

Dying Well at Home Programme

Information and resources to support End of Life care for people
who wish to die at home and those who care for them

Siobhán Murphy

Our Work Focus

1.



**Conversations
about Death**

2.



**End of Life
and Dying**

3.



**Bereavement
and Grief**

Dying, Death & Bereavement



35,477 deaths
were registered in
Ireland in 2022



83% of these
deaths are people
aged 65+



Up to **10** people
are significantly
impacted for every 1
death



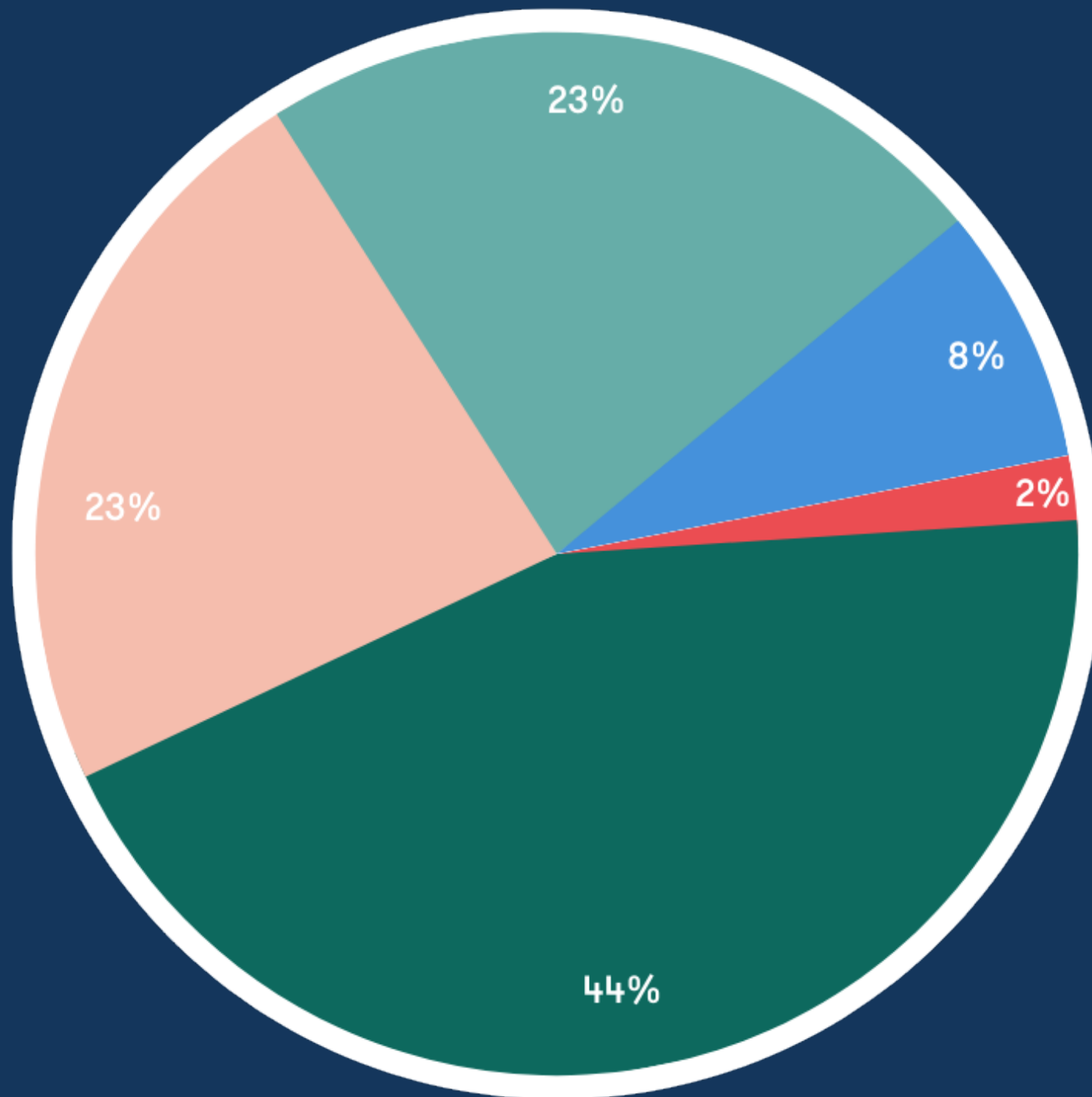
Nearly **100** people
die in Ireland every
day



Cancer (**31%**) and
heart-related disease
(**29%**) are the leading
causes of death



Over **350,000**
people are grieving
a death every year



Place of Death - Ireland 2018

- Hospitals
- Nursing Homes
- Home
- Hospices
- Elsewhere

Irish Hospice Foundation

Supports best practice in palliative and end-of-life and bereavement care in all settings through it's multiple programmes:

- Home Setting: Dying Well at Home
- Acute Hospitals: Hospice Friendly Hospitals
- Nursing Homes: Caru
- Public Engagement- Think Ahead
- Bereavement
- Grief in the Workplace



Dying Well at Home

Developing and building on existing IHF initiatives such as:

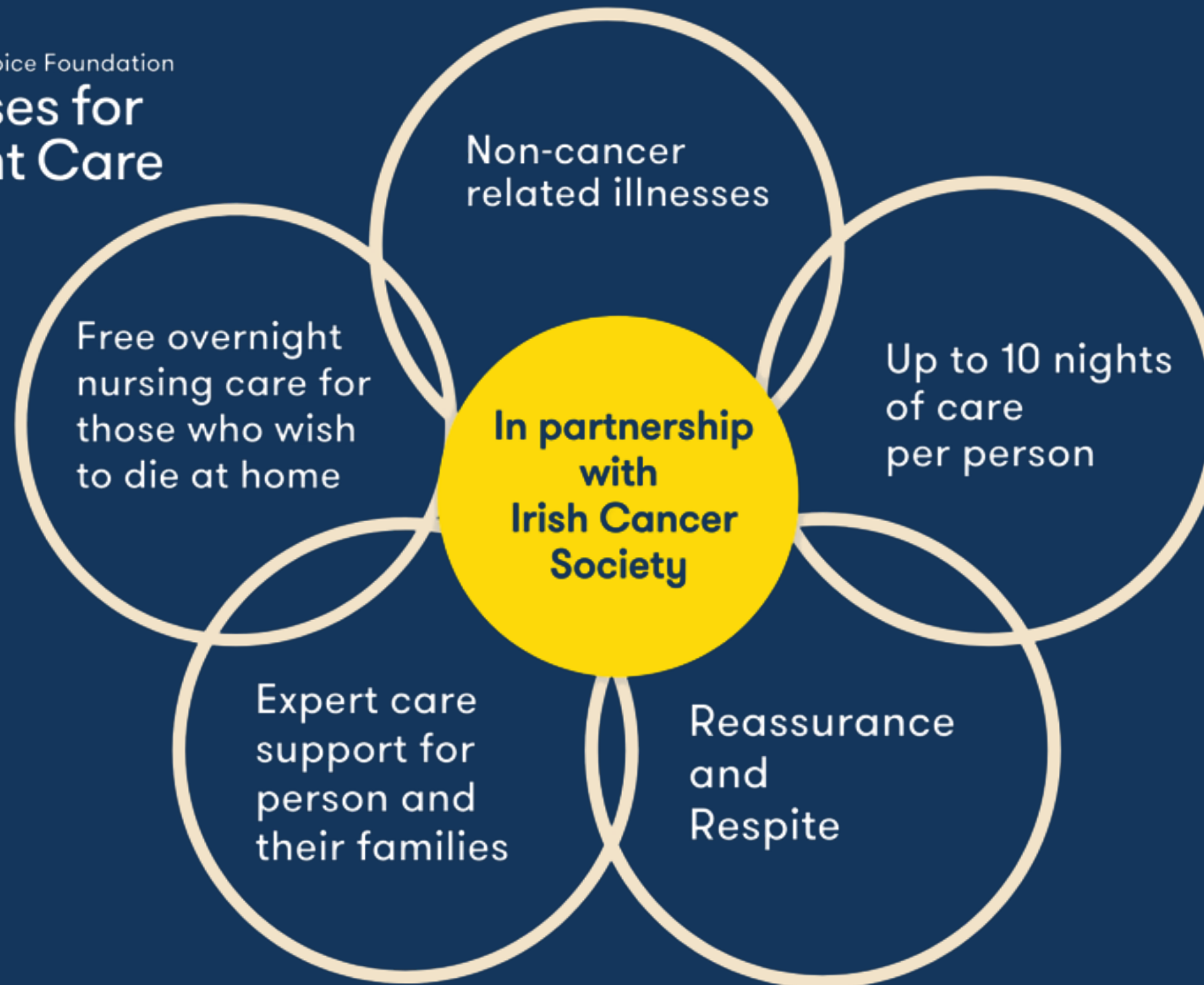
- Primary Palliative Care Programme (PPC)
- Palliative Care for All (all life-limiting conditions)
- Advocacy
- Nurses for Night Care Service





Irish Hospice Foundation

Nurses for Night Care



Irish
Hospice
Foundation

Dying Well at Home - in Development

Dying Well at Home Focus Group Report

- Conducted to inform DWAH development
- 15 focus group discussions and interviews, across 49 participants
- Included family carers, healthcare professionals, patient advocacy groups
- Participants often drew on both professional and personal care experience



Who We Spoke To



- Alzheimer Society of Ireland
- Progressive Supranuclear Palsy Association
- Care Alliance Ireland
- Family Carers
- Irish Cancer Society Night Nurses
- Community Pharmacists (Irish Pharmacy Union)
- Specialist Palliative Care Community Nurses
- Traveller Mental Health & Primary Healthcare Services
- Voices4Care Members
- Primary Palliative Care Steering Committee

Questions we asked

**What factors
enable a good
death at home?**

**What
constitutes a
good death?**

**What barriers
prevent
home deaths?**



Defining a Good Death

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

Defining a Good Death

- Having loved ones 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.”

Defining a Good Death

- Having loved ones present
- Knowing who is responsible for 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.”

Defining a Good Death

- Having loved one's present
- Knowing who is responsible for what
- Access to clear, written information at home

“ .. 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.”

Barriers

- Limited access to 24 hour care
- Difficulty accessing information

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

“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.”

Enablers

- Practical Care: Information on oral care, eye care and hygiene
- Equipment Sourcing: Where to access equipment in your area
- Resources: Information and signposting to services and supports

“[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.”

“It would be great to have a map, search for support’ it is the things like the bed, were 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.”

Identified Needs and Future Resources

- Central contact point or liaison for families
- Interactive map to locate services, equipment, and supports
- Information on patient hygiene, moving patients, oral care
- Clear, accessible guides on practical steps (e.g., getting a death certificate)



Strengths and Gaps

Strengths:

Wide range of voices and care providers included

Limitations:

Lacks voices from rural, economically deprived, migrant and disabled communities

Does not capture direct experiences of care recipients



What We Learned

- Inconsistencies across provision of end-of-life care
- Pressures placed on both families, carers, and healthcare professionals' results from not only a lack of resources but systemic.
- Information on how to access care needs to be transparent, inequity of services across all regions need to be addressed
- Care systems need to be mapped out clearly.
- Out of hours services need to be reviewed.

Recommendations

1. To scope and develop an Information and Support Line
2. Create an accessible service/resource map
3. Support further research to identify barriers
4. Review existing resources and training and make them accessible to the wider community
5. Identify best-practice, culturally appropriate community end-of-life models of care
6. Strengthen advocacy for primary palliative care supports that help people remain in their community and die at home if it is their wish and possible



Dying Well at Home - In Development

New Developments:

Information and Support Line - October 2024

eLearning Programme : 2025

Information Leaflets and Booklets: 2025

Research to support new developments: 2025



Irish Hospice Foundation Information and Support Line

End-of-Life Care | Advance Care Planning | Palliative Care

1800 60 70 66

Mon - Fri | 9am - 1pm



Information and Support Line

End-of-Life Care - Advance Care Planning - Palliative Care

Provides information and practical support on:

- **End-of-Life Care:** An important part of palliative care provision and usually commences when a person is in their last year of life.
- **Advanced Care Planning:** Thinking about, talking about, and recording your choices, values, and preferences for your care at end of life and your wishes for your funeral.
- **Palliative Care:** Supportive care offered throughout the progression of your life-limiting illness or at phases of your illness



Enquiries and Statistics

Pre-launch (1 Jan – 31st August 2024):

- 49 enquiries

Post-launch (1st January - 31st August 2025):

- 296 enquiries
- An increase of 504%

Post launch statistics

- 10 month period 30th October 2024 to 31st August 2025 371 calls to line
- 335 calls have been successfully answered
- Those that don't progress are due to:
 - Person not leaving voicemail
 - Person not responding to phone call or email

Post launch statistics

Estimated impact of 1709 people reached

Of calls received:

- 31% from a loved one
 - 27% from a professional
 - 23% from members of the public
 - 4% from a person with a LLC
-
- Enquiries have been received from all health regions
 - Enquiries received from all counties except Carlow and Leitrim

Enquiry Method



64% by phone



36% by email



Lisa Dunne, Information and Support Line Lead

Who's Contacting Us?

Carers, family members, friends, relatives, healthcare professionals, and members of the public

What Are People Calling About?

Primary Call Topics:

- Advance Care Planning
- Promotional Material
- Dying Well at Home
- Education
- Palliative Care

Secondary Call Topics:

- Palliative care
- Advance Care Planning
- Advocacy
- Education
- Volunteering

Emerging Themes

- **Understanding palliative care** - What it is, and how to access it
- **Information Sharing** - Lack of communication
- **Confusion** around DWAH care packages
- **Loved one left to coordinate care** - Left to case-manage the dying person
- **Bereavement** - we can provide support through our Bereavement Support Line.



Irish
Hospice
Foundation

To die and grieve well wherever the place

Dying Well at Home eLearning



Overview

Dying Well at Home eLearning

Recommendation 4 from Focus Group Report : Conduct a review of existing resources and training with a view to making these accessible to the community.

- Aim is to support formal and informal carers providing end of life care at home
- Accessible, free eLearning resource that is aligned with the National Palliative Care Competence Framework
- Target audience is anyone providing care for a person who is at end-of-life care in their home (this could be carers, healthcare assistants, community-based professionals)

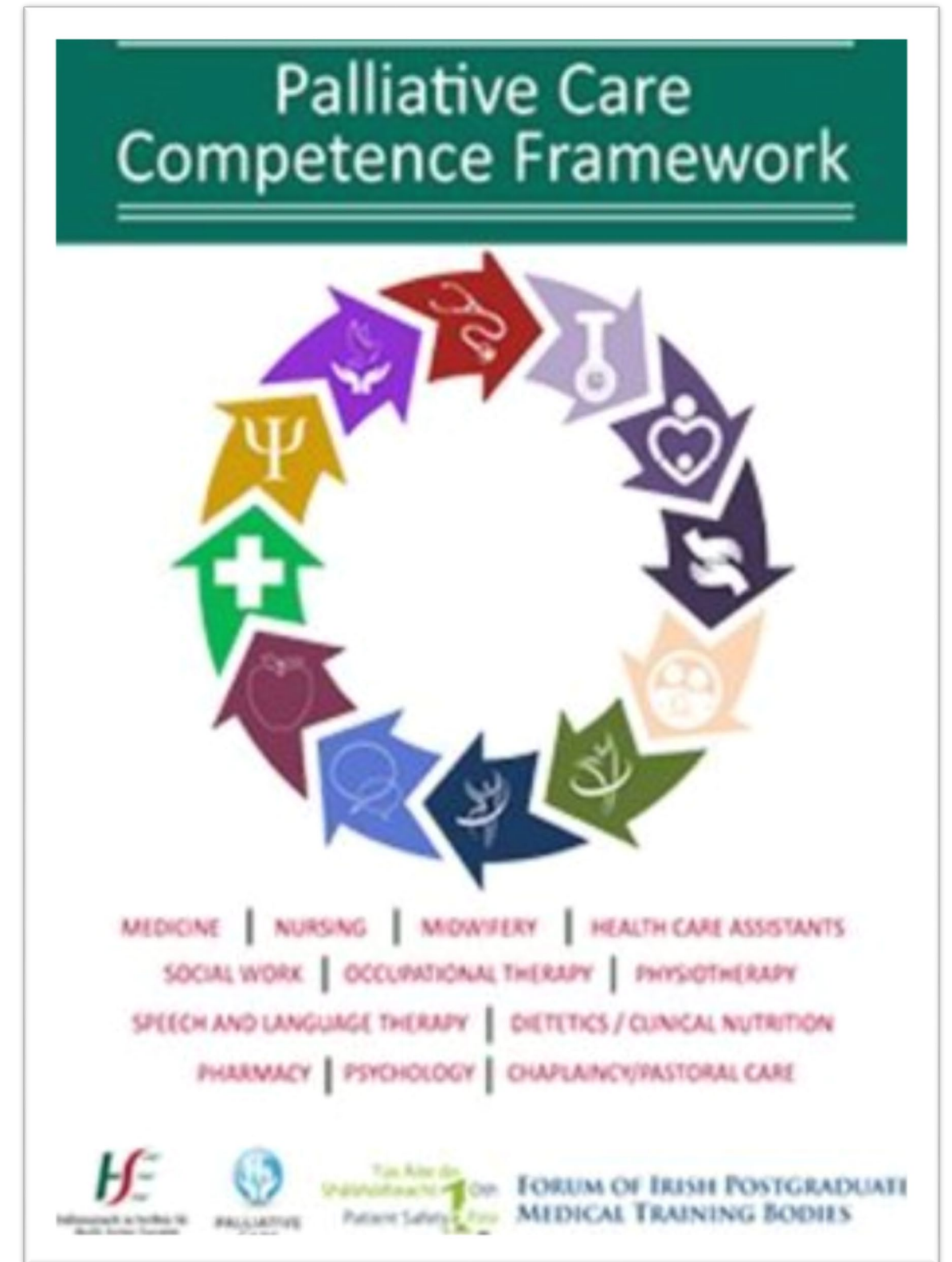
Core Modules

- **Module 1:** Palliative and End-of-Life Care
- **Module 2:** Advance Care Planning
- **Module 3:** Communication Skills at End of Life
- **Module 4:** Preparing to Care for Someone at Home at End of Life
- **Module 5A & 5B:** Practical Tips when Caring for Someone at End of Life
- **Module 6:** Loss, Grief and Bereavement



Dying Well at Home eLearning Development

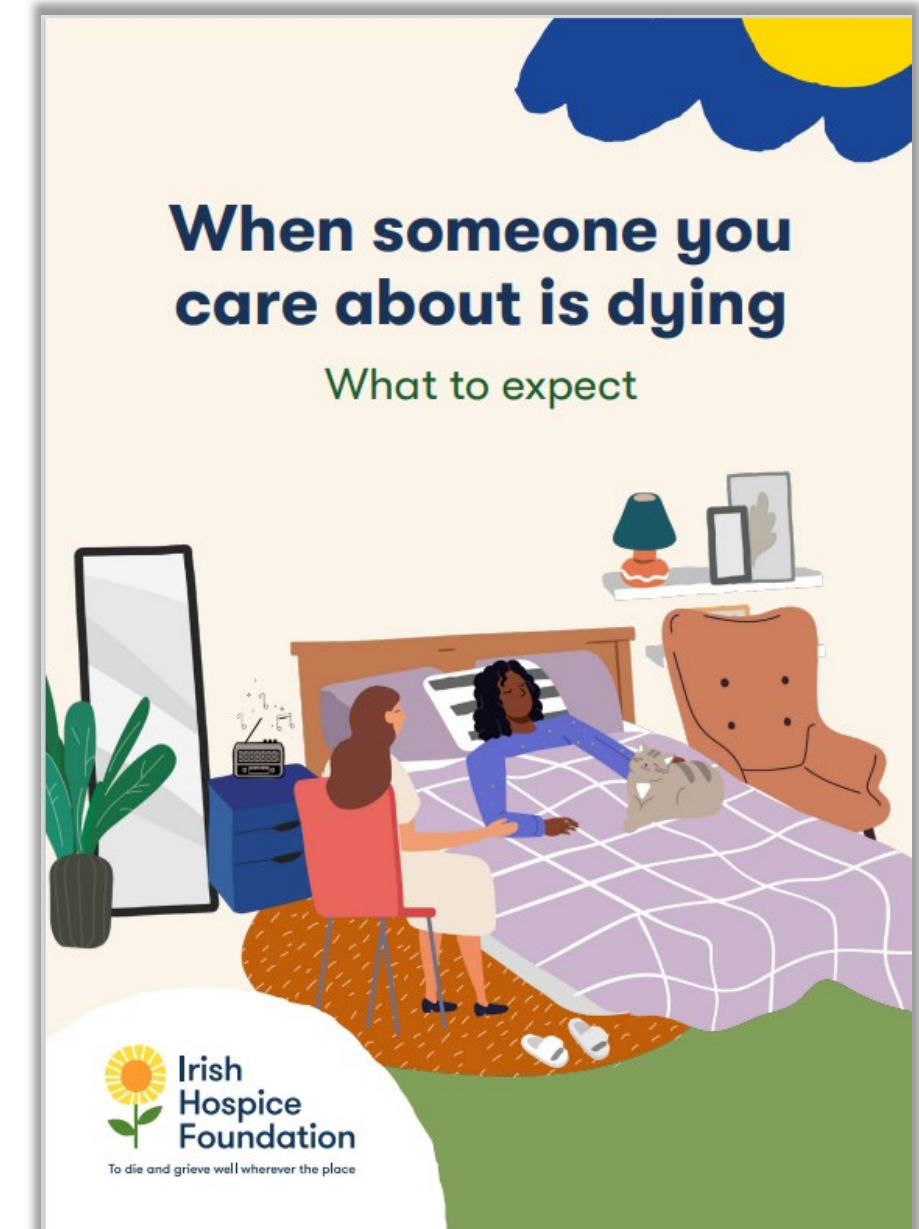
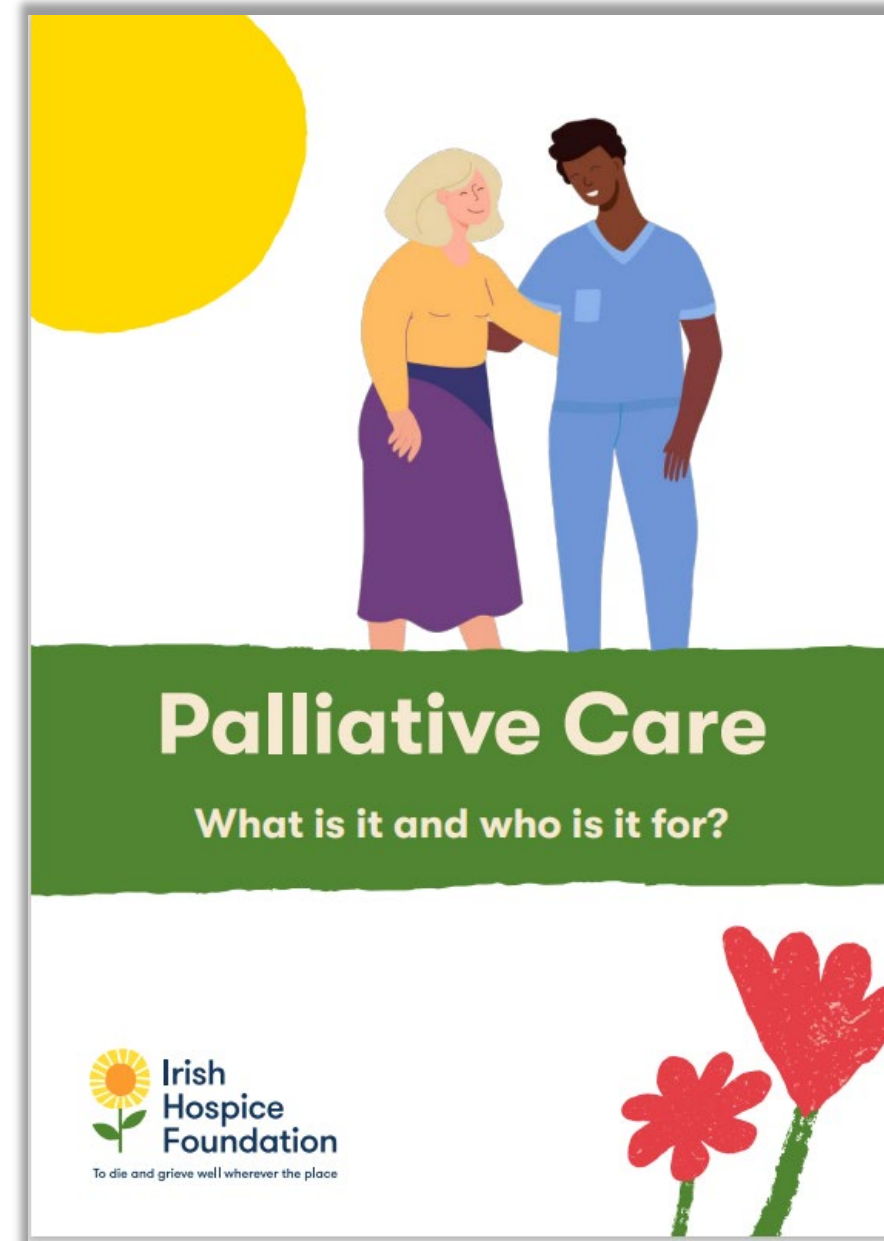
- Content aligned with the National Palliative Care Competence Framework
- Content reviewed by internal and external reference groups (with both lived and professional experience)
- Created by a Learning Design Agency
- Multimedia (animation, video and voiceovers)
- Pilot review of programme
- Review and edits following pilot

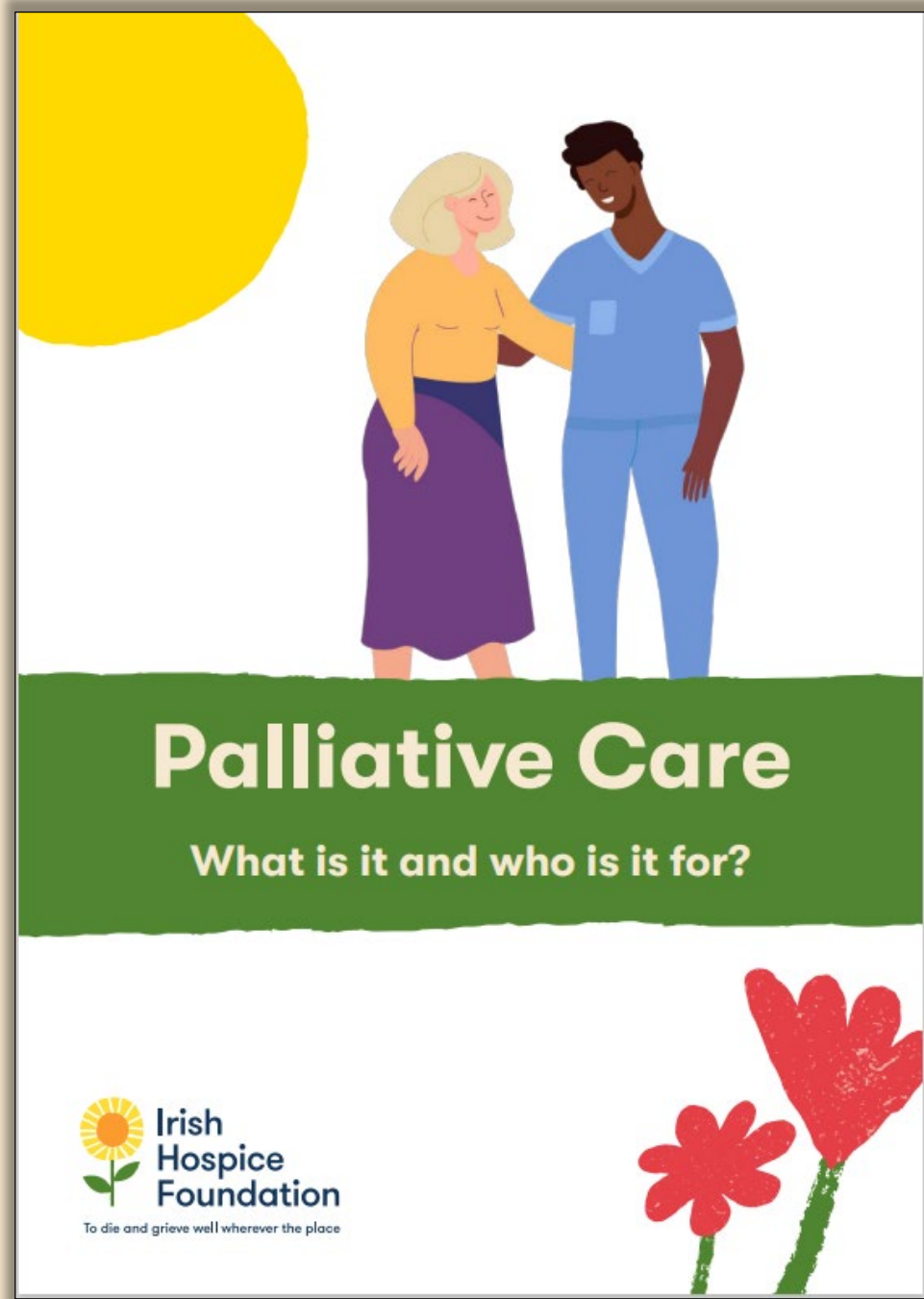




Toolkit and booklets to support carers and those with life limiting illness

Resources





Arabic



Download

Hindi



Download

Portuguese



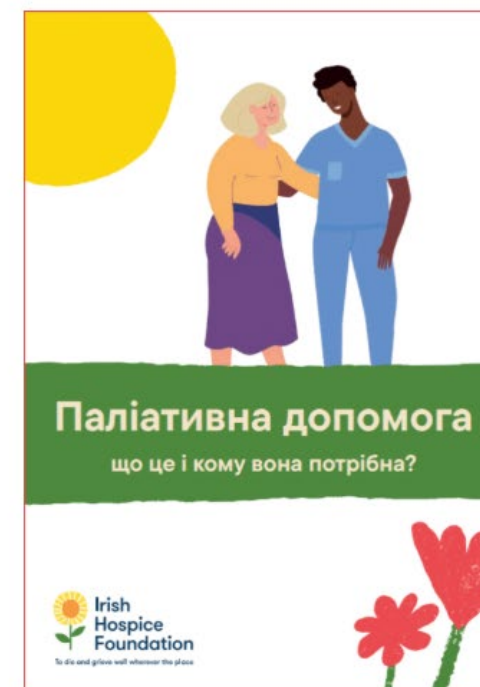
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Polish



Download

Ukranian



Download

Romanian



Download



Arabic



Download

Hindi



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Portuguese



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Polish



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Ukrainian



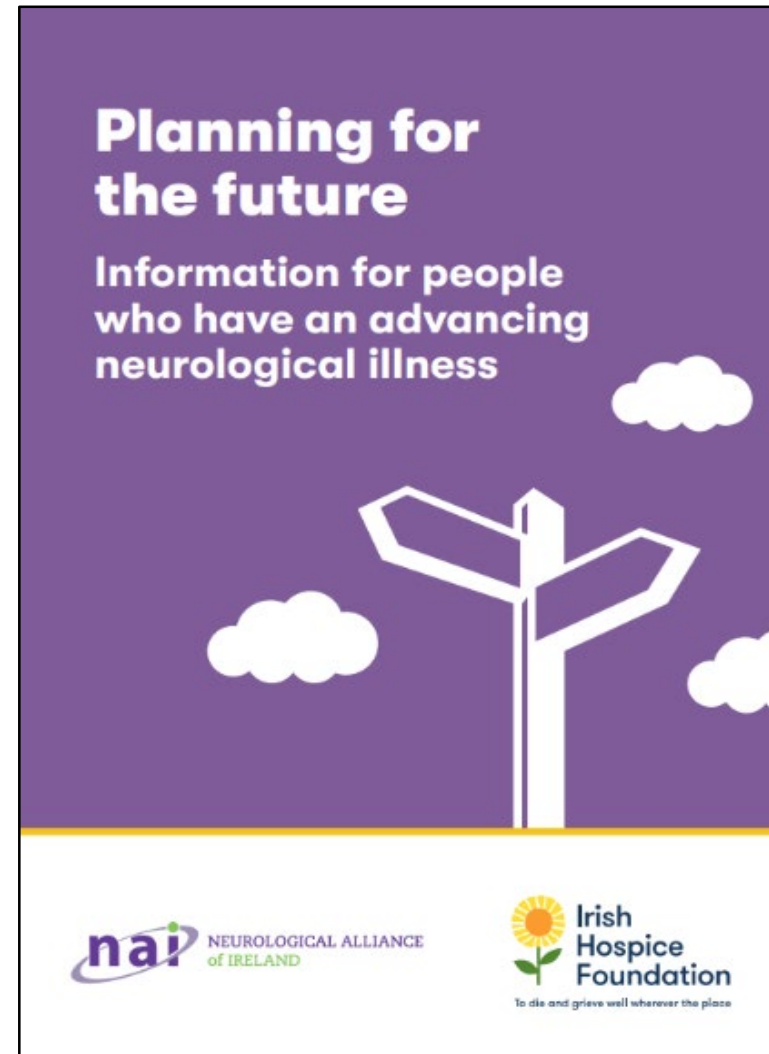
Download

Romanian



Download

Resources



Thank you

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Dying Well at Home:

dwah@hospicefoundation.ie

Information and Support Line: 1800 60 70 60

support@hospicefoundation.ie



Dying Well at Home

Resources to support caring for someone at end of life at home.



Practical tips to help you care for a person who is dying at home.



Six short modules designed to help inform you and make you feel more confident while caring for a person.



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and Support Line**
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Providing information and support on end-of-life care, advance care planning and palliative care.



← Scan for
resources



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