

Top 10 research priorities for palliative and end of life care

Palliative and end of life care
Priority Setting Partnership (PeolcPSP)

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1 What are the best ways of providing palliative care **outside of working hours** to avoid crises and help patients to stay in their place of choice?

This includes symptom management, counselling and advice, GP visits and 24-hour support, for patients, carers and families.

2 How can access to palliative care services be improved for **everyone regardless of where they are in the UK?**

3 What are the benefits of **advance care planning** and other approaches to **listening to and incorporating patients' preferences?** Who should implement this and when?

4 What **information and training** do carers and families need to provide the best care for their loved one who is dying, including training for giving medicines at home?

5 How can it be ensured that staff, including healthcare assistants, are **adequately trained** to deliver palliative care, no matter where the care is being delivered? Does increasing the number of staff increase the quality of care provided in all settings? To what extent does funding affect these issues?

6 What are the best ways to determine a person's palliative care needs, then initiate and deliver this care for patients with **non-cancer diseases** (such as chronic obstructive pulmonary disease (COPD), heart failure, motor neurone disease (MND), Aids, multiple sclerosis, Crohn's disease, Parkinson's disease, dementia and stroke)?

7 What are the **core palliative care services** that should be provided no matter what the patients' diagnoses are?

8 What are the benefits, and best ways, of **providing care in the patient's home** and how can home care be maintained as long as possible? Does good coordination of services affect this?

9 What are the best ways to make sure there is **continuity for patients at the end of life**, in terms of the staff that they have contact with, and does this improve quality of palliative care? Would having a designated case coordinator improve this process?

10 What are the best ways to **assess and treat pain and discomfort** in people at the end of life with communication and/or cognitive difficulties, perhaps due to motor neurone disease (MND), dementia, Parkinson's disease, brain tumour (including glioblastoma) or head and neck cancer, for example?