Research priorities for palliative and end of life care

Identified and prioritised by people with lived and/or professional experience

PARTNERED WITH

In 2025 Marie Curie, in partnership with the James Lind Alliance and other charities and research funders completed a priority setting partnership to agree on the top priorities for future palliative and end of life care research. These priorities were identified and prioritised by people affected by serious life-limiting illness.

What did we do?

We followed the James Lind Alliance Priority Setting process to consult people affected by serious life-limiting illness across the UK. This involved the following stages:

- An online survey to ask people affected by serious life-limiting illness (patients, families, friends and health and social care professionals) what they thought future research should focus on. 1032 people completed this survey.
- A second survey to prioritise the issues identified in the first survey, which was completed by 626 people.
- An in-person workshop where 20 people affected by serious life-limiting illness agreed on the ranking of the prioritised issues, and a top 10.

How did we involve people affected by serious life-limiting illness?

Twenty people affected by serious life-limiting illness joined our Lived Experience group. The group met regularly online throughout the project to make sure the project was grounded in lived experience and to advise us on how to make the project and its findings as accessible as possible.

What are the priorities for palliative and end of life care research?

1 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?

2 How can NHS, 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 carers, friends and families?

3 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?

4 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?

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

6 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?

7 What **skills, training and information do carers, friends and family members** need to be able to care for someone who is dying at home (eg giving medicines safely by injection, managing incontinence, moving people)? What is the impact (pros and cons) of upskilling the people giving care?

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

9 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)?

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

11 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?

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

13 How can palliative and end of life care better meet the **needs of people with illnesses other than cancer** eg chronic obstructive pulmonary disease (COPD), pulmonary fibrosis, organ failure, motor neurone disease (MND) or chronic fatigue syndrome (CFS)?

14 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?

15 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?

16 What are the best ways to **prepare carers, friends and families for what will happen** while the person they care for is dying? What information about symptoms during the last few days and hours is helpful to know?

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

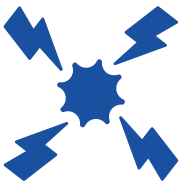
18 What are the best ways to manage people who are **restless, agitated or experience sudden confusion** (delirium) at the end of life?

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

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

21 What are the best ways to provide **palliative and end of life care in the community**, for example what are the roles of different services and professions?

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



23 What are the **best ways to provide support to children** when someone important to them is dying, or has died (eg psychological and social support)?

24 Can **medicines** be changed so that they can be **more easily administered at home and in the community** at end of life eg through injection under the skin, or under the tongue?

Next Steps

These priorities represent the range of issues that influence people's experiences towards the end of life and present an opportunity for researchers and research funders to consider where they place their efforts, in order to fund and deliver research with the potential to improve end of life experiences.

Please help us by sharing these priorities widely. If you have any questions about the priorities or would like to get in touch with the team please email PEoLCPSP@MarieCurie.org.uk.

With thanks to

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- And all supporting organisations.