hscni.net/ireland-institute-hospice-palliative-care-aiihpc-seeking-new-volunteers-voices4care/>



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To die and grieve well wherever the place

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