

All Ireland Research Priorities for Palliative and End-of-Life Care



Below are the top 24 priorities for palliative and end-of-life care research, guided by people with lived and/or professional experience, in order, starting with the highest priority.

1

What are the **best ways to provide personalised palliative and end-of-life**

care that meets all the physical, mental, practical, social and spiritual needs of a person with a serious life-limiting illness?



2

How can **communication and care co-ordination**

be improved across the teams of health and social care professionals caring for people with any serious life-limiting illness?



3

What are the **best ways to provide emotional and psychological**

support to people with a serious life-limiting illness, from diagnosis through to end of life?



4

What kinds of palliative and end-of-life care and support need to be in

place **to enable people to die well at home**? What skills do staff need? What helps or hinders the delivery of care at home?



5

How can it be ensured that everyone has **access to the palliative and end-of-life care** they want or need?



6

What are the **best ways to provide support to children**

(e.g. psychological and social support) when someone important to them is dying, or has died?



7

What are the **best ways to train and support staff who provide care**

at the end of life - either at home, in care homes or nursing homes?



8

How can palliative and end-of-life care better **meet the needs of people with illnesses other than cancer** e.g. chronic obstructive pulmonary disease (COPD),

pulmonary fibrosis, organ failure, motor neuron disease (MND)?



9

How can the **quality of palliative and end-of-life care in hospital be improved**? What helps or hinders improvement?



10

What **skills, training and information** do carers, friends and family

members need to be able to care for someone who is dying at home (e.g. giving medicines safely by injection, managing incontinence, moving people)? What is the impact (pros and cons) of upskilling the people giving care?



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11 How can palliative and end-of-life care better meet the needs of people who have **communication difficulties** (e.g. people with learning disabilities, or people who have lost their speech or language)?



12 When and how can people with a serious life-limiting illness best be supported to **make decisions about their future care**, e.g. advance care planning?



13 How do people with **dementia experience end of life**? How can palliative and end-of-life care better meet their needs and those of their carers, friends and families?



14 How can **symptoms at the end of life be managed** in a timely way, including by rapid access to medicines?



15 How can palliative and end-of-life care **better meet the needs of people who live alone**, or are socially isolated?



16 What are the **best ways to provide palliative and end-of-life care, support and advice at all hours** (24/7 or out of hours)?



17 How can palliative and end-of-life care better meet the complex needs of people with **multiple health needs**?



18 How can **health, social services and charities work more collaboratively to provide joined-up care** that better meets the needs of people with a serious life-limiting illness and their friends and families?



19 What are the best ways to ensure **adequate pain relief** for people with a serious life-limiting illness?



20 What **stops people's wishes from being acted upon** (e.g. with future or advance care plans)? How can any barriers be overcome?



21 What are the best ways to meet the palliative and end-of-life care **needs of teenagers/ young adults moving into adult services**?



22 What are the best ways to manage people who are **restless, agitated or experience sudden confusion** (delirium) at the end of life?



23 What are the **best ways to identify that a person is dying or is near to death** (in their last year, months, weeks, days of life)? How can health professionals better recognise these stages in people with any serious life-limiting illness?



24 How can **discharge from hospital** be improved for people with any serious life-limiting illness?



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