Palliative Care and End-of-Life Care

Opportunities for England

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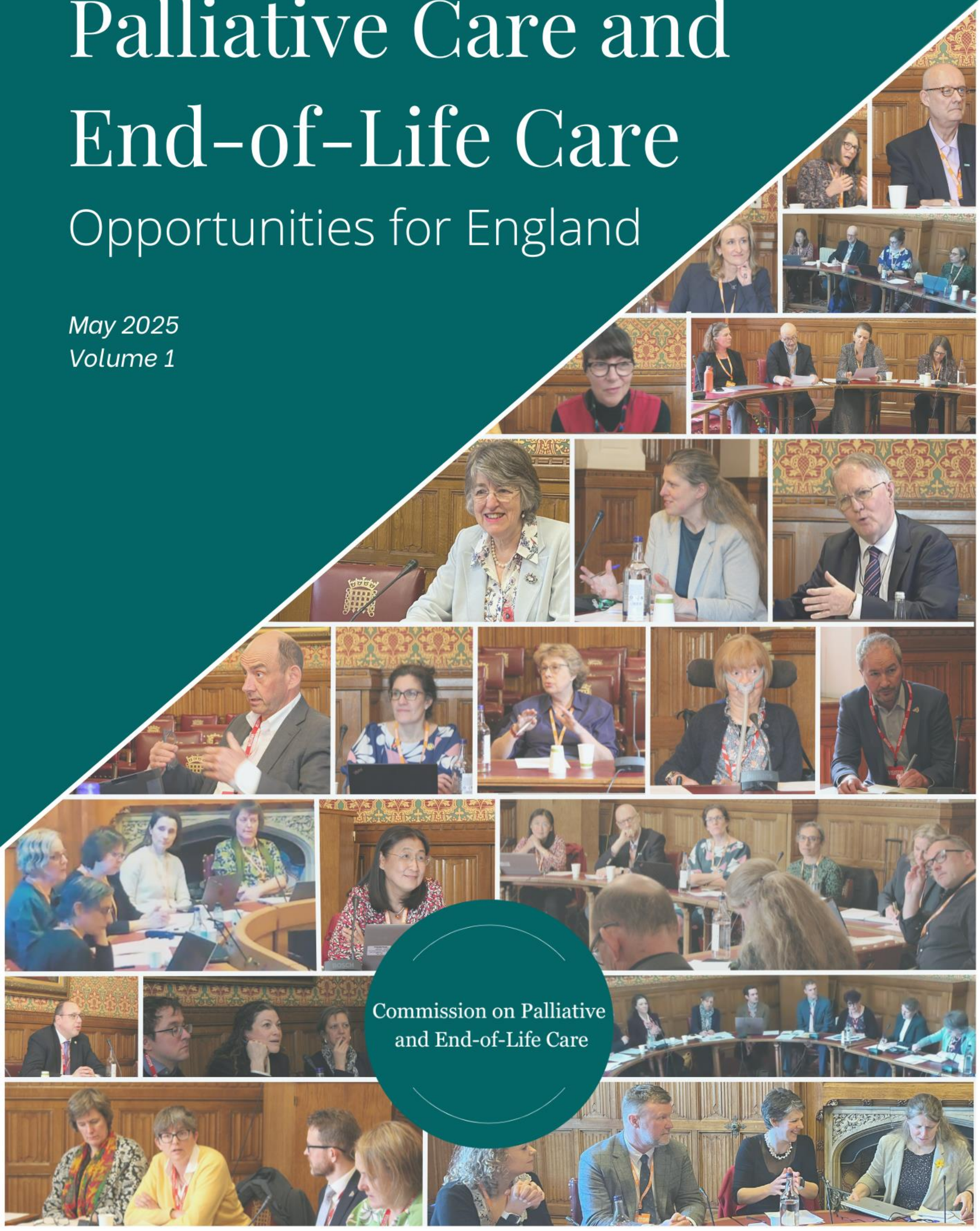

Commission on Palliative
and End-of-Life Care

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72. Dr Ernie Marshall, The Clatterbridge Cancer Centre NHS Foundation Trust
73. Dr Steve Marshall, Cicely Saunders Institute, King’s College London
74. Lindsey Martindale, FuneralExperts
75. Caroline Mawer, Marie Curie Research Voices Group
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114. Dr Andrew Severn, Retired pain consultant and lived experience, Lancaster

115. Professor Katherine Sleeman, King’s College London

116. Emily Stowe, The Association of Chartered Physiotherapists in Oncology and Palliative Care

117. Kate Tantam, University Hospitals Plymouth NHS Trust

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119. Professor Keri Thomas, Gold Standards Framework

120. Dr Sadie Thomas-Unsworth, University Hospitals Bristol NHS Foundation Trust

121. Jamie Thunder, Marie Curie

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125. Dr Amy Volans, Cambridge University Hospitals NHS Foundation Trust

126. Mary Walding, Oxford University Hospitals NHS Foundation Trust

127. Professor Catherine Walshe, Lancaster University

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129. Dr Hilary Williams, Royal College of Physicians

130. Dr Iain Wilkinson, British Geriatrics Society

131. Kerry Worsfold, Rowans Hospice, Hampshire and Isle of Wight Healthcare, NHS Foundation Trust

132. Melanie Worthington, Motor Neurone Disease Association

Chapter 1: Key Findings

- Access to high-quality palliative care is unevenly provided across the UK. Many people die in hospital when they would prefer to be at home, families lack essential support and recognition, round-the-clock services are often unavailable, and access to specialist palliative care is patchy. In addition, the need for palliative care overall is rising due to increasing multiple long-term conditions and rising numbers of annual deaths due to population changes. Palliative care is important for adults and children. Urgent action is needed.

- Community services, including in primary and social care, are also vital to support people with palliative care needs in the community, where they often want to be. Although the majority of the care of most dying patients is provided by hospital and community general services, the resource of specialist palliative care supports improved care in a wide variety of complex scenarios and should be an education and training resource to upskill generalists. All staff at every level require education in core principles of palliative care, including understanding when to seek a referral.

- The Commission heard evidence of how specialist palliative care offers high-value evidence-based care, which can help to alleviate symptoms, lessen suffering, support patients and those close to them, and prevent hospital admissions often at lower overall cost to the NHS. It therefore presents good value for money.

- Based on evidence, the Commission recommends priority actions to improve palliative care access, quality, and sustainability. Each action delivers clear benefits in terms of financial sustainability, improving patient and carer wellbeing, and supporting the Government shifts of hospital to community, focus on prevention, and leveraging technology to improve healthcare.

- The lack of a cohesive National Strategy for effective palliative care delivery has resulted in fragmentation of specialist palliative care services, with inequity of provision, confusion over who takes responsibility for each patient and lack of advice and support to the public and to staff in all services. A National Strategy must be developed setting out responsibilities for each provider at every level, to ensure all staff work to all their competencies, receive adequate training in palliative care for their role and can seek timely help from appropriate specialists. Annual reporting on key milestones in the Strategy must be a Ministerial responsibility of the Department of Health and Social Care.

Chapter 2: The Three Shifts for the NHS Ten Year Plan

Improved palliative care and end-of-life care has the potential to be a prime example of the 'three shifts' advocated by the Secretary of State for Health and Social Care, delivering benefits both for patients and for the NHS. The importance of excellent palliative care to the whole of society was encapsulated in Dame Cicely Saunders statement:

> "How people die remains in the memory of those who live on".

1. Prevention

Emergency admissions, ambulance conveyances, and lengths of stay in hospital amongst those nearing the end-of-life can all be reduced.[1] Modern specialist palliative care which integrates rehabilitation can increase independence and reduce disability, which in turn reduces hospitalisation and support needs.

Patient suffering can be reduced. High-quality research undertaken over the past decade has shown that specialist palliative care works well, providing better quality of life, better outcomes including symptom control and emotional wellbeing, and reduced healthcare intervention. Specialist palliative care needs at least three months to achieve optimal benefit (although some benefit is achieved before then).[2] A 2019 systematic review concluded that palliative care is cost-effective compared to standard practice.[3] Earlier identification of people with needs can be achieved by specialists in palliative care working alongside other secondary services (e.g. oncology, respiratory care, care for older people, long-term neurological conditions, renal, and cardiology).

An enhanced supportive care programme with palliative/supportive care specialists working alongside oncologists in eight acute trusts demonstrated benefits for patients and major cost savings for the NHS (£1.7 million spent and £8.4 million saved).[4] Evidence that specialist palliative care delivered at least three months before death results in sustained improvements in quality of life.[5] Enhanced supportive care services improve quality of life, outcomes from treatment and overall survival. [4]

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[1] Clarke G, May P, Cook A, et al. Costs and cost-effectiveness of adult palliative and end-of-life care. 2025. Evidence briefing summary. London: National Institute for Health and Care Research (NIHR) Policy Research Unit (PRU) for Palliative and End-of-Life Care. accessed on 8/4/2025

[2] Ibid.

[3] Mathew C et al. *Economic evaluation of palliative care models.* Palliative Medicine 2019 34(1) 69-82

[4] Monnery D, Tredgett K, Hooper D, et al, *Delivery Models and Health Economics of Supportive Care Services in England: A Multicentre Analysis.* Clin Oncol (R Coll Radiol). 2023 Jun; 35(6):e395-e403. doi: 10.1016/j.clon.2023.03.002. Epub 2023 Mar 11. PMID: 36997458.

[5] Johnson MJ, Rutterford L, Sunny A, et al, Benefits of specialist palliative care by identifying active ingredients of service composition, structure, and delivery model: A systematic review with meta-analysis and meta-regression. PLoS Med. 2024 Aug 2;21(8):e1004436. doi: 10.1371/journal.pmed.1004436. PMID: 39093900; PMCID: PMC11329153.

The suffering of informal carers and families while the patient is alive and into bereavement can be reduced.[6] This is likely to reduce physical and mental health problems of relatives following bereavement, enable them to return to work and to education, and improves long-term outcomes.

The timely administration of medication to patients at home is important, and delays can be very distressing for both the patient and their family. With training and support, some relatives can learn to give medications including injectable medications, avoiding delays caused by slowly responsive or absent community services, preventing ambulance call-outs and preventing traumatic memories in the bereaved.[7] Carers must be able to access 24/7 telephone support.

Easy detection of symptoms by carers, both unpaid and from social care, who have been trained and know how to summon palliative care support to advocate for the patient, can avoid symptom escalation and subsequent distress.[8]

2. Hospital to community

A study by the Nuffield Trust in 2017 concluded that the evidence for successfully shifting from hospital to the community is stronger for palliative care and end-of-life care than for several other conditions.[9]

Although the proportion of deaths in hospital has fallen over recent years (from around 58% in 2008 to 43% in 2023), the need for inpatient care in hospice or hospital will continue to increase for those with complex needs, whose care can no longer be managed at home and for those with acute serious episodes as well as those who die whilst still undergoing acute treatment.

In 2025, despite all the benefits of proactive and planned palliative care and end-of-life care in the community, the Nuffield Trust found that 81% (£9.6 billion) of UK public healthcare spend on people in the last year of life is on hospital care. In comparison, only 11% (£1.3 billion) of public sector spending on healthcare for people in their last year of life is on primary and community healthcare, with less than 4% (£414 million) spent on hospice care.[10]

Place-based integrated neighbourhood teams need to consider palliative care at all levels as a core component of their care provision duties, not only the provision of task-related interventions. To meet need, the fast-track and the long-term continuing care funding systems must be reformed and repurposed to recognise the cost-saving potential to the national purse of maintaining care in the community rather than in hospital.

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[6] Harrop E, Morgan F, Longo M, et al. The impacts and effectiveness of support for people bereaved through advanced illness: A systematic review and thematic synthesis. *Palliat Med* 2020; **34**(7): 871-88.

[7] O'Hara L. Evans CJ, Bowers B, Family carers' administration of injectable medications at the end of life: a service evaluation of a novel intervention British Journal of Community Nursing June 2023 Vol 28, No 6 284-292

[8] Evidence provided to the Commission by the UK Homecare Association

[9] Imison C, Curry N, Holder H, et al. *Shifting the balance of care: great expectations.* Research report. Nuffield Trust 2017

[10] Cummins L, Julian S, Georghiou T, et al. (2025) Public expenditure in the last year of life. Research report, Nuffield Trust and Health Economics Unit for Marie Curie. accessed on 8/4/25

Maintaining a terminally ill person in the community requires access to specialist palliative care advice to be available 24/7, with in-person care from professional carers in the home at all times, including community nursing and support for medication administration.

Medication

Patients being cared for in the community must have rapid access to medication on a 24/7 basis. Patient needs can change rapidly, and anticipatory prescribing can be helpful, but unused medication can be a significant cost. Local pharmacies are at increased risk of closure and large chains do not provide extensive out-of-hours services, hampering the ability to deal with problems out of hours. Although 'just in-case' boxes of medication have become popular, evaluation of their provision suggests that it may be better to ensure tailored supplies rather than a rigid prescription.[11]

Currently medication is not taken back by pharmacies and manufacturers, nor is it supplied to other countries in the developing world in great need. Previous schemes to recycle high-cost medications, such as St Mary's manufacturing pharmacy in Cardiff, have ceased.

During the Covid-19 pandemic group prescribing for care homes allowed 'just in case' medications to be stored and available on site. These emergency regulations lapsed, but there is a strong case for re-exploring ways to support care homes to ensure adequate supplies for dying residents.

The regulatory and logistical barriers of timely pharmacy supplies in the community need to be urgently addressed and innovative models found.

Equipment

Timely provision of aids and appliances can enhance quality of life and independence but delays all too often mean that the time for maximum benefit is lost. We heard evidence of delays in supply of equipment and distressing delays in equipment being collected after a person had died.

3. Analogue to Digital

Improvements in palliative care and end-of-life care will be significantly enhanced through a shift from analogue to digital. Information on patients' wishes need to be accurately recorded and updated through Future Care plans. Records of their current problems and treatment need to be shared between relevant professionals in hospitals, hospices, the community and care homes, ambulance services and the social care workforce. IT systems need to be developed/modified and interoperable across all settings to make this possible and data sharing protocols agreed.

Research is urgently needed into whether Artificial Intelligence (AI) algorithms could help to identify people with palliative care needs and/or those who may be approaching the end of life, triggering appropriate referral to relevant services.

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[11] Anticipatory Prescribing preliminary report (prior to British Journal of General Practice publication)

Chapter 3: Key Recommendations in Summary

1. **Develop a National Strategy for palliative care and end-of-life care**
   A National Strategy must be developed setting out a framework for the commissioning and delivery of specialist palliative care and end of life care services, and the workforce requirements to implement this, recognising the general palliative care responsibilities of all working in health and social care.
   The strategy should set short- and longer-term milestones. Annual reporting on key milestones in the Strategy must be a Ministerial responsibility of the Department of Health and Social Care.

2. **Mandate and fund 24/7 specialist palliative care, working with coordinated general care in every area**
   Specialist palliative care must be commissioned at a defined level based on local need, recognising the contribution of their local hospice. For any patient with palliative care needs whose distress is not beginning to ameliorate within a maximum of 48 hours, advice should be sought from the local specialist service.

   Benefits: Amends inequity; reduces expensive unplanned hospital care; prevents crises and unnecessary Emergency Department attendances; improves symptom control and support including at the end-of-life; enables coordinated care; provides better long-term outcomes for the bereaved of all ages; provides a resource of skills and knowledge to other health and social care services in the area for advice and for training.

3. **Improve rapid response to advice and access to community services**
   Expand rapid response out-of-hours support, including access to medicines and equipment, in all settings. A single telephone point of access is required for 24/7 advice to professionals in all settings, and to families and carers caring for a patient at home, and with capacity for specialist palliative care rapid response visiting 8 am-8 pm, with advice available at other times to generalist teams.

   Benefits: Lowers costs from and reliance on emergency services and unplanned hospital care; helps patients stay at home during potential crises; provides support to families, carers and other professionals.

4. **Education and training for all health and social care staff**
   Build confidence across the wider workforce, ensuring more staff are equipped to communicate with skill and kind honesty, and to recognise palliative care needs and assess problems. Palliative care must be a core part of undergraduate programmes for medicine, nursing and allied health professionals with training modules available for all those in practice in health and social care. Clinicians must be able to work collaboratively, able to seek the interventions patients need for good management.

Benefits: More efficient care; better patient experiences and evaluations, with fewer complaints; facilitates timely referrals and care; improves communication and patient outcomes; wider benefits for all people with long-term conditions.

5. **Dual accreditation and recognition of prior experience**
   We strongly recommend dual accreditation in specialist palliative medicine is available for those training in general practice, and to allow accreditation of experience in general practice.

   Benefits: Support the shift from hospital to community; retain in the workforce general practitioners who wish to move on from GP practice.

6. **Fund research to improve care, especially evaluating community-based interventions and treatments**
   Generate evidence for an Impact Centre, which will collate and disseminate evidence on where resources are most cost-effective, and including research undertaken in clinical settings provided by all health and care professionals.

   Benefits: Identifies cost-effective treatments and models of care delivery; supports innovation in community care; advances care quality and equity; takes advantage of digital innovations; wider benefits for people with long-term conditions and care needs.

7. **Support informal carers and families**
   Recognise and resource carers, providing tailored support around dying, including bereavement issues.

   Benefits: Strengthens unpaid care; reduces risk of carer burnout and hospital use; protects carers mental health and fosters resilience, and supports carers to manage their own grieving processes.

8. **Integrate health and social care data systems, including with outcomes data**
   Integrate secure data systems for seamless communication between health and social care providers. Move to recording symptoms, concerns and outcomes, not only processes.

   Benefits: Reduces duplication and unnecessary procedures; improves care delivery; wider benefits for all people with long-term conditions; improves integration across primary and secondary care and across clinical specialties in a unified electronic shared record-keeping system.

9. **Ensure compassionate, open, and timely communication, supporting future care plans**
   Give every patient the opportunity to communicate their own, personalised wishes to plan for future care, at the time of being diagnosed with a terminal illness, progression of a life-limiting illness or during uncertainty. This will be a dynamic document, regularly reviewed with the patient and those close to them, such as their family. Clinicians will be trained in kind and honest communication and developing future plans, including for care, with patients and their families.

***Benefits**:* Improves kind and honest communications, and listens to patients and families concerns, which has been a key failing noted in other reviews.[12]

10. Improve understanding around palliative care, hospices and dying

Promote public and professional understanding of what palliative care can offer, and how to access timely support, particularly care around dying, to avoid distress. Death is a normal part of life.

Benefits: Timely support during illness and bereavement; improved long-term social and employment outcomes for the bereaved of all ages.

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[12] Department of Health, 2013, More care, less pathway. A review of the Liverpool Care Pathway. London.

Chapter 4: Introduction

A Commission on Palliative Care and End-of-Life Care has been established by Professor Ilora Baroness Finlay of Llandaff and Rachael Maskell MP, with Professor Sir Mike Richards as its independent chair. It has the full support of the Secretary of State for Health and Social Care. The Commission was established because parliamentarians on both sides of the assisted dying debate recognised the urgent need to improve the quality of palliative care and the care given to people approaching the end-of-life. [13] [14] There are 25 commissioners from a wide range of backgrounds. To date the Commission has held ten evidence sessions and eight roundtables on a variety of topics and individual meetings. In addition, the Commission received 506 pieces of written evidence from a range of clinicians, commissioners, academics, the public and families with lived experience, and took oral evidence from 129 witnesses. Those who submitted or gave oral evidence were asked for their top three 'magic wands' citing both their priorities and concerns in the current system.

Definitions

The ethos behind modern palliative care echoes Cicely Saunders statement:

> *"You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die."*

Palliative Care – improves the quality of life of patients and that of those important to them, such as their families, who are facing challenges associated with life-threatening illnesses, whether physical, psychological, social or spiritual. The quality of life of caregivers improves as well.[15] Palliative care offers support during bereavement. It should be noted that palliative care is potentially needed over prolonged periods, from diagnosis in some diseases in adults or in children with congenital life-limiting diseases. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death[16].

Specialist Palliative Care – is evidenced-based high-value care which is provided by multidisciplinary clinical teams who have specialist expertise assessing physical, psychological, social and spiritual needs. These teams support complex decision making and communication and offer specialist advice to other clinical teams. Specialist palliative care is provided across all settings, wherever it is needed, and supports children and adults, as well as those important to them, in the place they hope they can be cared for, often at home if possible, working in partnership with other services.[17] In many life-threatening illnesses, symptoms and problems can become highly complex. A person may have on average 13-14 different symptoms, as well as other practical, financial or

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[13] Higginson IJ, Ramjeeawon N. In a healthcare system under increasing pressure, can a palliative care commission drive meaningful change? *BMJ* 2025; 388 :r610 doi:10.1136/bmj.r610

[14] Hansard. House of Commons Terminally Ill Adults (End of Life) Bill. Volume 757: debated on Friday 29 November 2024. Accessed 27/04/2025

[15] World Health Organization**.** (2020). *Palliative care*. Retrieved from https://www.who.int/europe/news-room/fact-sheets/item/palliative-care Accessed on 8/4/2025

[16] National Institute for Health and Care Excellence (NICE). (2021). *Palliative care – general issues: Definition*. Clinical Knowledge Summaries. Retrieved from https://cks.nice.org.uk/topics/palliative-care-general-issues/background-information/definition Accessed on 8/4/2025

[17] NHS England, Specialist palliative and end of life care services: Adult service specification, (2023)

emotional challenges.[18] [19] [20] When these issues become difficult for general services to manage, input from palliative care specialists is often needed to improve symptom control, enhance quality of life and provide more tailored support. This approach is underpinned by a very strong evidence base demonstrating its value and effectiveness. [20] [21] [22] [23] [24]

End-of-Life Care/ Care around Dying – End-of-life care aims to ensure comfort in the time that is likely to be a person's last year of life, offering early support to manage symptoms and continuing to help the person to live as well as possible until life ends, maintaining dignity around the time of death, taking into account what matters to the person and respecting their family's needs. This is also a time when the person is eligible for Department of Work and Pensions SR1 (special rules) financial benefits.

We heard repeatedly of the real confusion that exists amongst healthcare professionals, as well as members of the public, about the meaning of "palliative care". It is widely viewed as synonymous with the end-of-life and to only apply in the last hours or days of life, i.e. a time when all factors contributing to decline are irreversible and death looks imminent. This is usually perceived to be linked to patients with terminal cancer and deemed not applicable to patients with longer term, life-limiting conditions, or older patients with multiple conditions including dementia and frailty. This, together with a general reluctance to talk about death, gives little opportunity for patients and families to have the necessary conversations with healthcare professionals about their condition and how it is changing, what matters to them, and their preferences and priorities. As a result, patients are not being referred to the services that are available to improve their quality of life, and which can avoid time spent in hospital, particularly for those people with highly complex needs.

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[18] Namisango E, Bristowe K, Allsop MJ, et al. Symptoms and Concerns Among Children and Young People with Life-Limiting and Life-Threatening Conditions: A Systematic Review Highlighting Meaningful Health Outcomes. Patient. 2019 Feb;12(1):15-55.

[19] Moens K, Higginson IJ, Harding R; EURO IMPACT. Are there differences in the prevalence of palliative care-related problems in people living with advanced cancer and eight non-cancer conditions? A systematic review. J Pain Symptom Manage. 2014 Oct;48(4):660-77.

[20] Bajwah S, Oluyase AO, Yi D, et al. *Specialist palliative care is associated with improved patient and caregiver outcomes in hospital settings: A Cochrane systematic review and meta-analysis.* Cochrane Database of Systematic Reviews, 2022 Issue 9. Art. No.: CD012786.

[21] Gomes B, Calanzani N, Curiale V, *Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers.* Cochrane Database of Systematic Reviews, 2013 Issue 6. Art. No.: CD007760.

[22] Higginson IJ, Finlay IG, Goodwin DM, et al. *Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers?* Journal of Pain and Symptom Management, 2003; 25(2), 150–168.

[23] Johnson MJ, Rutterford L, Sunny A. Benefits of specialist palliative care by identifying active ingredients of service composition, structure, and delivery model: A systematic review with meta-analysis and meta-regression. PLoS Med. 2024 Aug 2;21(8):e1004436.

[24] Sarmento VP, Gysels M, Higginson IJ, et al. Home palliative care works: but how? A meta-ethnography of the experiences of patients and family caregivers. BMJ Support Palliat Care. 2017 Dec;7(4):0.

Chapter 5: Everyone's business

Palliative care and end of life care is not only the responsibility of specialists; every health care and social care professional has a role to play. Primary care and community services usually will have some involvement with patients with life-threatening conditions or who are dying, although the relative workload varies widely, with some disciplines such as geriatric medicine caring for many with frailty and dementia, while others such as dermatology may be involved in diagnosis but only provide ongoing care for very few dying patients. [25] This means that some core skills in palliative care are essential for every health and social care professional, as well as encouragement of informal care across communities.[26]

When Care Needs Become Complex or Unresolved

When a person's symptoms or challenges go beyond what general services can manage alone, the involvement of specialist palliative care is vital to improving quality of life and ensuring personalised, coordinated support.

Specialist palliative care is a distinct specialty. In palliative medicine there is a mandatory four-year postgraduate training programme with progress assessment and a final exam before entry to the specialist register. In other health care professions palliative care training to various levels is offered through various universities or training providers, including formal degrees, shorter focussed courses, and in role training.[27] [28] For a specialist team ongoing supervision and professional development are a key part of their role.

A specialist palliative care team will consist of a consultant in palliative medicine lead, working with specialist nurses, and with attached physiotherapy, occupational therapy, social work and chaplaincy services, sometimes with paramedics and with full time care assistants. Other professionals such as speech and language therapists, pharmacists and dieticians may also be part of the team. This team can provide on-going education and training across health and social care and participate in evaluation and research initiatives.

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[25] British Geriatrics Society, 2023. *Joining the Dots: A blueprint for preventing and managing frailty in older people*. Available: https://www.bgs.org.uk/joining-the-dots-a-blueprint-for-preventing-and-managing-frailty-in-older-people accessed 29 April 2025.

[26] Kellehear A. Compassionate communities: end-of-life care as everyone's responsibility. *QJM : monthly journal of the Association of Physicians* 2013; 106(12): 1071-5.

[27] Kings College London Palliative Care MSc, PG Dip, PG Cert accessed on 23/4/25

[28] Palliative Care Clinical Nurse Specialist Development Programme accessed on 23/4/25

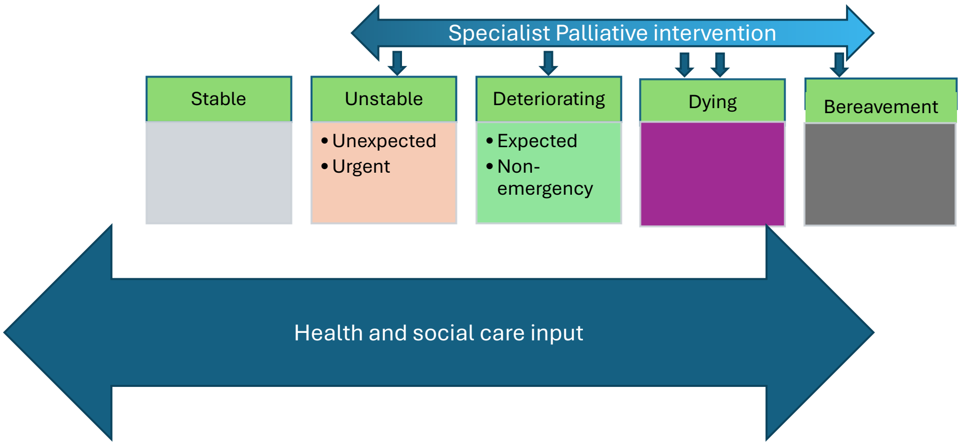

Figure 1: Joint working of specialist palliative care with other disciplines in the phases of life-threatening illness – modified from Palliative Care Outcomes Collaborative Assessment tool definitions: Phase V 1.2 December 2008[29]

Specialist palliative care: a summary of demonstrated benefits

The UK has long been recognised as a world leader in specialist palliative care, with significant influence on global palliative care knowledge and practice, and with pockets of excellent practice across a myriad of different health and care providers and settings. There is evidence from randomised trials, Cochrane reviews, meta-analyses and other studies that specialist multiprofessional palliative care delivers multiple benefits: it enhances quality of life, emotional wellbeing, and symptom management for individuals.[30] [31] Cost savings are larger for people with more comorbidities,[32] and when consultations are offered earlier than currently.

Overall, models of enhanced integrated palliative care are proving to be both effective and cost saving. Many are hospital-based, with palliative care specialists working alongside oncologists, respiratory clinicians, neurologists, primary care and care of the elderly, typically from the point at which it is recognised that a patient’s illness(es) are complex, symptomatic and not responding to

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[29] Palliative Care Outcomes Collaboration Clinical Manual 2021 accessed on 29/4/25

[30] Gomes B, Calanzani N, Curiale V. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. Cochrane Database Syst Rev 2013; (6): CD007760.

[31] Bajwah S, Oluyase AO, Yi D, et al, The effectiveness and cost-effectiveness of hospital-based specialist palliative care for adults with advanced illness and their caregivers. Cochrane Database Syst Rev 2020; 9: CD012780.

[32] May P, Garrido MM, Cassel JB, et al, Palliative Care Teams' Cost-Saving Effect Is Larger For Cancer Patients With Higher Numbers Of Comorbidities. Health Aff (Millwood) 2016; 35(1): 44-53.

potentially curative treatments. [33] [34] [35] In some hospitals specialist palliative care works closely alongside emergency and acute medicine.

For some patients this integrated working is needed from diagnosis, to support decision making, symptom control and holistic care. The evidence shows that these services improve quality of life, improve independence and reduce healthcare costs including reducing emergency admissions to hospital. [36] [37] [38] [39] [40] [41] Early palliative care has also been demonstrated to improve outcomes for people with cancer and other diseases, including survival.[42] [43] [44]

In the UK, community-based earlier short-term integrated palliative and supportive care has been shown to reduce symptom distress for older people with chronic non-cancer conditions compared with usual care and to offer economic benefits. [33] Short-term integrated palliative and respiratory care offered over six weeks has been shown to improve quality of life and improved survival for people who were severely affected by breathlessness and chronic respiratory conditions. [34] [45]

Timely hospital-based palliative care shortens hospital stays. By providing comprehensive, continuous care, systematic reviews find that specialist palliative services can reduce emergency

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[33] Evans CJ, Bone AE, Yi D, et al. Community-based short-term integrated palliative and supportive care reduces symptom distress for older people with chronic noncancer conditions compared with usual care: A randomised controlled single-blind mixed method trial. Int J Nurs Stud 2021; 120: 103978.

[34] Higginson I.J., Bausewein C., Reilly C.C., et al. An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial. The Lancet Respiratory medicine 2014; 2(12): 979-87.

[35] Yi D, Reilly CC, Wei G, et al., Optimising breathlessness triggered services for older people with advanced diseases: a multicentre economic study (OPTBreathe). Thorax 2023; 78(5): 489-95.

[36] Matthews S., Hurley E., Johnston B.M., et al. Does a palliative medicine service reduce hospital length of stay and costs in adults with a life-limiting illness?-a difference-in-differences evaluation of service expansion in Ireland. Ann Palliat Med 2024; 13(4): 766-77.

[37] Oluyase AO, Higginson IJ, Yi D, et al., Hospital-based specialist palliative care compared with usual care for adults with advanced illness and their caregivers: a systematic review. 2021. Southampton (UK): NIHR Journals Library (Health Services and Delivery Research).

[38] McCarroll S, Avsar P, Moore Z. The impact of specialist community palliative care teams on acute hospital admission rates in adult patients requiring end of life care: A systematic review. Eur J Oncol Nurs 2022; 59: 102168.

[39] Dalal S, Bruera E, End-of-life care matters: palliative cancer care results in better care and lower costs. The Oncologist. 2017;22(4):361–368. https://doi.org/10.1634/theoncologist.2016-0277

[40] Vanbutsele G. Pardon K. Van Belle S. et al. Effect of early and systematic integration of palliative care in patients with advanced cancer: a randomised controlled trial. Lancet Oncol. 2018;19(3):394–404. https://doi.org/10.1016/S1470-2045(18)30060-3

[41] Monnery D, Tredgett K, Hooper D, et al. Delivery Models and Health Economics of Supportive Care Services in England: A Multicentre Analysis, Clinical Oncology, Volume 35, Issue 6, 2023, Pages e395-e403, ISSN 0936-6555, https://doi.org/10.1016/j.clon.2023.03.002.

[42] Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. The New England Journal of Medicine, 2010; 363(8), 733–742. https://doi.org/10.1056/NEJMoa1000678

[43] Lancellotti P., Suter T.M., López-Fernández, T., et al., (2019), Cardio-oncology services: rationale, organization, and implementation. Eur Heart J. 2019;40(22):1756–1763. https://doi.org/10.1093/eurheartj/ehy453

[44] Lyon AR, López-Fernández T, Couch LS et al. (2022) ESC Guidelines on cardio-oncology developed in collaboration with the European Hematology Association (EHA), the European Society for Therapeutic Radiology and Oncology (ESTRO) and the International Cardio-Oncology Society (IC-OS). Eur Heart J. 2022;43(41):4229–4361. https://doi.org/10.1093/eurheartj/ehac244

[45] Yi D, Reilly CC, Wei G, et al.,Optimising breathlessness triggered services for older people with advanced diseases: a multicentre economic study (OPTBreathe). Thorax 2023; 78(5): 489-95.

admissions by up to around 30%, improve outcomes and enable more people to stay in the community.[46]

The Need for Palliative Care is Growing

The need for palliative care is growing, driven by two major trends shaping our society: more people are living longer with several long-term health conditions, and the number of deaths each year is gradually increasing.

The number of people in England with two or more long-term conditions is projected to nearly double from 19.2 million in 2019 to 35.3 million by 2049.[47] [48] [49] As people live longer with complex and often changing needs, there is a growing need for palliative care that can help manage symptoms, support decisions about treatment and care, and address physical, emotional, social and spiritual concerns. This approach helps people live as well as possible, throughout the course of serious and often fluctuating illnesses and at the end of life.

In 2023, 544,054 people died in England, and 36,054 people died in Wales.[50] In Scotland, 63,445 people died in 2023.[51] In 2025 an estimated 660,000 people in the UK will die. Due to our overall population increase and longevity, this number will continue to increase significantly every year and is projected to increase by 2040 to reach 790,000 a year (Figure 2). [52]

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[46] Matthews S, Hurley E, Johnston BM, et al. Does a palliative medicine service reduce hospital length of stay and costs in adults with a life-limiting illness?-a difference-in-differences evaluation of service expansion in Ireland. Ann Palliat Med 2024; 13(4): 766-77.

[47] Head A, Birkett M, Fleming K., et al., Socioeconomic inequalities in accumulation of multimorbidity in England from 2019 to 2049: a microsimulation projection study. Lancet Public Health. 2024 Apr;9(4):e231-e239.

[48] Kingston A, Robinson L, Booth H., et al., (2018), MODEM project. Projections of multi-morbidity in the older population in England to 2035: estimates from the Population Ageing and Care Simulation (PACSim) model. Age Ageing. 2018 May 1;47(3):374-380. doi: 10.1093/ageing/afx201.

[49] Higginson, I. J., Shand, J., Robert, G., et al., Reimagining Health and Care to Tackle the Rising Tide of Inequity, Multimorbidity, and Complex Conditions, 12 Sept 2024, In: NEJM Catalyst. 5, 5, 11 p., 5.

[50] Office for National Statistics (ONS), released 10 October 2024, ONS website, statistical bulletin, Deaths registered in England and Wales: 2023 Accessed on 8/4/25

[51] National Records of Scotland, retrieved from https://www.scotpho.org.uk/population-dynamics/deaths/key-data-sources/ accessed on 8/4/25

[52] Etkind SN., Bone AE., Gomes B., et al., How many people will need palliative care in 2040? Past trends, future projections and implications for services. BMC Med. 2017;15(1):102.

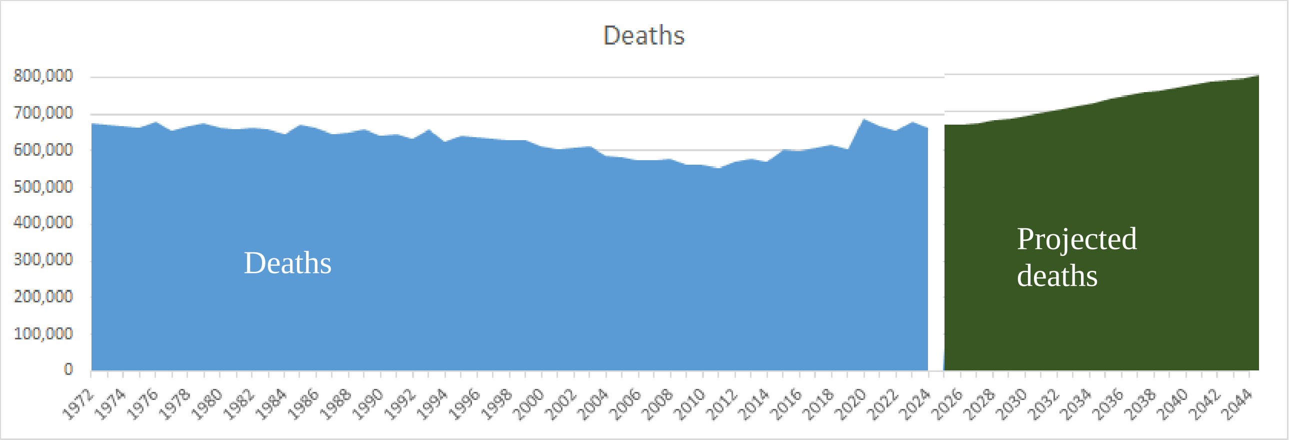

Figure 2: Annual deaths in the UK, actual and future projections 1973-2044 (2024 data not collated). Based on data from the Office for National Statistics (ONS) [53]

Over seven million people are expected to die in the UK over the decade covered by the NHS 10 Year Plan which is expected imminently. This will be a million more deaths than over any comparable 10-year period. As a nation, we are not sufficiently prepared for this change. We must act now, and with speed and purpose.

It is predicted that there will be a 42% increase in the need for specialist palliative care services, [52] and unless community care is expanded the pressure on hospitals will become even greater.[54]

Chapter 6: The current state of palliative care and end-of-life care

People with life-limiting conditions deserve excellent palliative care from the moment they need it, which for many is from the time of diagnosis. However, many people across the UK do not receive specialist palliative care when they need it. Of the over 600,000 people who died in the UK in 2023, it is estimated that 75- 90% of them would have benefited from palliative care. [10] However, according to the National Confidential Enquiry into Patient Outcome and Death (2024) only around half (51%) of the people died in their sample had specialist palliative care involvement at some point during their final admission. [55]

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[53] National population projections: 2020-based interim (2022) accessed 16/4/25 and Office for National Statistics (ONS). Vital statistics in the UK: births, deaths and marriages (2023) accessed on 16/4/25.
. https://www.hospiceuk.org/about-us/key-facts-about-hospice-care

[54] Bone AE, Gomes B, Etkind SN, et al., What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death. Palliat Med 2018; 32(2): 329-36.

[55] National Confidential Enquiry into Patient Outcome and Death. Planning for the end: A review of the quality of care provided to adult patients towards the end of life. 14 Nov 2024. https://ncepod.org.uk/2024eolc.html

This is despite strong evidence to show that specialist palliative care improves quality of life, is cost effective, and decreases emergency admission to hospital. [1] [56] [57] [58] [59]

Many currently die without their physical, psychological, social and spiritual needs and their preferences in care being adequately assessed, respected and acted on. Patients who could benefit from palliative care interventions are often only identified when they are close to death, meaning that opportunities to provide better care are being missed, along with the opportunity to reduce inappropriate emergency admissions. [1]

NICE guidance, published in 2015, on ‘*Care of dying adults in the last days of life*’ has not been fully implemented.[60] Neither the 2004 and 2011 NICE guidance recommendations on 24/7 access to specialist palliative care services have been implemented.[61] [62] Currently only around 60% of NHS Trusts provide seven-day on-site specialist palliative care and only a minority of localities (around one third) have out-of-hours access to advice for professionals, patients and relatives, but this is not always a single point of contact.[63]

A comparison of the results of the ‘VOICES’ post-bereavement survey (2015) and the ‘Better End of Life’ post-bereavement survey (2023) reveals a decline in the overall quality of end-of-life care over this period (See Figure 3). The percentage of people rating care as good or better reduced, and the percentage rating care as poor or very poor increased.

	From the *VOICES* survey (2015)		From the *Better End of Life* survey (2023)	
	% rated care in last 3 months as poor or very poor	% rated care in last 3 months as good, very good, or excellent	% rated care in last 3 months as poor or very poor	% rated care in last 3 months as good, very good, or excellent

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[56] Gomez-Batiste X, Martinez-Munoz M, Blay C, et al, Identifying needs and improving palliative care of chronically ill patients: a community-oriented, population-based, public-health approach. Curr Opin Support Palliat Care. 2012; 6(3): 371–8

[57] Johansson T, Pask S, Goodrich J, Better End of Life 2024 Report

[58] Johnson MJ, Rutterford L, Sunny A, Benefits of specialist palliative care by identifying active ingredients of service composition, structure, and delivery model: A systematic review with meta-analysis and meta-regression. PLoS Med. 2024 Aug 2;21(8):e1004436. doi: 10.1371/journal.pmed.1004436. PMID: 39093900; PMCID: PMC11329153.

[59] May P., Normand C., Cassel J.B., et al., Economics of Palliative Care for Hospitalized Adults With Serious Illness: A Meta-analysis. JAMA Intern Med. 2018;178(6):820–829. doi:10.1001/jamainternmed.2018.0750

[60] National Institute for Health and Care Excellence (NICE), (2015) *Care of dying adults in the last days of life*, accessed on 8/4/25

[61] National Institute for Health and Care Excellence (NICE), (2004*), Improving supportive and palliative care for adults with cancer*, accessed on 29/04/25

[62] National Institute for Health and Care Excellence, (NICE), (2011), *End of life care for adults*, accessed on 29/4/25

[63] National Confidential Enquiry into Patient Outcome and Death, (NCEPOD) , Gulland A. *Access to specialist palliative care is still inadequate, audit finds BMJ* 2016; 352 :i1784 doi:10.1136/bmj.i1784

General Practitioners	13%	70%	20%	57%
District and community nurses	7%	81%	8%	66%
Hospital doctors	9%	76%	13%	64%
Hospital nurses	10%	74%	12%	65%

Figure 3: A comparison of the VOICES (2015) and Better End of Life (2023) post-bereavement surveys [64] [65] [66]

Inequity

Reports on palliative care and end-of-life care consistently highlight variable and inequitable access to all levels of palliative care and end-of-life care across different geographies and communities. This inequitable provision is particularly marked for children, for adults with non-cancer conditions, those in areas of socio-economic deprivation, rurality, ethnic minority communities, those with dementia and LGBTQ+. In recent years this inequity has not improved and evaluations of care by bereaved people have shown deteriorating experiences of end-of-life care (see Figure 3).

Access to and quality of palliative care are generally poorer for people with non-cancer diagnoses, those who are socially deprived, minority ethnic groups, and individuals living in rural areas. There is wide variation in palliative care from one Integrated Care Board (ICB) area to another. [67] [68] [69] [70] Access is variable also for people with physical and intellectual disabilities living out their lives in the context of serious illness, when clinicians lack awareness and knowledge of disabled people's access requirements, and funding frameworks used by ICBs in allocating support can vary widely.[71]

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[64] Office for National Statistics (ONS), *National Survey of Bereaved People (VOICES): England 2015* accessed 8/4/2025

[65] Johansson T., Pask S., Goodrich J., et al., (2024). *Time to care: Findings from a nationally representative survey of experiences at the end of life in England and Wales.* Research report. London (UK): Marie Curie. accessed 8/4/25

[66] Presented as oral evidence to the commission, session 4, Prof Fliss Murtagh

[67] Hussain JA, Hanchanale S, Khan N, et al. The experience of racial prejudice and discrimination in palliative care settings – An APM survey of UK specialist palliative care services *BMJ Supportive & Palliative Care* 2023;**13:**A4.

[68] Clarke G., Hussain J.A., Allsop M.J., et al., Ethnicity and palliative care: we need better data - five key considerations. BMJ Support Palliat Care. 2023 Dec;13(4):429-431. doi: 10.1136/bmjspcare-2022-003565. Epub 2022 May 19. PMID: 35589123; PMCID: PMC10803990.

[69] Pask S., et al., Mind the gaps: understanding and improving out-of-hours care for people with advanced illness and their informal carers. Better End of Life 2022 Research report. London (UK): Marie Curie.

[70] Bradshaw A, Richards N, Hussain JA, et al. We need to talk about social class: Why theories of social class matter for understanding inequities in palliative and end-of-life care. Palliative Medicine. 2024;38(10):1076-1078. doi:10.1177/02692163241296478

[71] Evidence from session with parents of children with life-threatening conditions

These problems of access to care are made worse by poor coordination of care between multiple agencies in the community, particularly when availability of support out-of-hours is very limited, leaving patients and their families unsupported.[69] [72]

The key improvement we must make is to provide rapidly responsive services to deliver the right care at the right time in the right place, meeting people's needs as they arise. [73] [74]

How much do we spend in the UK on palliative care and end-of-life care?

The answer, quite literally, is currently anyone's guess. The financial data available at national as well as ICB level on what we currently spend on palliative care and end-of-life care in the UK is demonstrably inadequate. This has been and remains a significant inhibiting factor in efforts both to assess and ultimately to expand and improve palliative care services. Notably, more is spent on prescribed drugs in the community than on community services (see Figure 4). [10]

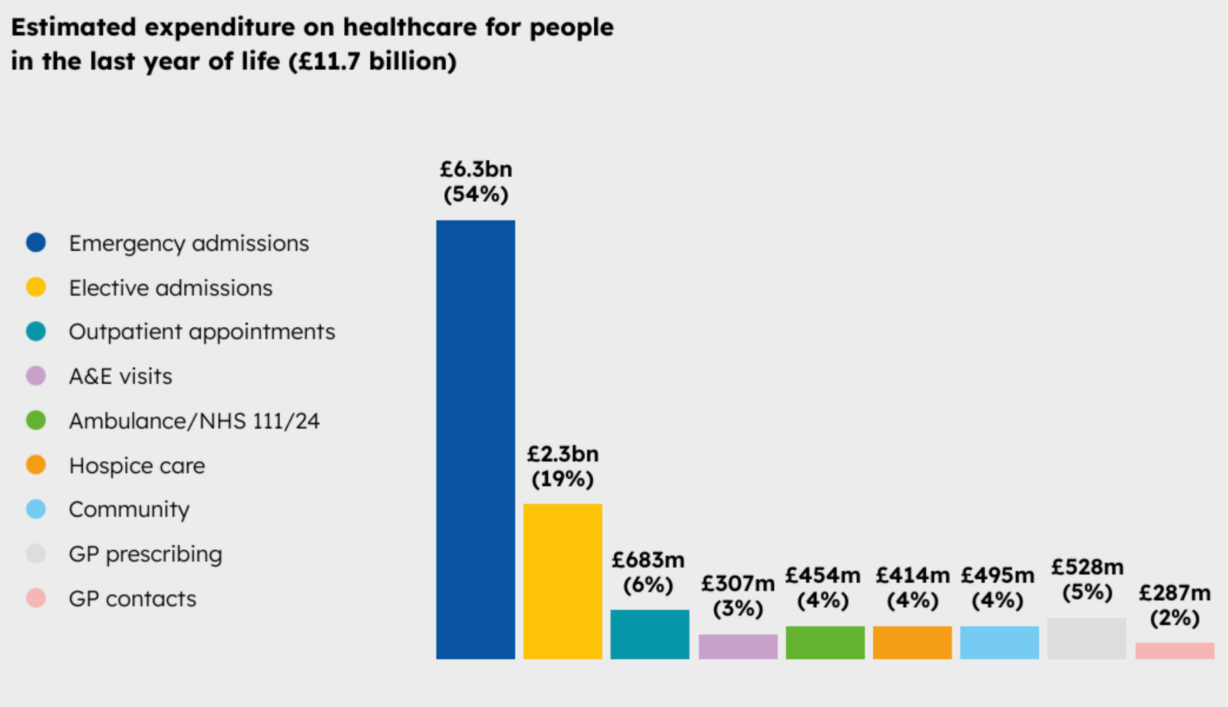

Figure 4: Estimated annual expenditure on healthcare in the last year of life: Marie Curie Report 2025[75]

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[72] Better End of Life 2022 Research report. London (UK): Marie Curie.

[73] Smith S, Brick A, Johnston B, et al., Place of Death for Adults Receiving Specialist Palliative Care in Their Last 3 Months of Life: Factors Associated with Preferred Place, Actual Place, and Place of Death Congruence. Journal of palliative care, 2024; 39(3), 184–193.

[74] Higginson, I. J., Daveson, B. A., Morrison, R., & BuildCARE. Social and clinical determinants of preferences and their achievement at the end of life: prospective cohort study of older adults receiving palliative care in three countries. BMC geriatrics, 2017; 17(1), 271.

[75] ibid.

In March 2025 the Public Accounts Committee heard how little financial information is available monitor performance and investment in this area, with one Committee member (Anna Dixon MP) noting to the Director General for Finance at the Department of Health and Social Care:

> *"I did not really see anything that gave a sense of how much we were spending on palliative or end-of-life care. Indeed, in the performance report, which goes into great detail on many topics with pages of information, there are but four lines, two sentences, on your performance on end-of-life care.....*
>
> *Given the importance and the costs that are spent on people in the last six months of their life, it seems a huge omission that nowhere in this report do we have any accountability for what is being spent on palliative care and end-of-life care, or indeed what outcomes that spend is delivering."* [76]

There are undoubtedly challenges in developing a methodology to count expenditure on palliative care and end-of-life care across so many areas of care and different providers, but that doesn't mean it should not be done.

As Professor Sir Chris Whitty said in his reply to Anna Dixon MP at the Public Accounts Committee:

> *"We all die and we all need end-of-life care. It is central to medicine. To give you a serious answer on this would take a long time, but it does deserve a serious answer at some point. It is not one where a Treasury minute will help. We can give you the numbers now, but, if you want to look at this seriously, it is a big and important subject."*

The saying "you value what you measure" highlights the importance of aligning metrics with what is truly valued. By focusing on what gets measured, individuals and organizations often inadvertently prioritize and value those specific aspects, potentially overshadowing other equally or more important elements.

Without better financial data it will not be possible to demonstrate the cost-efficacy of spending on palliative care and end-of-life care, nor will our progress in making improvements be regionally, nationally and internationally comparable.

"Too little too late"[77]

Timely identification of palliative care needs

The Commission heard repeated evidence of clinicians being reluctant to refer patients to specialist palliative care services early enough, with an often-repeated comment of 'they are not palliative yet'

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[76] Anna Dixon MP - Public Accounts Committee. Oral evidence: DHSC Annual Report and Accounts 2023-24, HC 639
Thursday 13 March 2025

[77] Evidence from sessions with (i) bereaved relatives, (ii) patients and families, and (iii) parents of children with life-threatening disorders

or ‘they are not ready for your team yet’, resulting in patients’ problems being poorly addressed for long periods and making it harder for palliative care interventions to be maximally effective.[78]

In contrast, we heard of clinical services labelling patients as ‘palliative’ when the patient was deteriorating from reversible causes such as dehydration.[79]

We heard from pressurised hospital services, whose specialist palliative care teams sometimes have great difficulty finding a suitable bed for a patient who cannot be cared for at home, particularly in a crisis. In areas previously reliant on hospice beds, bed-closures have aggravated this problem.

Prognostication and uncertainty

Palliative care aims to enable patients to live as well as possible, with quality of life and dignity, accepting the inevitability of death. We heard numerous examples of the prognosis being seriously underestimated or overestimated by months or years.

The inherent uncertainty of clinical conditions in each individual make prognostication dangerously inaccurate and it can feel like a ‘death sentence’, when people need support to live with the uncertainty imposed on them by their illness. We received evidence and heard many examples of patients who had lived to achieve their goal of a specific event or date and died gently after reaching it.[80] We also heard of inaccurately pessimistic prognostication by clinicians, with some patients outliving their prognosis by years.[81]

Many studies have attempted to develop tools to predict those patients who are in the last six months or last year of life to identify pointers to palliative care needs such as by looking at illness trajectories. [82] These tools do not attempt to *prognosticate* i.e. they cannot determine the time that someone has left to live.

The course of illness is particularly variable for individuals with multiple long-term conditions or frailty, who often experience complex symptoms and require palliative care. So-called ‘prognostic tools’ may fail to identify these individuals, potentially excluding them from receiving appropriate care. To ensure this group is not overlooked, it may be more helpful to consider the concept of ‘total uncertainty’, which takes into account not only physical and practical aspects, but also social, psychological, and existential components of care.[83]

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[78] Johnson MJ, Rutterford L, Sunny A, et al, Benefits of specialist palliative care by identifying active ingredients of service composition, structure, and delivery model: A systematic review with meta-analysis and meta-regression. PLoS Med. 2024 Aug 2;21(8):e1004436. doi: 10.1371/journal.pmed.1004436. PMID: 39093900; PMCID: PMC11329153.

[79] Evidence to the Commission from session with relatives

[80] Benor DJ, Survival predictions may hasten death. BMJ. 2003 Nov 1;327(7422):1048-9. doi: 10.1136/bmj.327.7422.1048-d. PMID: 14593055; PMCID: PMC261702

[81] Evidence to the Commission from the session with Relatives

[82] Murray S.A., Boyd K., Moine S., et al., Using illness trajectories to inform person centred, advance care planning *BMJ* 2024; 384 :e067896 doi:10.1136/bmj-2021-067896

[83] Etkind SN, Li J, Louca J, Total uncertainty: a systematic review and thematic synthesis of experiences of uncertainty in older people with advanced multimorbidity, their informal carers and health professionals. Age Ageing. 2022 Aug 2;51(8):afac188. doi: 10.1093/ageing/afac188. PMID: 35977149; PMCID: PMC9385183.

Co-production with patients and families

Patient choice can only be supported by early identification of a life-limiting illness, and open conversations to explore what they prefer or do not want, and their needs and concerns. Such conversations should commence from the point of a terminal diagnosis or identification of a life-limiting illness.

Many people prefer to spend as much time as possible during their illness at home, where they may also wish to die, providing that they are able to access appropriate services. [84] However, recording preferences alone does not support choice and can be cruelly misleading, as it can create false expectations that cannot be met.[85] Early holistic assessment of needs at home requires services to be in place to meet needs. To provide care effectively at home, it is vital to ensure patients, and their caregivers feel safe. This requires competent care to be present when needed, supported by specialist palliative care around the clock (Figure 5). If this is not available then emergency admissions occur, many of which could have been avoided and crises averted. [74] [86] [87]

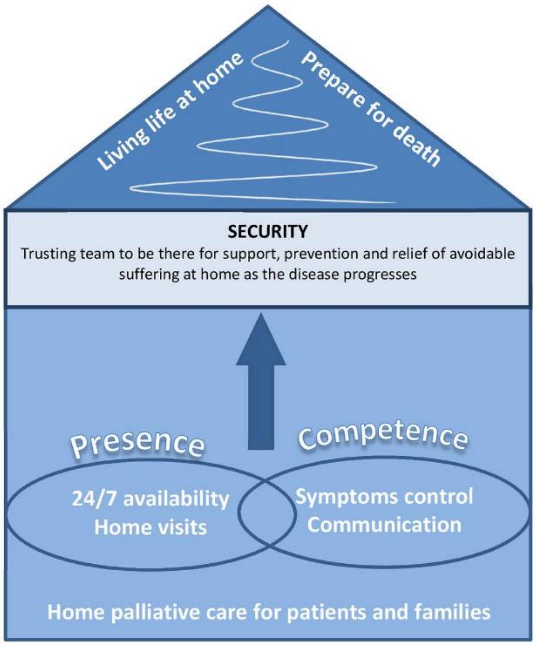

Figure 5: Safely cared for at home [88]

Patients and those caring for them at home, who are often family and may include child-carers, need to be able to have open conversations as they come to terms with the reality of illness and living with

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[84] McCarroll S, Avsar P, Moore Z, et al. The impact of specialist community palliative care teams on acute hospital admission rates in adult patients requiring end of life care: A systematic review. Eur J Oncol Nurs 2022; 59: 102168.

[85] Evidence from sessions with (i) parents and (ii) relatives

[86] Sarmento VP, Gysels M, Higginson IJ, et al. Home palliative care works: but how? A meta-ethnography of the experiences of patients and family caregivers. BMJ supportive & palliative care 2017; 7(4): 0.

[87] Schoth DE, Holley S, Johnson M, et al. Home-based physical symptom management for family caregivers: systematic review and meta-analysis. *BMJ supportive & palliative care* 2025. Pub Online: 31 Jan 2025. doi: 10.1136/spcare-2024-005246

[88] Sarmento VP, Gysels M, Higginson IJ, et al. Home palliative care works: but how? A meta-ethnography of the experiences of patients and family caregivers *BMJ Supportive & Palliative Care* 2017; 7: 390–403

uncertainty. People often find it easier to state what they do not want and what matters to them, than to state what they want as they face the unknown and uncertainty of their illness. Their needs, priorities and preferences may change rapidly, making open access to continuity in care particularly important. Such changes need to be documented and instantly available to clinicians providing care to ensure appropriate responses at all times and to restore a sense of control to the person and their family and avoid the person having to repeat their 'story' multiple times. Records of preferences must be regularly reviewed, updated and shared to be effective, but evidence suggests this is not happening.[89]

The required interoperable electronic systems must be put in place to ensure that there are no impediments to sharing records across all settings, including NHS 111 and 999, secondary, primary and social care settings.

Future Care Planning (also known as Advance Care Planning (ACP))

The current misunderstanding and lack of health literacy about end-of-life care, palliative care and Future (or Advance) Care Planning is vast.

Although much has been made recently of future or advance care planning to document wishes, studies showing benefit from such documentation have been limited to people already receiving good palliative community support (such as those already receiving hospice care)[90] or in very selected populations with comparisons which are biased e.g. selecting people who have resources to remain at home.

Too often any requirements to discuss needs and preferences are reduced to tick-box exercises.[91] [92] Despite its intuitive appeal, recent high-quality evidence—including Cochrane and other reviews – has shown limited impact on patient outcomes, and in some cases, ACP may lead to unintended harms such as reduced flexibility in care or misinterpretation of patient wishes.[93] [94] [95] Discussing future care must be an iterative co-production process by a skilled practitioner, subject to dynamic review with the patient and those they wish to be involved, and recognising that increasingly illnesses are uncertain, 'can go either way'. [96] We repeatedly heard of the importance of good

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[89] Allsop et al., (2025), Optimising Digital Advance Care Planning Implementation in Palliative and End-of-life Care: A multi-phase mixed-methods national research programme and recommendations. In press: BMC Medicine

[90] Abel ,J. Pring A, Rich A et al., et al., The impact of advance care planning of place of death, a hospice retrospective cohort study. BMJ Supportive & Palliative Care 2013; 3: 168-173

[91] Morrison RS, Meier DE Arnold R.M., Controversies About Advance Care Planning-Reply. *Jama* 2022; 327(7): 686

[92] Morrison RS, Meier DE, Arnold R.M. What's Wrong with Advance Care Planning? *Jama* 2021; 326(16): 1575-6

[93] Nishikawa Y, Fukahori H, Mizuno A et al., Cochrane corner: advance care planning for adults with heart failure. *Heart* 2021; 107(8): 609-11

[94] Nishikawa Y, Hiroyama N, Fukahori H et al. Advance care planning for adults with heart failure. *Cochrane Database Syst Rev* 2020; **2**(2): CD013022

[95] Malhotra C, Shafiq M, Batcagan-Abueg APM, What is the evidence for efficacy of advance care planning in improving patient outcomes? A systematic review of randomised controlled trials. *BMJ Open* 2022; **12**(7): e060201

[96] McFarlane PG, Bunce C, Sleeman KE, et al., Advance care planning before and during the COVID-19 pandemic: an observational cohort study of 73 675 patients' records. *BJGP Open* 2024; 8(4).

communication and listening to the person and their priorities, and note that many recommendations in the More Care Less Pathway[8] report around communication and listening have not been enacted.[97]

There are a plethora of interesting initiatives, including guidance on the principles of 'advance care planning',[98] but there is a lack of evidence on its efficacy and sustainability, or how to implement it across populations. [99] [100] Some are best suited to specific settings and others such as the TalkCPR website can help demystify the controversial topic of cardio-pulmonary resuscitation (CPR).[101]

The lack of training available to clinicians in undergraduate and post-graduate programmes lead to poor confidence and competencies of clinicians in knowing how best to engage in care planning conversations with patients and their families.

We heard evidence from patients about hospital staff pushing for ReSPECT, or similar forms, to be completed to avoid CPR. This happened without sensitive conversations with the patient and to their family, confirming the need for extensive staff training, as well as public understanding about futile interventions. Worryingly, we heard how the presence of a form to avoid CPR was sometimes interpreted as removing other support, and resulted in a drop in standards of care, including a denial of food and fluids by nursing staff, and a sense of abandonment.[102]

Children, teenagers and young adults with life-limiting diseases

Care for children with life-limiting and life-threatening illness is inequitable and often inadequate, with families left overwhelmed by the care burden. Parents usually become experts in their child's condition yet find that non-specialist hospital staff often fail to respect their knowledge of the condition, their skills in complex care and their ability to communicate with their child. When communication is difficult through either physical or intellectual disability, co-production with the child and parent is particularly important to understand needs. [103] [104] For children and young people, including those with intellectual or physical disabilities with, clearly documented preferences,

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[97] Department of Health. More care, less pathway: a review of the Liverpool Care Pathway. Report on the use and experience of the Liverpool Care Pathway (LCP). 2013 London. https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients

[98] https://www.england.nhs.uk/publication/universal-principles-for-advance-care-planning/

[99] Koffman J, Droney J, BMJ Opinion response 04 April 2025 https://www.bmj.com/content/388/bmj.r610/rapid-responses

[100] Mitchell S, Turner N, Fryer K, et al. Integration of primary care and palliative care services to improve equality and equity at the end-of-life: Findings from realist stakeholder workshops. Palliat Med. 2024 Sep;38(8):830-841. doi: 10.1177/02692163241248962. Epub 2024 May 11. PMID: 38733139; PMCID: PMC11448105

[101] Haire E, Bralesford C, Botting J, et al., Do not attempt cardiopulmonary resuscitation documentation: a quality improvement project. BMJ Supportive & Palliative Care 2023 10.1136/spcare-2022-004133

[102] Evidence to the Commission from session with families of patients who died. Held on 24 April 2025

[103] Makhoul K., S., & Gur, A., From Darkness to Light: Co-Production in Psychosocial Support for Parents of Children with Duchenne and Becker Muscular Dystrophy. Journal of Social Service Research, 2025: Pub. online: 03 Mar 2025 https://doi.org/10.1080/01488376.2025.2471396

[104] Bruun, A., Cresswell, A., Jeffrey, D., et al., The All Together Group: Co-Designing a Toolkit of Approaches and Resources for End-of-Life Care Planning with People with Intellectual Disabilities in Social Care Settings. Health Expectations, 2024;27: e14174. https://doi.org/10.1111/hex.14174

including who advocates for them when communication is difficult, are essential for holistic care to be tailored to their needs and for more appropriate targeting of resources.

Other research shows that for adolescents, as with older people, preferences are sometimes not achieved, even when stated, because the available services, including out-of-hours care, are not available.[105]

At the time of transitioning from paediatric to adult services these difficulties become greater, and we heard of delays in obtaining Court of Protection deputyships to allow the parent to continue to advocate for the young adult. Transition to adult services often presents a cliff edge as a multiplicity of fragmented services become involved, which fails to meet their needs in a holistic way.

Overall, the numbers of these children and young people needing palliative care are relatively small compared to older people, but their needs are very complex and under-recognised in many clinical services, in health and social care provision and in service planning and commissioning. This is potentiated by the use of adult systems to collect data, resulting in the contribution of parents and families being ignored or undervalued and the importance of respite care being under-recognised.

Unpaid Carers

Unpaid carers (also known as informal carers, usually those close to the patient, such as family members and friends) provide an enormous amount of care for people with life-limiting diseases amounting to the equivalent of £41,000 per patient, and more than half of the total costs of care in the last three years of life.[106] We do not sufficiently value the contribution of unpaid carers and are not offering them sufficient support. Alarmingly 9% of these carers felt they would not provide personal care for someone in the future. [107]

Despite the legal duty to assess carers' needs, formal assessment of their needs is not happening; professionals need the time to assess and support carers.

We heard from families of patients of all ages that although there are often many different professionals involved, no one seems to have overall responsibility. This results in duplicative and repetitive assessments, often with slow actions after assessment. When a crisis arises, their various contact numbers are connected to answerphones. NHS 111 services are often unaware of a terminally ill patient's wishes and preferences, nor of their clinical details, resulting in transfer to an emergency department, even when such a transfer was against the patient's wishes and seemed inappropriate to their carer. We also heard of supportive GPs giving the practice by-pass number to the carer of a person dying at home, but this was unusual. In providing co-ordinated care, there needs to be one point of access for a patient or their carers to call in order to receive a response to their care needs.

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[105] Odejide OO, Cernik C, Uno H, et al. Preferred and Actual Location of Death in Adolescents and Young Adults with Cancer. JAMA Netw Open. 2025; 8(1): e2454000. doi:10.1001/jamanetworkopen.2024.54000 and

[106] Johnson MJ, Currow DC, Chynoweth J, et al., The cost of providing care by family and friends (informal care) in the last year of life: A population observational study. Palliat Med. 2024 Jul;38(7):725-736. doi: 10.1177/02692163241259649. Epub 2024 Jun 22. PMID: 38907630

[107] ibid.

The co-ordination of care is essential for children and adults, in order to receive timely and appropriate interventions.

It is essential that care at home is supported if the transfer of care from hospital to the community is to be realised. Carers can benefit from early teaching in some aspects of care at home, including in manual handling, and in what to expect as life slips away. Training of family carers in giving breakthrough medication by subcutaneous injection warrants further careful research if more care is moved into the community, as the district nursing services cannot even meet need at present.[108] An initiative in Wales is evaluating ambulance paramedics being trained to carry medication to administer to the patient with doses tailored to the patient's immediate need at home, to avoid transfer to hospital.

The UK Hospice Sector

Hospices take a holistic approach to care, addressing the physical, emotional and spiritual needs of the patient, their family and others important to them. Hospice multi-disciplinary teams (MDTs) provide care tailored to the patient and their family's identified needs.

Last year, 200 hospices across the UK provided palliative care and end-of-life care to 310,000 people and provided support services to 59,000 family members and loved ones, delivering a wide variety of community palliative care and end-of-life care services across their inpatient units, outpatient facilities and in people's homes and care homes. [109] These include specialist and generalist healthcare across all settings, domiciliary care, physiotherapy and other rehabilitative services and financial, bereavement and carer support.

There are 880,000 specialist palliative care community visits and 540,000 generalist palliative care community visits annually, with additionally 820,000 outpatient contacts. [118]

Hospices collectively provide around 600,000 bed days / nights each year in these in-patient units. An additional 350,000 bed days and nights could be provided by hospices, but the rooms are currently out of use, in part due to workforce or financial constraints. Only 18% of total activity is delivered in a hospice inpatient unit, and almost every hospice now has a diverse and ambitious portfolio of community services delivered to patients who have chosen to receive them at home. [118]

Care Homes

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[108] Poolman M, Roberts J, Wright S, et al., Carer administration of as-needed subcutaneous medication for breakthrough symptoms in people dying at home: the CARiAD feasibility RCT. Health Technol Assess 2020 ;24(25)

[109] Data taken from Hospice UK's Hospice Activity and Demographic survey, 2023-24. 82% of Hospice UK members providing direct hospice services responded to the survey. The data provided has been used to calculate figures for UK hospices as a whole.

For many elderly or disabled people a care home becomes their permanent home for the last phase of their life, particularly those with frailty.[110] [111] Amongst those over the age of 65 years, over 20% of all deaths occurred in care homes.[112] For this population, the mainstay of their medical care is through primary care and community geriatric teams, able to call on specialist palliative care as needed. Different models of care provision have been developed but few have been subject to rigorous evaluation as there is a lack of digital infrastructure to collect, transfer and analyse outcome data.

The need for training and staff support in these setting is important and must address the palliative needs of these people. Often residents do not receive the level of support they need, resulting in escalation into secondary care, when better planning and interventions would determine better outcomes for the person. The Independent Commission into Adult Social Care Review, led by Baroness Casey, will need to address this as part of its remit in ‘reducing unnecessary hospital admissions and addressing delayed discharges’. [113]

Home care

Quality care for people nearing the end-of-life, needs both well trained, generalist frontline teams and specialists in palliative care, oncology, care of the elderly and other specialties working well together. [114]

The integration of primary care and palliative care services has the potential to improve equity at the end-of-life. [115]

For people receiving care at home, the social care workforce provides crucial support but staff usually work separately to the health care providers. Homecare workers deliver 23 million hours of end-of life care annually in England. [116] They are often the first responders to a crisis or to recognise signs of imminent dying. Homecare workers can be trained to give subcutaneous breakthrough medication and provide psychological support to patients and families, particularly when integrated with community health. Worryingly, 78% of homecare workers report insufficient training in pain management or anticipatory prescribing, 63% had never received formal end-of-life care training and 89% lacked access to specialist palliative care advice during shifts.[117]

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[110] British Geriatrics Society, 2025. *BGS End of Life Care Key Messages*. accessed 29 April 2025.
[111] British Geriatrics Society, 2021. *Ambitions for change: Improving healthcare in care homes.* accessed 29 April 2025.
[112] Office for Health Improvement & Disparities, 2025. Palliative and end of life care profiles January 2025 update: statistical commentary.
[113] UK Government. (2024). *Independent Commission into Adult Social Care: Terms of reference.* GOV.UK.
[114] British Geriatrics Society, 2025. *BGS End of Life Care Key Messages*. Available: https://www.bgs.org.uk/sites/default/files/content/attachment/2025-02-19/BGS%20EOLC%20Key%20Messages.pdf (accessed 29 April 2025).
[115] Mitchell S., Turner N., Fryer K., et al., Integration of primary care and palliative care services to improve equality and equity at the end-of-life: Findings from realist stakeholder workshops. Palliat Med. 2024 Sep;38(8):830-841. doi: 10.1177/02692163241248962. Epub 2024 May 11. PMID: 38733139; PMCID: PMC11448105
[116] Evidence submitted to the Commission from the UK Homecare Association
[117] SUPPORTED study in Hull. National Institution for Health and Care Research, Health and Social Care Delivery Research Programme. Project number: 135128

For patients at home, access to the GP by-pass phone line is not widely used as a route to access help in-hours but was cited to us by some GPs as a route of support from a GP practice.

Hospitals

We heard that the late identification of patients with palliative care needs in hospitals is linked to clinicians' hesitancy to seek support from specialist palliative care teams. It has been estimated that "90% of patients dying in hospital without a referral to specialist palliative care have unmet needs.[118] Failure to recognise palliative care needs also delays important conversations about future care and delays discharge of patients to their preferred place of care. Identification of patients and their needs can be improved by staff training.[119]

Audit data shows teams that have undergone Gold Standards Framework Hospital training demonstrate earlier identification of patients needing end-of-life care and offer ACP targeting their individual care needs.[120] The model has been taken up by over 350 hospital wards, with a large number seeking accreditation to demonstrate sustainability of good practice in end-of-life management.

Although the majority of in hospital deaths occur in intensive care and on medical wards, pressures in emergency departments make care of dying patients particularly difficult.[121] The presence of a palliative medicine specialist in the emergency department can resolve some problems as ambulances arrive and avoid admission or facilitate early discharge from medical assessment units. Where specialist palliative care teams are working alongside other disciplines such as neurology, respiratory medicine and acute oncology, earlier palliative interventions, fewer futile investigations and earlier discharge are evident.

For patients who are dying in hospital, the Commission heard evidence of good practice, with special units established for people and their family to spend their remaining hours and days together, if it is not possible to discharge the patient.

Chapter 7: Pain, other symptoms and distress

The founder of the modern hospice movement, Dame Cicely Saunders, created the term 'total pain'. It describes how pain (and other symptoms) at the end of life are not just physical but have psychological, social, emotional and spiritual dimensions.

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[118] Tavabie S, Ta Y, Stewart E, et al. Seeking Excellence in End of Life Care UK (SEECare UK): a UK multi-centred service evaluation. *BMJ Supportive & Palliative Care* 2024; 14 (e1), e1395-e1401. 10.1136/spcare-2023-004177

[119] Thomas K, Armstrong-Wilson J, Clifford C. The Gold Standards Framework Hospital programme: implementation and progress. Int J Palliat Nurs. 2022 Apr 2;28(4):172-177. doi: 10.12968/ijpn.2022.28.4.172. PMID: 35465704

[120] Thomas K., Armstrong W.J., Foulger T., et al., Evidence that GSF helps reduce hospitalisation in all settings. National GSF Centre Sept 2016

[121] Guen M., & Tobin, A. Epidemiology of in-hospital mortality in acute patients admitted to a tertiary level hospital. Internal medicine journal. 2016; 46. 10.1111/imj.13019

Pain is one of the most feared consequences of cancer and remains common with almost 70% of patients with advanced, metastatic or terminal disease experiencing pain caused by multiple factors.[122] Pain usually responds to analgesic medications, but for a relatively small number of patients alternative strategies are required.[123] These, such as nerve block or palliative radiotherapy can usually be performed as a single intervention and may only require day hospital attendance and can reduce pain scores by over 50% and decrease medication requirements.[124] Anaesthetic pain clinics need to be able to rapidly respond to referrals for coeliac axis block for pancreatic cancer pain, sacral neurolytic saddle block and longer term intrathecal drug delivery pumps to provide continuous analgesia, but such clinics are not established in every hospital, requiring patients to travel. Similarly, patients need to travel to radiotherapy, making early referral essential to maximise benefit.

The Commission also heard how adults and children with other serious illnesses or at the end of life can experience a range of distressing symptoms and concerns in addition to pain, such as breathlessness, constipation, fatigue, nausea, vomiting, dry mouth, or cough, all of which require careful assessment and management, as specialist interventions and management are able to palliate such symptoms.

Psychological support from the outset

There is inequity in provision of psychological support by disease group despite evidence for equivalent need. Only 19% of hospices have access to clinical psychology. [125] All patients should have their psychological needs assessed and responded to after the diagnosis of a life-limiting condition. The six months after diagnosis is the most vulnerable time psychologically, with a higher risk of suicide than later in the terminal illness. Psychological support, including psychotherapy and short-term psychosocial interventions at the time that bad news is given to a patient, can mitigate symptoms of depression and anxiety and improve quality of life, even where the physical condition is severe.[126] Timely specialist palliative care with management of symptoms, can also prevent or reduce depression among people facing terminal illness. [42] [127] [128]

Pre-bereavement and bereavement support

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[122] Van Den Beuken-Van Everdingen MHJ, Hochstenbach LMJ, Joosten EAJ, et al., Update on Prevalence of Pain in Patients with Cancer: Systematic Review and Meta-Analysis. *Journal of Pain and Symptom Management* 2016; **51**: 1070–90. https://doi.org/10.1016/j.jpainsymman.2015.12.340

[123] Fallon M., Giusti R., Aielli F., et al., Management of cancer pain in adult patients: ESMO Clinical Practice Guidelines. *Annals of Oncology* 2018; **29**: iv166–91. https://doi.org/10.1093/annonc/mdy152

[124] World Health Organisation (WHO), (2018), *WHO Guidelines for the Pharmacological and Radiotherapeutic Management of Cancer Pain in Adults and Adolescents*

[125] McInnerney D, Candy B, Stone P, et al. Access to and adequacy of psychological services for adult patients in UK hospices: a national, cross-sectional survey. *BMC Palliat Care* 2021:20 31. https://doi.org/10.1186/s12904-021-00724-3

[126] British Geriatrics Society, 2020. *End of Life Care in Frailty: Psychological support.* accessed 29 April 2025.

[127] Brighton LJ, Miller S, Farquhar M, et al, Holistic services for people with advanced disease and chronic breathlessness: a systematic review and meta-analysis. Thorax. 2019 Mar; 74(3):270-281

[128] Farquhar MC, Prevost AT, McCrone P, et al. The clinical and cost effectiveness of a Breathlessness Intervention Service for patients with advanced non-malignant disease and their informal carers: mixed findings of a mixed method randomised controlled trial. Trials. 2016 Apr 4;17:185

People of all ages need information and support as they face bereavement and during their loss. There are clear points to risk factors for complicated grief, which can reverberate down generations.[129] Bereavement support is underfunded and inequitably provided, despite bereavement having impacts on health, ability to work, and for children, their educational outcomes.[130]

Children are particularly vulnerable as they are often not included in conversations, glean information from overheard conversations and their emotional reactions to trauma, which vary at different ages, are poorly understood by many adults. Just under half of the bereaved children, young people and adults who shared their experiences with the UK Commission on Bereavement said they got only a little or no support from their education setting after their bereavement.[131] The UK Commission on Bereavement recommended that all education establishments should be required to have a bereavement policy including staff training, and a process for supporting bereaved children and their families. It also recommended that all schools and other education settings must be required to provide age-appropriate opportunities for children and young people to learn about coping with death and bereavement as part of life. Direct references to death, dying and bereavement were included as proposed revisions to the statutory guidance on Relationships, Sex and Health education in spring 2024 (Department for Education), which was welcomed, but no formal Government response has yet been published to the consultation, following the General Election.

Bereavement costs the UK economy an estimated £23 billion a year in lost Gross Value Added (GVA) and costs the UK Treasury an estimated £8 billion in reduced tax revenues, increased healthcare costs and income support payments.[132]

The Medical Examiners' role now involves speaking with the key contact of each person who died. We heard that this is now providing a rich insight into patterns of care, which can inform the Care Quality Commission and, if appropriately reported, could inform commissioners of trends of excellent care and areas needing to be improved.

Chapter 8: Public understanding around palliative care, hospices and dying

Death is a natural part of life, Yet culturally we have very poor understanding of end-of-life and dying in the UK. Nearly a quarter (24%) of people across the UK say they do not know much about or have not heard of palliative care, with no awareness being more pronounced in ethnic minority groups (22%).[133] 18% of people from ethnic minority groups and 5% of white people believe that palliative care involves giving people medicines in order to shorten their lives. Importantly, this belief is factually incorrect.

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[129] Parkes CM Bereavement: studies of grief in adult life. 1998 London Penguin Books ISBN 9780140257540
[130] Written Evidence submitted to the Commission from the National Bereavement Alliance
[131] UK Commission on Bereavement (2022) Bereavement is Everyone's Business
[132] Sue Ryder. (2022) *Grief in the workplace: a report on grief, bereavement and the workplace in the UK*. Sue Ryder.
[133] Awareness, knowledge, and trust about palliative and end-of-life care among different ethnic groups in the UK. NIHR Policy Research Unit in palliative and end of life care Policy Briefing

People do not seek to discuss the end-of-life and therefore do not engage in good care planning for the end of their life. The process of dying is often reduced to the physical aspects of dying when it is discussed, following a medical, rather than a psychosocial and spiritual model. Palliative care unlocks this through its holistic approach; however, it is important that understanding is improved across the whole population. This can provide people with a better understanding of dying, reduce the speculation of what happens through the dying process and improve coping in bereavement.[134]

People have to deal with dying at all stages of life, and therefore improved understanding should commence in an age-appropriate way at school and with the opportunity to discuss death and dying in communities. Those running bereavement services are often best at engaging people in conversations about death. Government should also commission good materials which are age appropriate to support people in having a better understanding of death and dying.

Solicitors have many opportunities to raise awareness of mortality, such as advising on making a will at the time of purchase of a home, marriage or other events when their advice is sought. The Law Society could provide resources to solicitors.

Funeral Directors encounter almost all bereaved families. Experiences shared with funeral directors' staff could inform improvements in all aspects of care around dying. Funeral Directors provide important support to the bereaved. Closer working with this sector could ensure they have access to useful resources, especially age-specific resources for children, people with learning difficulties and other disabilities. [135]

Chapter 9: Commissioning

ICBs have had a legal duty to commission palliative care and end-of-life care since the Health and Care Act 2022 with statutory guidance published by NHS England, but their performance has varied widely. [136] There is no common data set for minimum standards, patient-centred outcome measures, and inclusive data collection that would allow ICBs to be either aware or accountable for what and for how much they are commissioning from NHS services or from charitable sector providers. This results in widely inconsistent service provision, and worsening inequity. Crucially, it does not tell ICBs what a minimum level of provision of palliative care and end-of-life care looks like.

We heard evidence of great distress caused by cut-backs in ongoing care support to children and young patients with very severe life-limiting conditions in the community, which result in crises that incur far higher expenditure per person and increase morbidity in family carers. Such false economy is in part exacerbated by the complexity of different budgeting systems for social and health care. The statutory tool for ICBs to assess the needs of children and young people has not been updated since 2016 and, unlike the adult framework, does not include the statement that 'a well-met need is

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[134] Harrop E, Morgan F, Longo M, et al, The impacts and effectiveness of support for people bereaved through advanced illness: A systematic review and thematic synthesis. *Palliat Med* 2020; 34(7): 871-88

[135] Evidence from FuneralExperts at Patients Roundtable 10/04/2025

[136] Palliative and end of life care: Statutory guidance for integrated care boards (ICBs) 2022, NHS England

still a need'. We heard evidence of parents having to repeatedly fight to maintain even a basic level of a care package for their child in the community.

Specialist palliative care is provided directly by NHS Trusts, both in hospitals and in the community, as well as by the voluntary sector through hospices. Hospice UK's Freedom of Information (FOI) requests to ICBs made in mid-2023 found significant variation in the spending on adult hospices in each ICB, ranging from £10.33 per head of population to just 23p per head.[137] Analysis of ICS plans found that while there was often now some mention of palliative care, key patient priorities, such as timely access to care and 24/7 services were missing. [138]

Despite our rapidly ageing population, growing numbers of deaths, and huge pressures on hospitals caused by last year of life admissions, a survey of ICBs revealed only 35% understood the palliative care needs of their local population and only 25% highlighted palliative care as a priority, area of focus, or an ambition.[139]

The reality of ICB awareness and commissioning is at odds with the need and would surely not be accepted in any other area of healthcare.

ICBs need support and guidance from the centre on:

- how to assess population need for palliative care and end-of-life care and commission against the need of their populations;
- the minimum provision of specialist palliative care and end-of-life care that should be available in every area and how to contract services from the charitable hospice sector;
- reference costs for palliative care and end-of-life care services, according to patient complexity.

Specialist palliative care teams also need to be able to feed their patient outcome data into this process. Better commissioning would then enable ICBs to appropriately support specialist palliative care, including placing charitable hospices on multi-year NHS contracts, with annual reviews that reflect any changes in service need and cost. There needs to be recognition that better interoperability between different settings demands a new model of hospice funding which enables staff to work across different environments when required and to remove geographical inequity in provision.

Once in place, such contracting should align the incentives of hospices and ICBs for sustainable growth in palliative care access and service provision, with developments in the community to improve outcomes and take pressures off hospitals.

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[137] All-Party Parliamentary Group for Hospice and End of Life Care (2024) *Government Funding for Hospices*. Hospice UK. accessed: 28 April 2025

[138] Chambers R.L, Pask S., Higginson I.J., et al., Inclusion of palliative and end of life care in health strategies aimed at integrated care: a documentary analysis. AMRC Open Res. 2023 Jan 10;4:19

[139] Marie Curie. Palliative and end of life care in Integrated Care Systems: Exploring how Integrated Care Systems are responding to the Health and Care Act 2022. Marie Curie November 2023.

Hospice services have been reliant on community grants from ICBs but successive years of no or minimal uplifts from ICBs to these grants despite rapidly rising costs of delivering care directly led to the funding crisis many hospices experienced in 2024. Although DHSC stepped in directly in December 2024, awarding a one-off £100 million of capital grants to hospices, this does not help with clinical service salary costs. A better and fairer long-term funding model is required nationally.

Research undertaken by the Nuffield Trust shows that the cost to the public purse of health care in the last year of life is very high (around £12 bn)* [140], of which £8.6 billion is hospital inpatient care, compared with only £1.3 billion on primary and community health care. [10] Other reports suggest hospitals spend £6.6 bn on emergency care for those at the end-of-life, which is more than the total spend of £5.282 bn on all homecare.[141] Thus one day in a hospital bed could pay for a week of homecare, whose current minimum price is £32.14 per hour.[142]

The lack of a detailed service specification defining what to commission in terms of workforce and expected patient centred outcomes makes success impossible to measure.

Areas covered by GP and other primary care services vary widely. Specialist palliative care services should be commissioned to cover a specific population size or area coterminous where possible with groups or clusters of GP and community services, as in neighbourhood teams (greater detail will be provided in Volume 3).

Chapter 10: Education and Training

Many health and social care professionals receive little or no training in palliative or end-of-life care. In some areas, 75% of nurses and many doctors have qualified overseas, where they had no undergraduate palliative care training and palliative care is culturally a different concept.[143] This is not rectified by job induction programmes; in 2023 training in end-of-life care was included in the induction programme in only 137/214 (64.0%) hospitals and in mandatory or priority training in 110/214 (51.4%) hospitals.[144] UK medical schools all include some palliative care in their undergraduate medicine curriculum, but with variable clinical exposure. Questions are included in the medical finals examination question-bank. [145] However around 4 in 10 registered doctors graduated overseas and the majority had inadequate induction and supervision in their roles. [146]

The failure of schools of nursing and induction programmes for nurses to ensure knowledge, skills and attitudes towards palliative care patients are exemplary flies in the face of the Nursing and Midwifery Council standards of proficiency for registered nurses, which lists several relevant core

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[140] Corrected from previous version of the report
[141] LaingBuisson Adult social care market report https://www.homecareassociation.org.uk/resource/laingbuisson-adult-social-care-market-report.html
[142] Homecare Association Minimum Price for Homecare - England 2025-2026
[143] Evidence submitted to the Commission from the session with nurses
[144] National Confidential Enquiry into Patient Outcome and Death. Planning for the end: A review of the quality of care provided to adult patients towards the end of life. 14 Nov 2024. https://ncepod.org.uk/2024eolc.html
[145] Evidence from Medical Schools Council
[146] Lane J, Shrotri N, Somani BK, Challenges and expectations of international medical graduates moving to the UK: An online survey. Scottish Medical Journal. 2024;69(2):53-58. doi:10.1177/00369330241229922

requirements of nurses at the point of registration.[147] All undergraduate programmes for health care professionals must include palliative care education in the curriculum and in their final qualifying assessment. This training must also ensure students have the competencies and confidence to undertake future care planning assessments and communication skills to support patients and their families to talk about their end-of-life preferences. Continual professional development must include core elements of palliative care training in all disciplines as patients needing care around dying are ubiquitous.

Other health professional undergraduate programmes have limited or no content appertaining to palliative care, nor is this part of clinical continuous professional development.

For paediatric palliative care a framework has been developed depicting four levels of knowledge and skills: Public Health, Universal, Core, Specialist. Each level has four learning outcomes: Communicating effectively, working with others in and across various settings, identifying and managing symptoms, sustaining self-care and supporting the wellbeing of others.[148] An equivalent framework should be considered for adult palliative care.

A key role of specialist palliative care is to be a resource to all other specialties and disciplines, to undertake extensive education and to participate in research. This role must establish standards of excellence in practice in order to set an example and to be an expert resource (see Figure 6). Specialist and generalist collaboration is essential, meaning a both/and approach is required for strong frontline generalist teams working alongside specialists. Moreover, financial investment in training will reduce hospital admissions and costs. Shifting resources towards community-based and anticipatory palliative care prevents emergency hospital admissions.

Those providing homecare need comprehensive training, with their time purchased by outcomes, not by task and time, and career pathways that recognise and reward expertise in end-of-life care.

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[147] Nursing and Midwifery Council (2018) standards-of-proficiency-for-nurses.pdf

[148] Neilson S, Randall D, McNamara K. *et al.* Children’s palliative care education and training: developing an education standard framework and audit. *BMC Med Educ* 2021**21**, 539. https://doi.org/10.1186/s12909-021-02982-4;

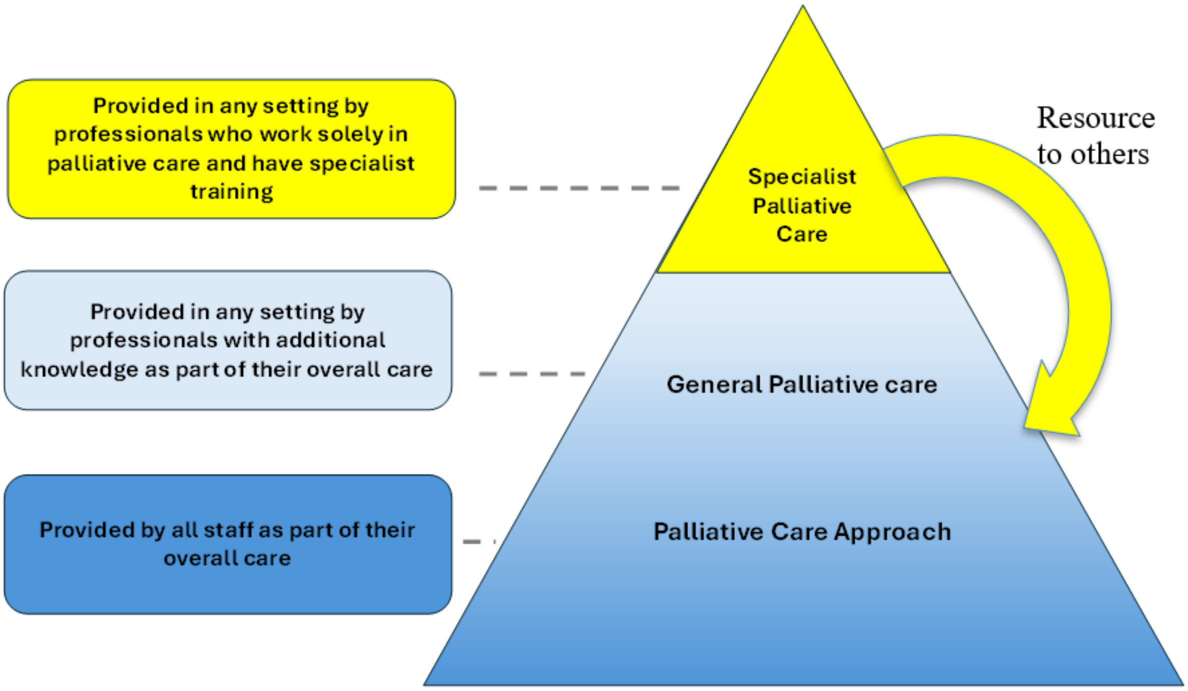

Figure 6: Specialist palliative care as a resource to health and social care, in advice, education and research (adapted from Milford Care Centre, Ireland)

Chapter 11: Workforce Challenges

We heard evidence of the number of health and social care staff who were neither trained nor graduated in a UK institution, as documented in the education and training section. This created knowledge and cultural difficulties for them when working in the NHS.

Staff without adequate training and support can feel deeply traumatised when dealing with issues around severe illness and death.[re nurses roundtable] Managers must ensure that staff support provides immediate debrief sessions in a dedicated safe space, and regular meetings involving staff at every grade, which can allow problems to be aired and resolved. [149]

There is a workforce crisis in specialist palliative care as with many other specialist services. In addition, we heard evidence of severe shortages of highly trained district nurses and of community nurses, forcing a tasks-driven rather than a holistic approach to patients in the community.

Without a nursing workforce in the community, it will not be feasible to make the shift of care out of hospital.

Nursing

We heard evidence from our nurses’ roundtable that there are now fewer than 4,000 full time equivalent district nurses in England, which represents less than one district nurse per 15,000 population, and only one district nurse for every 62 deaths each year which occur out of hospital and

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[149] Evidence from Nursing Roundtable 13/03/2025

with palliative care needs. In 2019 the Queen's Nursing Institute reported that the number of district nurses working in the NHS has dropped by almost 43 percent in England alone in the preceding ten years.[150] As a result, there were only some 4,000 district nurses providing care for a population of around 55.8 million in England, a ratio of only one district nurse for every 14,000 people. This compares with one GP for every 1,600 people.

Although about 10% of all district and community nurse face-to-face contacts concern care of a person nearing death and over 90% of those dying will have palliative care needs, NHS workforce data reveals that among NHS community nursing staff (including nursing assistants) less than 3,000 full time equivalents had any palliative care and end-of-life role documented in their electronic staff record (this includes primary, secondary or tertiary roles). [151] [nb queens NI]

There are not enough hospice nurses to meet this shortfall in community nursing. A survey of 150 adult hospices revealed that amongst the 57 responding hospices the types of support provided are: telephone advice 72% (*n*=41); care at home 70% (*n*=40); and rapid response 35% (*n*=20). There were variations between services regarding referral mechanisms, availability and workforce, and integration with statutory services was limited. This variation in the type of provision and delivery of out-of-hours palliative care services alongside limited integration with statutory care have contributed to inequity of access to community-based palliative care, and potentially suboptimal patient and informal caregiver outcomes.[152]

Specialist palliative medicine

Specialist palliative medicine training requires four years specialty training after four years prior postgraduate medical training. There are training bottlenecks with only 30-40 doctors achieving consultant certification annually despite 80 consultant vacancies. This has worsened as the number of trainees since 2022 has reduced, with regional disparities. This is predominantly a female workforce: 78% of consultants are female and 60% work less than full time.

Solutions are being sought to provide additional training to GPs, who might move into palliative care rather than retire, bringing with them extensive experience in the community. Regrettably it is not yet agreed that they will have consultant status, which may act as a disincentive to some. We strongly recommend dual accreditation for primary care and palliative care, which would support the shift from hospital to community and provide career progression.

There are significant shortages in those who are trained and providing specialist interventions like neurosurgeons providing neuromodulation or anaesthetists providing nerve blocks, leaving some

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[150] Outstanding Models of District Nursing Report – The Queen's Institute of Community Nursing (2019) A joint project by the Queen's Nursing Institute and the Royal College of Nursing.

[151] Ibid.

[152] Fee A, Hasson F, Slater P, et al., Out-of-hours community palliative care: a national survey of hospice providers Int. J. Palliative Nursing 2023; 29(3) Pub.Online: 23 Mar 2023 https://doi.org/10.12968/ijpn.2023.29.3.137

regions without such services. Each ICB must have access to the provision of such services to be integrated into a patient's care when required.

Social Services

The isolation of social services from health and the overlap in patient needs means that a radical solution needs to be found urgently if patients are to be adequately supported in the community. We had no specific evidence of such solutions in place as the main block to better integration appears to be that the two systems are financially and organisationally separate. Local initiatives are trying to decrease silo working, but in the care of seriously ill children this seems to be particularly problematic as continuing care budgets are squeezed.

Core training of people working in social care must also include specific palliative care modules, and their ongoing training and development must be addressed, including preparation for career paths between social care and health care.

There can be multiple duplicating assessments of patients which are exhausting for patients and families, leaving them not knowing who is in charge, or who to contact if services and equipment does not materialise.

Overall

We are concerned that staff are working within too rigid role boundaries, sometimes described as 'taskification' and 'silo' working, and associated with risk-aversion rather than undertaking a balanced assessment of risks as applicable to the individual patient's situation. This results in staff failing to fulfil their core general competencies. Policies of 'signposting' rather than 'doing' can leave patients frustrated, waiting for repeat duplicative assessments and without their immediate needs being adequately responded to.

We strongly recommend that all staff with a clinical training should work up to the level of their clinical competency, know who to seek help from when they need additional expertise and have protected time for education and training.

The social care workforce could benefit from being integrated with healthcare in the community.

Chapter 12: Research and Innovation

To evolve, all health and care systems need to build intelligence and to discover better treatments and ways of providing care. Palliative care is no exception but has been considerably neglected, with only 0.3% of all health research spending on palliative or end-of-life care, highly disproportionate to the level of people with needs, or the health care spending.

Research and innovation across the country are essential to ensure palliative care keeps pace with changing demographics, disease patterns, and societal needs, and new models of care, treatments and interventions are properly evaluated. As more people live longer with complex, chronic conditions, we must generate high-quality evidence to improve care, reduce unwarranted variation, improve equity and take advantage of new digital innovations to improve care.

Research should be seen as part of the practice of all clinicians and social care leaders and should be recognised as a crucial part of staff development and advancing practice.

Future strategy must include a clear commitment to fund palliative care research and to build research capacity, including clinician-led research, at a level proportionate to its growing relevance, with dedicated infrastructure to support long-term studies, data systems, and interdisciplinary innovation and capacity building. This will enable earlier identification of needs, development of more scalable models of care, and improved outcomes for patients, families, and the wider health and care system.

Research priorities

- Research must fulfil policy, public, carer and practitioner needs, and we need knowledge mobilisation to ensure that research reaches people who can use it to improve care.[153]

- New models and approaches to care should be subject to robust evaluation and research before they are widely implemented. This research should be co-designed with the people receiving the care and assess any benefits, downsides and costs for people, their families and the health and care systems. It should assess the effects on people from diverse communities or disadvantaged backgrounds, and the requirements for implementation.

- Research collaboratives need to be built with approaches which are agile and efficient, with a focus on outcomes on a large scale, and on building research capacity, across all levels of the workforce across the country.

- It must become easy for people to access good quality evidence quickly, for example via an Impact Centre (a ‘What Works Centre’) point of contact, and we must find what people need in all populations, rather than relying on opinion polls with simplistic questions, to look at attitudes to death and dying.

- Risk assessment must be carefully undertaken to understand the pharmacodynamics of medication, and off-label use of medications in those who are frail, when unexpected symptoms arise, and in specific disease and genetic groups, and other factors that put patients at higher risk of adverse experiences. This will reduce inappropriate off-label prescribing and develop more effective alternatives, tailored to individual needs.

- Research publications should include all negative and long-term findings, as well as positive results.

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[153] James Lind Alliance and Marie Curie research priorities for palliative and end-of-life care. Feb 2025

- An assessment of the data sets which should be available to enable research, including in social care settings.

Pharmacological and pharmacodynamics research is urgently needed to understand how medications are handled in the frail or very ill. This may be markedly different to the physiological information initially available when drugs were licensed following studies in healthy volunteers and in less ill populations. Such studies could provide better understanding of end-stage events and improve symptom control, building on the pattern of inquiry that Cicely Saunders instigated.

Developing new models

Locally developed solutions should be encouraged, evaluated and their learning shared. The specialist palliative care workforce continues to show great energy and enthusiasm to improve the quality of life of patients and families, and to find new, more cost-effective ways of working. Research funding must be increased to ensure high quality evaluation of pilot projects and assess their widespread applicability, as well as fostering research into new ways of managing distress and difficult symptoms in those of all ages with complex conditions. Various specialist palliative care teams are developing virtual wards and outreach teams, integrated with other community and other services. We heard from commissioners about the RIPEL and REACT programmes in Oxford and Bradford (see appendix 1). Such initiatives, underpinned by robust evaluation and research in different communities, are being piloted in 2025/26 with support from Social Finance or other sources. If these or other initiatives show benefits, broader dissemination across England should then be initiated.

Currently there are pilots of potentially exciting different models of care delivery, funded through research initiatives, to improve access to timely specialist palliative care, working with others. These are undergoing robust evaluation to determine their cost-effectiveness and applicability in other places. It is notable that each of these maps onto the three shifts of the 10 Year Plan, preventing distress, avoiding unnecessary hospital admission by integration with community services and using digital advances to support information transfer and inform policy and research. We heard of a plethora of such projects, often led enthusiastically.

Chapter 13: A public health approach

Death is a normal part of life for everyone. Seriously ill and dying people spend about 5% of their final year of life in the direct care of healthcare services, with the vast remainder being supported by their friends, family and community members without healthcare training.[154] Public trust of the healthcare professionals to provide high quality end-of-life care is low, as stated by 30% in ethnic minority groups compared with 17% of white people.[155]

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[154] Kellehear, A., The social nature of dying and the social model of health. In: Oxford textbook of public health palliative care, 2022. eds. Abel J, Kellehear A. Oxford University Press, p.22–29

[155] Awareness, knowledge, and trust about palliative and end-of-life care among different ethnic groups in the UK. NIHR Policy Research Unit in palliative and end of life care Policy Briefing

Voluntary, Community and Social Enterprise sector organisations provide a valuable resource to specialist palliative care, often helping to tackle inequities by addressing social determinants of health, as well as providing direct benefit, e.g. information and support related to future care planning, the end-of-life and bereavement; social activities that counter isolation and loneliness; or creative activities with psychosocial benefits. [156] [157]

Chapter 14: A vision for end-of-life care in the UK

The Ambitions for Palliative and End-of-Life Care, co-produced by 34 national organisations, provides a national framework for local action to improve palliative care and end-of-life care.[158] Against this backdrop, care for people with serious and complex illness, and for those at the end-of-life could be a prime test of the "three shifts". Better service provision could prevent symptom escalation, avoid waste from duplication and silo-working, decrease emergency attendances and admissions and prevent entirely avoidable suffering both for patients and those facing bereavement, including children. There is strong evidence that care can be shifted from hospital to community, provided coordinated services are made available. The two previous shifts would be further enhanced by moving to integrated digital communication, enabling earlier identification of patients who would benefit from palliative care and sharing of records across all sectors, including into social care.

The rewards both in terms of patient outcomes and hospital capacity of providing more palliative care in the community and in supporting the shift from hospital to community are as significant as they are obvious. As Amanda Pritchard, then CEO of NHS England, said in 2024:

> "Around a third of all bed days are accounted for by the tiny proportion of our population, around 1% who are in their last year of life. Now, if we can shift that by just 10%, by better caring for those people at home and in the community, then as well as giving them, and their families, a better experience, nationally we'd deliver the same effect as building three large new hospitals."[159]

Digital futures

We repeatedly heard of failure to integrate digital systems, with widespread fragmentation of patient information and duplication of assessments.[160] Although the 'tell us once' principle has been successful for social security systems after a person's death, patients find they are having to repeat their story many times and relatives report extreme frustration at having to repeatedly justify their role as an advocate, whether a Lasting Power of Attorney for Health and Welfare is in place or not.

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[156] APPG Arts, Health and Wellbeing and the National Centre for Creative Health. Dec 2023. Creative Health Review.

[157] Clabburn, O., et al., Co-production in practice: A qualitative study of the development of advance care planning workshops for South Asian elders. Palliat Med. 2024 Dec 8:2692163241302678. doi: 10.1177/02692163241302678

[158] Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026. 2021 NHS England

[159] Pritchard A., NHS ConfedExpo conference, 12 June 2024

[160] Forward C., Bayley Z., Walker L., *et al* Homecare workers needs and experiences in end of life care: rapid review. BMJ Supportive & Palliative Care 2024;14:e2330–e2340.

As not all home care settings have reliable broadband or access to NHS data systems, the digital divide is widened.

Digital coordination such as the NHSMail pilot in south London has shown how secure information sharing between social care teams and healthcare professionals improved coordination for end-of-life care.[161]

Ensuring all patient records are digitally accessible to all providers, including ambulance services, is essential in supporting the patients' preferences while meeting their clinical needs in a co-ordinated way. Removing barriers to the sharing of records to all involved in a person's care is vital in a patient-centred, integrated approach.

Waste

Waste occurs at many levels. Examples include: duplicative assessments, equipment not being rapidly recycled for patient-use, unused medication that is disposed of and multiple staff members visiting the same patient when the staff have overlapping roles and with better communication could have avoided duplicating workloads.

Underpowered studies that include too few subjects waste research effort, underlining the need for collaborative research networks.

In many areas there are inadequate generalist staff, and lack of pharmacy services, to provide care at home. This often results in families calling 111 or dialling 999 and ending up in Emergency Departments and medical assessment units.

Patients asked for 24/7 services, with calls for help answered by a human voice who can act on their needs, not a chatbot or answerphone or having to wait hours for a call-back. Such a helpline is contacted for a wide range of reasons (see Figure 7). The Goldline telephone hub in Airedale provides a 24/7 telephone contact point for patients considered to need palliative care at some level, and for their families. Specialist nurses answer the calls, and a palliative care consultant is available to the hub team at all times. [162]

We heard strong evidence that 7-day specialist palliative care that is available from 8 am to 8 pm, backed up by specialist advice that can be directly accessed by all involved in social and health care out-of-hours, can avoid unnecessary admissions and avert crises. However, the failure of many areas to have any such service to support the community and for hospital staff advice needs to be urgently addressed to ensure the shift to care in the community is sustainable.

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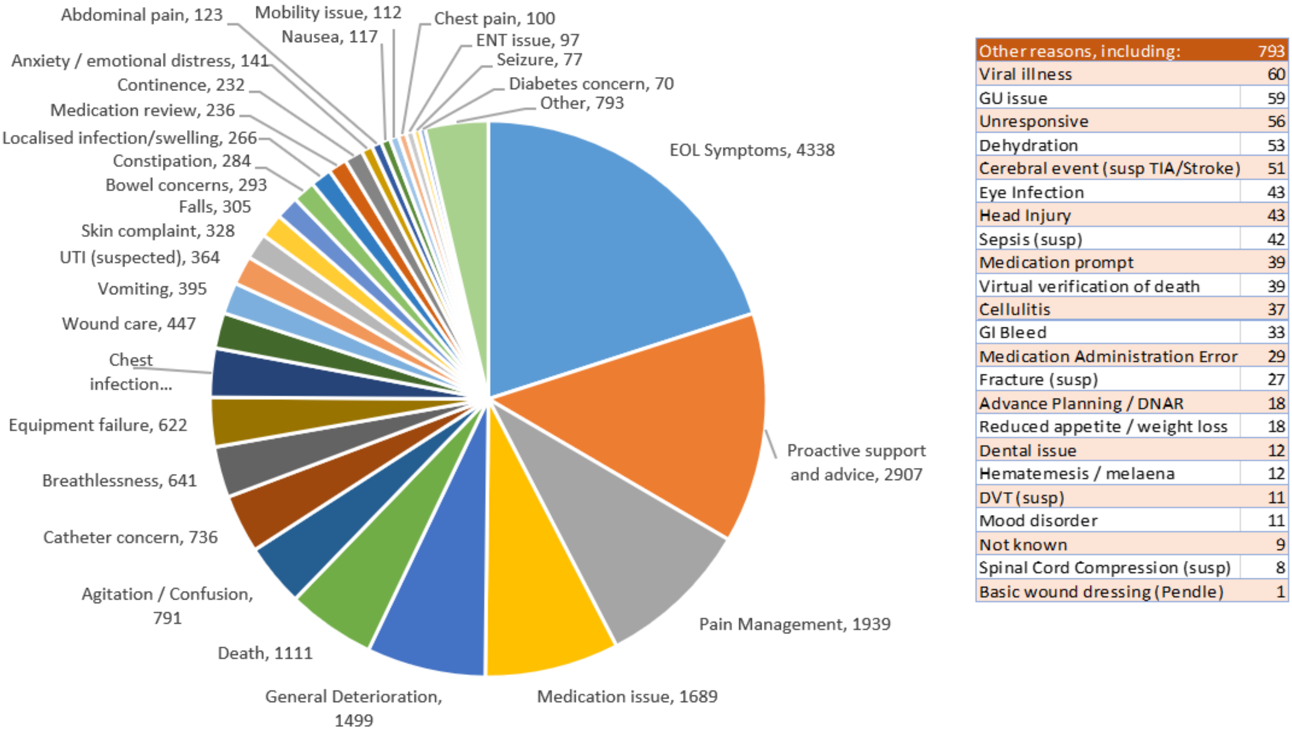
[161] NHS Mail pilot in National End of Life Care Programme (2008) The route to success in end of life care—achieving quality in homecare providers.

[162] Wilson L., (2024), Goldline Annual Report 2022/23. Airedale Digital Hub and Airedale NHS Foundation Trust



Other reasons, including:	793
Viral illness	60
GU issue	59
Unresponsive	56
Dehydration	53
Cerebral event (susp TIA/Stroke)	51
Eye Infection	43
Head Injury	43
Sepsis (susp)	42
Medication prompt	39
Virtual verification of death	39
Cellulitis	37
GI Bleed	33
Medication Administration Error	29
Fracture (susp)	27
Advance Planning / DNAR	18
Reduced appetite / weight loss	18
Dental issue	12
Hematemesis / melaena	12
DVT (susp)	11
Mood disorder	11
Not known	9
Spinal Cord Compression (susp)	8
Basic wound dressing (Pendle)	1

Figure 7: The reasons for calls to the Goldline hub in 2022/23

Anticipatory interventions

We heard how anticipatory interventions can provide timely support to patients and their carers. This can be through the timely provision of equipment, so that people have access to relevant equipment ahead of their requirement, including adaptations and aids, including wheelchairs. Likewise we heard how anticipatory medication, available if needed is important in ensuring that there is no impediment to a patient having access to timely interventions. Working with pharmacies to secure a 24/7 service is vital if timely interventions are to be made.

Chapter 15: Recommendations to meet the aims of the NHS Ten Year Plan

Shifting care to community

Funding needs to be based on a national formula that recognises and provides:

- The current **guidance for commissioners** needs simplification and a core minimum palliative care service specification set produced as a blueprint for Integrated Care Boards (ICBs) to better understand what they should be commissioning from specialist palliative care, and address inequality of provision.[163]

- The provision of **appropriate 24/7 services** is essential and must be a core concern of commissioners, with a particular focus on fast-response to avoid inappropriate transfer to hospital through failure to control distressing symptoms.

- **Place-based** working of health and social care providers, working together to support people to live as well as possible, must include palliative care links in neighbourhood integrated generalist teams.

- A stipulated baseline recommended multiprofessional **workforce of specialist palliative care** staffing to work with all generalist services in the community: domiciliary and care homes, in-patient hospitals including with Emergency Departments

- Specialist palliative care and respite **beds** (hospice inpatients and/or virtual ward systems; designated care home respite provision; children's hospice beds to allow respite for complex needs)

- **Single 24/7 telephone** point of contact is commissioned to ensure advice to patients and their families, and to staff of all grades

- Ensures **24/7 rapid response** to crises in patients receiving home-care.

- **Pharmacy** services for a locality for anticipatory drugs and provision for 24/7 medication access in a crisis to avoid inappropriate hospital admission.

- Clinical leadership at strategic and operational levels to drive high quality delivery, service improvements, education, training, innovation and research.

- Improved data systems nationally on the outcomes of palliative care, and the delivery of services, so that care can be monitored

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[163] The NIHR Policy Research Unit in palliative and end of life care.

- Providing services for people of all ages in need of palliative care and supporting their informal carers and family members.

Prevention

Avoiding distress:

Specialist palliative care improves symptom control and quality of life. Specialist Palliative care services must be available 24/7 in all settings to all patients that need them.

General palliative care symptom control knowledge and communication skills training must be included in every healthcare undergraduate curriculum and qualifying examination; in continual professional development and in induction programmes for staff coming to the NHS who have trained and /or worked outside the UK.

Avoiding duplication:

"Care is everybody's job" - All staff must **work at all their general competency levels**, as well as at specialist level competency, working with colleagues to avoid unnecessary duplication and to ensure timely response to a patient's needs.

Decrease psychological distress and suicide risk:

The risk of patient suicide is highest within 6 months of being given a diagnosis that is life-threatening and devastating.[164] All clinicians must be trained in sensitive and culturally appropriate ways of breaking bad news, in establishing needs and what matters to the person, and in determining how to access additional support as needed.

Avoiding unnecessary admissions:

Adequate provision of community services, including specialist palliative care services and 24/7 support so that patients and families feel safe and can contact competent help when needed.

- **Single 24/7 telephone** point of contact to ensure advice to patients and their families, and to staff of all grades

- Community clinicians (community nurses, rapid response teams, paramedics etc) providing **24/7 rapid first response** to crises in patients receiving homecare must have appropriate training and be able to provide interventions as needed. They need to be able to access specialist palliative care advice.

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[164] Nafilyan V, Morgan J, Mais D, et al. Risk of suicide after diagnosis of severe physical health conditions: A retrospective cohort study of 47 million people. Lancet Reg Health Eur. 2022 Dec 14;25:100562. doi: 10.1016/j.lanepe.2022.100562. PMID: 36545003; PMCID: PMC9760649.

- **Pharmacy** services for a locality for anticipatory drugs and provision for 24/7 medication access in a crisis to avoid inappropriate hospital admission.

- **Teaching and supporting families** how to provide care at home, what to expect with normal dying, how to support family, especially children, as well as how to give breakthrough and emergency analgesia by oral, subcutaneous and other routes. Carers need a supply of the appropriate medication, tailored to the specific patient's needs, for patients being cared for at home or in a care home. Teaching carers aspects of care can encourage care at home and enhance unpaid family carers' confidence in care.

Future care plans must be easily kept under review by the patient, with staff recognising that needs can change rapidly, and with clear documentation of what patients do not want (e.g. not to be conveyed to hospital if possible, not for attempts at cardio-pulmonary resuscitation) as well as distinct wishes (e.g. religious or other customs when near death).

The federated data platform. Clinical records (including future care plans) must always be available to emergency services (ambulance etc).

A documented wish of where a patient wants to die is not a surrogate for their care needs to be able to live well during whatever time is left.

Decreasing morbidity in those bereaved, especially children:

Children need age-appropriate support prior to and in bereavement. School and education sector staff have an important role to play in the lives of children and young people; educational services should ensure that schools, club leaders etc have an awareness of issues for bereaved children, including how to engage local appropriate bereavement services if needed.

Preventing waste

Frugal interventions are required at all levels of Health and Social Care provision. Examples include:

- Staff working at all levels of their competencies, including at basic care levels, and seeking help when they have reached the limit of their competency.

- Making future care plans available to avoid unnecessary admission etc.

- Backroom functions for management of hospices and other providers could be shared to avoid duplication.

- Clinical staff contracts must allow working across all sectors.

- Access to medicines 24/7 in the community to minimise need for stockpiling of anticipatory medications.

Benefitting from digital

Although digital solutions allow rapid transfer of key data there is a large amount to care that requires careful interactions that cannot be captured by or replaced by digital solutions. Additionally, the vulnerability of digital systems to ransomware attacks and unauthorised access mean that some patients do not wish some or all their data to be held digitally.

Clinical and social care records should be able to be linked and include assessment of patient outcomes, so that their problems are clearly understood by all, and such assessment is available to all involved, and potentially involved, in a patient’s care, with wherever possible the patient as controller of which personal details are shared across sectors. The federated data platform should be used and simplified, including to allow data access for research.

Equipment provision and collection must be rapid to ensure the most cost-effective use of equipment and increase availability across a community (reference the service in Yorkshire). Delays in provision can result in inappropriate equipment supplies and delays in collection after a person has died can greatly increase distress for the bereaved, as well as delaying servicing and resupply of equipment to others in need.

Research should evaluate whether AI can be used to better identify patients who would benefit from palliative interventions, open conversations about future care and monitoring.

Chapter 16: Overall Recommendations

1. Develop a National Strategy for palliative care and end-of-life care

A National Strategy must be developed setting out a framework for the commissioning and delivery of specialist palliative care and end of life care services, and the workforce requirements to implement this, recognising the general palliative care responsibilities of all working in health and social care.

This should also cover requirements for data sharing, education and training, and research.

It should aim to ensure patients palliative care and end of life care needs are addressed at the right time, in the right place by the right level of professional by all staff working to all their competencies, receive adequate training in palliative care for their role and can seek timely help from appropriate specialists.

The strategy should set short- and longer-term milestones. Annual reporting on key milestones in the Strategy must be a Ministerial responsibility of the Department of Health and Social Care.

Benefits:

- A National Strategy allows commissioners of services to be held to account and it also allows commissioners to hold providers of services to account.

2. Mandate and fund specialist palliative care, working with coordinated general care in every area

Recommendation: Specialist palliative care should be available in all areas, commissioned by Integrated Care Boards (ICBs) and integrated with existing services to ensure adequate access for all populations. Face to face services should be available on a 7-day basis with 24/7 advice via a single contact point.

Children's hospice services require national commissioning or collaborative commissioning by a consortium of ICBs.

Specialist palliative care must be able to work collaboratively with other services to optimise pain and symptom management, psychological, spiritual and carer support. These services must provide care in multidisciplinary teams, and link to social care provision. Some patients need access to services at the time of a life-limiting diagnosis or advancing frailty.

To enable this, the existing service specification needs to be revised and improved, and issued nationally, requiring measurement of patient-centred outcomes. ICBs must be held accountable for what is being commissioned and for service improvement, with timetables for the publication of interim plans and service specifications. These must feed into the national report from the responsible Minister.

Benefits:

- Finances: Specialist palliative care services reduce costly hospital admissions, especially in the last months of life, and can lower emergency department visits and unnecessary acute care interventions.

- Preventing hospital admissions and ensuring transfer home: Rapid, specialist care in the community reduces the likelihood of unnecessary transfers to hospitals, which are often due to unmanaged symptoms, and help to facilitate appropriate planned discharge from hospital

- Well-being: Provides individuals with personalised, compassionate care that improves symptom management and enhances quality of life, allowing patients to live with dignity and comfort.

3. Improve rapid response to advice and access to community services

Recommendation: Strengthen community services by ensuring accessible 24/7 support for patients and families. Such support should cater for the wide range of needs by ensuring a human voice responds to phone calls for assistance and advice, has immediate access to the clinical record and can take action. This community support must include community clinicians, rapid response teams, pharmacy services, social care, arrangements for out-of-hours interventions, access to equipment, medications and specialist palliative care advice to improve support and prevent unnecessary hospital admissions. This service is to be fully commissioned by the ICB by 31 March 2028 and integrated with all palliative care services in other settings.

Benefits:

- Finances: Reducing hospital admissions leads to significant savings by cutting down on expensive emergency department visits, inpatient stays, and long-term hospital care.

- Preventing Hospital Admissions: Timely responses to symptoms in the community prevent the escalation of care needs, which otherwise result in hospital transfers.

- Well-being: Enables patients to stay in familiar surroundings, reducing anxiety and enhancing emotional well-being. Family caregivers benefit from knowing that support is available 24/7.

4. Education and training for all health and social care staff

Recommendation: Implement mandatory palliative care training for all health and social care staff in undergraduate programmes from September 2026 ensuring early identification of patients who would benefit from palliative care and enhancing communication skills. This training should be ongoing and specialist-level for those working in palliative care settings with higher education providing such courses. Clinicians working in specialist palliative care services should also have time allocated for continuous professional development.

Benefits:

- Reduction in complaints: Training all staff to effectively manage palliative care needs reduces the risk of complaints.
- Timely referral to specialist palliative care: Better recognition of palliative care needs can lead to more appropriate management and referral when needed.
- Rapid escalation of care planning when managing complex needs and requiring effective interventions

5. Dual accreditation and recognition of prior experience

Recommendation: Several consultants in palliative medicine and medical directors of hospices started their careers with Membership of the Royal College of General Practitioners (MRCGP). Subsequently, changes in training prevented their mobility. With increased care in the community, those with GP training, and who have undertaken additional specialist training in palliative medicine, should be able to be accredited based on prior experience.

Benefits**:**

- This career mobility would help retain senior experienced doctors in the workplace who have particular skills in community care and create a clear career pathway into this specialty.

6. Fund research to improve care, especially evaluating community-based interventions and treatments

Recommendation: Prioritise and fund research into palliative care to develop evidence-based practices and treatments, improve care models, and evaluate ways to improve palliative care for currently neglected and disadvantaged populations. This includes focusing on the effectiveness of community-based interventions, symptom treatments, and the integration of digital technologies into care delivery. New service models which combine several interventions (e.g. single point of access, hospice at home and/or virtual wards) should be evaluated at local level and for their applicability to be adopted and spread more widely.

The Government should encourage clinicians’ involvement in research and prioritise funding for clinical research from 1 April 2026.

Benefits:

- Finances: Investment in research helps identify cost-effective care models and interventions, which can inform policies that allocate resources more efficiently. It also contributes to understanding the long-term cost savings of early palliative care involvement, reducing avoidable hospital admissions and intensive care unit (ICU) stays. In addition, it will maintain the UKs leading position in palliative care, making it a ‘go to’ place to learn about palliative care, supporting our science industries.

- Preventing Hospital Admissions: Research into innovative models of care (such as virtual wards and integrated care pathways) can determine their effectiveness in reducing hospital admissions, ensuring that care is provided in the most appropriate setting — typically the home or community.

- Well-being: Research helps to continuously improve palliative care practices, ensuring that patients receive the most up-to-date, evidence-based treatments. This leads to better symptom management, improved quality of life, and higher patient satisfaction. It also ensures that care is personalised and tailored to the unique needs of individuals, improving their overall experience during a challenging time.

7. Support for informal carers and families

Recommendation: Provide robust support services for informal carers, including practical assistance, respite care, and training to build confidence in delivering care, available out-of-hours as family caregivers often play a key role in managing symptoms. Such support will include a single point of contact to address all palliative care needs of the patient, understanding how to contact 24/7 specialist care and access to a helpline within the local service. Holistic support for the wellbeing of carers must also be available to them throughout the time they provide care and beyond, and family members must have the opportunity to recognise their role as a carer but also as a family member, without the latter being neglected.

Each ICB should commission a comprehensive bereavement service or services to support adults and children who are bereaved.

Benefits:

- Well-being: Providing respite and training for carers helps reduce their stress and improves their mental health, leading to better care for the patient and a more positive caregiving experience. Well-supported carers are less likely to feel overwhelmed, reducing the risk of patient deterioration and preventing avoidable hospital admissions.

- Finances: Supporting informal carers reduces the need for formal in-home care or hospitalisation, which can be expensive. It also prevents the need for institutionalisation, and acute hospital costs.

- Good aftercare: this not only reduces costs to the NHS as people are able to better manage their grief but ensures that people are able to integrate well into their communities.

8. Integration of health and social care data systems

Recommendation: Develop integrated, secure data systems for seamless communication between health and social care providers, ensuring that key patient information is accessible to all involved in patient care, including GPs, ambulance services, emergency departments, care homes, social care providers and specialist palliative care teams as well as in hospital departments. Include appropriate assessments relevant to palliative care, including of symptoms and outcomes.

The Government should support development of systems to better identify patients who would benefit from palliative care interventions.

Staff contracts and indemnity must support integrated working between hospices, hospitals, care homes, and the community, including other settings, such as prisons, supported by integrated clinical communication.

Benefits:

- Finances: Improved data sharing reduces duplicated tests, procedures, and interventions, and provides more streamlined care resulting in cost savings for the health system. This also enables better resource allocation, ensuring services are deployed where they are most needed.

- Preventing Hospital Admissions: Timely access to comprehensive patient data allows for quicker decision-making and reduces the chances of inappropriate admissions to hospital, improving care continuity.

- Well-being: Patients and families feel more confident when all providers have access to up-to-date information. This ensures care is aligned with the patient's preferences and needs, improving overall satisfaction and reducing stress for patients and families.

9. Ensure compassionate, open, and timely communication, supporting future care plans

Recommendation: Following a diagnosis or progression of a life-limiting illness, advancing frailty/co-morbidity or during uncertainty, every patient must have the opportunity to communicate their own, personalised wishes and plan for future care. This must be a dynamic document and regularly reviewed with the patient. and those close to them, such as their family. Clinicians must be trained in compassionate, kind and honest communication and in developing plans for the future with patients and their families.

Benefits**:**

- Improved communication and listening to patients' and families' concerns will address a key failing noted in the review into the Liverpool Care Pathway [12] and in reports from other major inquiries.

- Patients, families and clinicians have a very clear focus on the patient's priorities and wishes, restoring to patients a sense of control in the face of illness that by its progressive nature is removing control. Patients can maintain their key roles in life, empowering independence.

- Listening to patients, supporting them in addressing their concerns and in finding solutions to their difficulties, decreases a sense of being a burden on family, society and the NHS.

It can reduce unnecessary escalation of care and ensure that a patient has more control over the decisions made about their management. This can significantly reduce costs by decreasing waste and avoiding unwanted interventions.

- It can decrease complaints and legal costs to the NHS.

10. Improve understanding around palliative care, hospices and dying

Recommendation: Age-appropriate dialogue concerning palliative care, hospices and dying is needed, starting at school and extending into the community, to increase understanding of what palliative care can offer during serious or life-threatening illness and how hospices promote living well even as death approaches. Bereavement services should out-reach to support public understanding about care around dying, making age-appropriate materials widely available to help people engage with the issue of death and dying.

Benefits:

Earlier engagement with palliative care services, allowing timely support during illness and bereavement, improved communication, more awareness of available services, possibly lessening morbidity in the bereaved, particularly children, and improving long-term social and employment outcomes for the bereaved of all ages.

Chapter 17: “Who does what”

Specialist palliative care, provided by multidisciplinary teams, must be mandated nationally and commissioned by ICBs, with services in all areas at a sufficient level for the population, stipulating that responsibilities are:

- Service providers – core service (assessment, symptom management, psychological support, carer support by a multidisciplinary team), education and training, evaluating and improving patient outcomes and experience.

- Commissioners – ensure/facilitate cross-agency collaboration, including across health and social care; access to medicines and equipment; mechanism for holding service providers to account (without being overly bureaucratic).

- Government – develop a National Strategy and funding template to guide commissioning of services and decrease inequity.

- Educators - Educate, both at core and at continuing workforce training, all in health and social care in the essentials of palliative care and in communication skills, with a focus on early identification of those patients of all ages and ability, who are likely to benefit from palliative care, and in the importance of collaborative working. Train to specialty competency level all working in specialist palliative care at every level e.g. care assistants, nurses, allied health professionals, doctors, and managers.

- Community service providers - bolster and improve community services and support for both patients and informal carers, especially out of hours, pharmacy, district nursing, community practical aids, social care and primary care, to provide a single point of access and rapid response 24/7.

- Technical support to health and social care - communication of key patient information must be available to all involved to avoid duplication, with access for GPs, community nurses, pharmacists, ambulance services and emergency departments. This requires an increase in the quality and availability of data, compatible IT systems for secure patient information transfer and increase in access with funding to develop the research infrastructure for palliative care.

- Researchers – establish networks nationally to ensure that studies are adequately powered to provide scientifically valid results, to evaluate initiatives, encourage publication, and promote ‘adopt and spread’ of beneficial changes, and abandon interventions of no proven value.

Appendix - Examples of integrated services

Integration of Palliative Care Across Conditions

Models of integrating palliative care across a range of serious illnesses — including cancer, respiratory disease, neurological conditions, heart diseases, frail older people, and in the community — have been developing and evaluated in recently years. Evaluations of the services to date find that early and integrated palliative care can improve patient-centred outcomes, enhance quality of life, reduce symptom burden, increase future care planning, and in some cases lower health care use. This underlines the importance of systematic, early integration rather than palliative care being reserved only for the end of life.

Integration models vary but typically involve early referral to specialist palliative care alongside disease-directed treatments, multidisciplinary collaboration, holistic approaches addressing physical, psychological, social, and spiritual needs and community integration.

The section below gives some examples of these for some conditions. Later examples include emerging models in earlier stages of development, which will require more robust evaluation.

In Oncology

Early integration of palliative care into oncology, usually within 8–12 weeks of an advanced cancer diagnosis, has been shown to improve quality of life, mood, patient and caregiver satisfaction, and in some studies even survival. Studies understanding the benefits of this integration and how to implement it have been growing over the last 14 years, since a landmark randomised trial in lung-cancer. [42] Early integration of specialist palliative care with oncology for patients with advanced cancers, usually via oncology clinics with joint consultations, or using a stepped approach prioritising those with more symptoms or more recently with virtual consultations, improves quality of life, reduces depression, enhances coping strategies, and can extended survival. Patients receiving early palliative care reported better communication, symptom control, psychological wellbeing and were more likely to receive goal-concordant care at the end of life.[165] [166] [167]

Acute oncology patients usually have unmet palliative care needs as part of an oncology emergency. Where specialist palliative care and oncology work jointly, sharing responsibilities in acute oncology, there are better outcomes and more efficient work patterns. [168] The American Society of

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[165] Greer J.A, Temel JS, El-Jawahri A., et al. Telehealth vs In-Person Early Palliative Care for Patients with Advanced Lung Cancer: A Multisite Randomized Clinical Trial. *Jama* 2024; 332(14): 1153-641-3

[166] Temel JS, Jackson VA, El-Jawahri A, et al. Stepped Palliative Care for Patients with Advanced Lung Cancer: A Randomized Clinical Trial. *Jama* 2024; 332(6): 471-81

[167] Temel JS, Petrillo LA, Greer JA. Patient-Centered Palliative Care for Patients with Advanced Lung Cancer. *J Clin Oncol* 2022; 40(6): 626-34

[168] Williams H., Marshall E., Lillis A., et al. The role of the acute oncology service in a comprehensive cancer management pathway. *J Cancer Policy* 2025; 44: 100583

Clinical Oncology (ASCO) guidelines recommend that all patients with advanced cancer should receive concurrent palliative care and oncology care throughout their disease trajectory. [169]

In Respiratory Medicine

Integration of specialist palliative care into respiratory medicine has been achieved through multidisciplinary services such as joint clinics triggered by escalating breathlessness for people with respiratory disease, holistic needs assessments, and regular collaborative respiratory–palliative clinics. Such services have been developed and tested in randomised trials in London, [34] Cambridge, [134] and from individual hospices, and have been replicated in Australia, [170], Germany and beyond.

Reviews of the evidence, including reviews supported by the UK National Institute for Health and Care Research (NIHR), find that integrated specialist palliative care for people with symptomatic COPD and interstitial lung disease improves symptom control (especially breathlessness and psychological distress) and quality of life, increases patient satisfaction, reduces hospital admissions, does not shorten life, and may even extend it. Such integration is recommended in guidance by the European Respiratory Society and the International Gold Guidelines for management in COPD. [133] [171] [172] [173] [174] [175]

In Care for Older People or those with Multiple Conditions

For older people who are becoming frail, have difficult symptoms or multiple conditions, integrating specialist palliative care with care services for older people has proven benefits. Integration is associated with better symptom management, improved alignment of care with patient preferences, greater caregiver support, may reduce hospitalisations and is cost-effective. [33] These benefits exist across a range of conditions, including in heart failure, show cost savings [176] and are recommended in policy reviews. [177]

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[169] Sanders JJ, Temin S, Ghoshal A, et al. Palliative Care for Patients with Cancer: ASCO Guideline Update. *J Clin Oncol* 2024; 42(19): 2336-57

[170] Smallwood N, Thompson M, Warrender-Sparkes M, et al. Integrated respiratory and palliative care may improve outcomes in advanced lung disease. *ERJ Open Res* 2018; 4(1)

[171] Pascoe A, Chen X, Smallwood N, A narrative review of proactive palliative care models for people with COPD. *Ther Adv Respir Dis* 2025; **19**: 17534666241310987

[172] Spathis A., Reilly C.C., Bausewein C., et al., Multicomponent services for symptoms in serious respiratory illness: a systematic review and meta-analysis. *Eur Respir Rev* 2024; 33(174)

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[174] Venkatesan P. GOLD COPD report: 2024 update. *The Lancet Respiratory medicine* 2024; 12(1): 15-6

[175] Maddocks M, Brighton LJ, Farquhar M, et al., Holistic services for people with advanced disease and chronic or refractory breathlessness: a mixed-methods evidence synthesis. *Health Services and Delivery Research* 2019; 7 (22)

[176] Janke K., Salifu Y., Gavini S.,et al., A palliative care approach for ault non-cancer patients with life-limiting illnesses is cost-saving or cost-neutral: a systematic review of RCTs. *BMC Palliat Care* 2024; 23(1): 200

[177] Kuebler K., Monroe T., Ricciardi R., et al., Integration of palliative care in the management of multiple chronic conditions: An expert consensus paper with policy implications. *Nurs Outlook* 2024; 72(6): 102273

In Neurology

Integrated specialist palliative care in neurology is evolving rapidly following earlier trials, especially in conditions such as motor neurone disease (MND), multiple sclerosis, Parkinson's disease and severe stroke.

Integration typically involves joint palliative-neurology clinics, early short-term integrated palliative and rehabilitation care providing home visits or clinic assessments, and multidisciplinary team working. [178] Studies, including those supported by the UK NIHR, find that such integrated care provides benefits including improved symptom control, and patient and family satisfaction without any negative effects. [179] [180] [181] [182] [183] The findings emphasise the value of identifying palliative needs earlier in the disease course, rather than waiting for late-stage decline.

In Bradford

The Marie Curie REACT (Responsive Emergency Assessment and Community Team) is an innovative Palliative Care Virtual Ward, underpinned by a partnership of Bradford Teaching Hospitals Foundation Trust, Social Finance and the Care and Wellbeing Fund. Emergency department in-reach by specialist palliative care proactively identifies patients with palliative care needs and offers 72 hours of virtual ward support at home rather than admission in a crisis. This has begun to address inequity of access to palliative care, better reflects Bradford demographics and has significantly reduced hospital use for patients known to REACT: the average number of bed days in the final year of life reduced from a baseline of 38 days to 18 days (53%), probably saving 8326 bed days in the last 12 months.

Other examples of integration in Bradford include:

- Use of shared clinical records and EPaCCS using SystmOne
- Goldline – a dedicated 24 hour telephone service for people who are thought to be in the last year of life, and the people looking after them. Calls are answered by experienced nurses and paramedics who give advice, support and guidance to help people remain in the place of their choosing (usually at home). 20% of people registered on Goldline died in hospital, compared to a national average of around 43%. An independent evaluation from York Health Economics Foundation found that patients receiving interventions through Goldline experienced a 23% reduction in non-elective hospital admissions.

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[179] Hepgul N, Wilson R, Yi D, et al., (2020), Immediate versus delayed short-term integrated palliative care for advanced long-term neurological conditions: the OPTCARE Neuro RCT. Southampton (UK)

[180] Chan LML, Yan OY, Lee JJJ, et al. Effects of Palliative Care for Progressive Neurologic Diseases: A Systematic Review and Meta-Analysis. *J Am Med Dir Assoc* 2023; 24(2): 171-84

[181] Solari A, Oliver D, Force EANGT. (2020), Palliative care in multiple sclerosis: European guideline. *Mult Scler* 2020; 26(9): 1009-11

[182] Oliver D, Veronese S, Specialist palliative care for Parkinson's disease. *Annals palliat med* 2020; 9 (Suppl 1): S52-62

[183] Kluger BM, Hudson P, Hanson LC, et al. Palliative care to support the needs of adults with neurological disease. *Lancet Neurol* 2023; **22**(7): 619-31

- A shared policy across the system supports families to be trained in giving subcutaneous medication to patients at home
- An enthusiastic hospital support team now tries to see all patients thought to be nearing the end of life to ensure optimal symptom control, with healthcare assistants as part of the team to allow time and dedicated responsibilities for patient comfort and cultural respect

A combined ‘one-stop shop’ neurology/palliative care motor neurone disease (MND) clinic at the hospice sees every new neurology patient at diagnosis, removing gatekeeping to specialist palliative care. It reduces duplication for the patient – the wider multiprofessional team all see the patient in one appointment, including speech and language therapy, dieticians, occupational therapy, respiratory specialists and physiotherapy. The patient only travels to one clinic, tells their story once, and can access coordinated services.

In Oxford

The Rapid Intervention for Palliative and End of Life Care (RIPEL) programme is a unique partnership between Oxford University Hospitals NHS Foundation Trust, Sobell House Hospice Charity and Social Finance (funded by Macmillan Cancer Support). RIPEL provides an enhanced multi-component response involving home hospice, hospice outreach, rapid discharge from hospital and 7-day multidisciplinary hub, integrated with existing specialist and generalist palliative care services in Oxfordshire. Since the full mobilisation of the programme in July 2024, patients supported by the RIPEL programme have spent on average 11.9 more days at home in their last year of life compared to the pre-project baseline. There is a significant reduction in the length of stay and number of non-emergency admissions for all patients during their last 90 days of life, avoiding >13,000 unplanned bed days per year. Notably this supports the principle that focusing efforts on high intensity users (those known to specialist palliative care) has an effect across the system.

In York- the Frailty Hub

Since it was formed on 1st November 2023, the York Frailty Hub has brought together several organisations from across the Voluntary and Community Sector, Adult Social Care, Community, Palliative Care and GP Services to address frailty management. The service runs from 8 am to 8pm, seven days a week and uses shared electronic records, including with emergency services.

The core aims of the service are to support those with frailty and/or long-term conditions to:

- Support people to remain independent for longer.
- Reduce avoidable hospital admissions.
- Provide person centred care in the right place at the right time.
- Deliver responsive community-based crisis care when needed.
- Expedite safe discharge from hospital.

By adopting a proactive and integrated crisis response model, in its first year the Hub has reduced over 1400 hospital admissions. The team have demonstrated that they have kept York residents safely in their usual place of residence, and streamlined efficient care delivery with benefits felt from all providers involved.

The Hub has three main aims:

1. Frailty Prevention
    a. To identify opportunities to meet unmet health and social needs as early as possible, thereby preventing escalation into crisis
    b. Case management of 3000 of the most vulnerable and frail people in York
2. Integrated Frailty Crisis Response
    a. To prevent unnecessary admissions to hospital for frail and vulnerable City of York residents whenever possible
    b. Delivery of a Frailty Crisis Advice & Guidance Line and the coordination of multi-agency, joined-up, community-based responses
3. Discharge Support
    a. In-reach model to support the hospital discharge of patients as early as possible, to promote independence and improve patient outcomes.

York has brought together a number of services, including Palliative Care, co-located in the community with a common goal – to support the frailest people in York. AI is now being applied to further determine patients who could benefit from these services.[184]

In London – connected digital care plans

Connected digital care plans, such as Coordinate My Care, which shape and inform the response of the urgent care services in real time in London have reduced end of life deaths in hospitals from 42% to 21%. [185] [186] [187] This reduces acute hospital bed days, accident and emergency admissions and minimises upsetting transfers and hospital stays for patients.

Further digital developments include identification patients who are frail, have dementia or a life limiting illnesses or fuel poverty so they can routinely be identified using AI and risk stratification algorithms, decreasing inequity. Each eligible patient can be proactively contacted and offered the opportunity to create their own plan giving patients real choice. Patients will be able to initiate their own plans on an app, via the NHS app, online or by phone. The patient-initiated plan is then submitted to a clinician, who knows the patient, to add the clinical details and complete the plan e.g. add a DNACPR and arrange for adequate medication at home. Medications, allergies and other valuable information will auto-populate into the plan from the patient's GP record. [188] The plan will then be shared in real time with the emergency services and connect to the first responders 24/7.

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[184] York Frailty Hub Written Evidence Submission

[185] Callender T, Riley J, Droney J, et al. The Determinants of Dying Where We Choose: An Analysis of Coordinate My Care. Ann Intern Med. 2017 Oct 3;167(7):519-521. doi: 10.7326/M17-0695.

[186] Macfarlane P, Sleeman KE, Bunce C, et al Advance Care Planning and Place of death During the COVID-19 Pandemic; A Retrospective Analysis of Routinely collected Data. Journal of Patient Experience 2023; 10(17),

[187] Orlovic M, Droney J, Vickerstaff V, et al Accuracy of clinical predictions of prognosis at the end-of-life; evidence from routinely collected data in urgent care records. BMJ Palliative Care 2023; 22 (51): 1-11 Https://doi.org/10.1186/s12904-023-01155-y

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The outcome of formal evaluation is awaited.

In General Practice – the Gold Standards Framework

The framework aimed to support general practice to better identify patients in need of palliative care at any level and was complemented by the Quality Outcomes Framework with GPs holding a Palliative Care Register that was remunerated. We heard concerns that the removal of this from the general medical services contact would exacerbate the decline in ability of GPs to undertake home visits to their patients.

The GP Quality Outcomes Framework and Palliative Care Register was brought in through the National End of Life Strategy in 2008, but has been abandoned in the latest General Medical Services contract. The loss of the Register runs the risk of reducing pressure on GPs to identify patients with palliative care needs. The register had facilitated the uptake by primary care of courses run by the Gold Standards Framework, with practices becoming certified when reaching a required standard. The Gold Standards Framework has also been taken up by home care providers, care homes and some hospitals.[189]

In Research – the importance of negative findings

If research or audit studies find that the expected benefits are not seen it is important that these ‘negative’ findings are published, as they play a crucial role in improving clinical practice and policy. There can be a tendency to avoid publishing negative findings, as they may be perceived as setbacks or failures, but doing so is essential for advancing practice and improving patient outcomes.[190] When research finds that certain treatments or interventions do not work as expected, sharing these negative results by publishing them, helps to better understand what doesn't help patients or families, refine care strategies, and focus resources on treatments and care that genuinely improve outcomes. This transparency ultimately strengthens the evidence base and ensures that care is both effective and person-centred.[191]

This importance is illustrated by the BETTER-B trial, which evaluated the medicine mirtazapine that had been proposed for alleviating severe breathlessness in patients with chronic obstructive pulmonary disease (COPD) or interstitial lung diseases. This multinational, multicentre, randomised, trial found that mirtazapine did not significantly improve breathlessness compared to placebo and was associated with more adverse reactions. These findings suggest that mirtazapine should not be recommended for this indication, highlighting the importance of rigorous evaluation even for quite widely used medicines that have been adapted and used for different purposes or in different groups.[192]

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[189] https://www.goldstandardsframework.org.uk/

[190] Hopewell S, Loudon K, Clarke MJ, Oxman AD, Dickersin K. Publication bias in clinical trials due to statistical significance or direction of trial results. *Cochrane Database Syst Rev* 2009; (1)

[191] Porter RJ, Boden JM, Miskowiak K, Malhi GS. Failure to publish negative results: A systematic bias in psychiatric literature. *Australian & New Zealand Journal of Psychiatry* 2017; 51(3): 212-4.

[192] Higginson IJ, Brown ST, Oluyase AO, et al. Mirtazapine to alleviate severe breathlessness in patients with COPD or interstitial lung diseases (BETTER-B): an international, multicentre, double-blind, randomised, placebo-controlled, phase 3 mixed-method trial. *The Lancet Respiratory medicine* 2024; 12(10): 763-74

Another illustration is the findings from the randomized controlled trial evaluated Advanced Care Planning (ACP) using the Respecting Patient Choices model among patients with incurable cancer. Among the 208 people studied there was no significant difference between the ACP and usual care groups in terms of family members reporting that patients' end-of-life wishes were discussed and met. Additionally, there were no differences in end-of-life care received, patient satisfaction, or family member well-being. These results suggested that this ACP intervention may not always lead to improved care or improved alignment of care with patient preferences in this population.[193]

Another example is the trial evaluating the Liverpool Care Pathway (LCP). The trial was conducted in Italy, after the pathway had been rolled out across the UK. It assessed the effectiveness of the LCP in improving care at the end of life for hospitalized cancer patients. Across 16 hospitals, with very careful and well supported implementation, the study found no significant benefit for those whose care was supported by the LCP compared to standard care in terms of the overall quality of care or for any secondary outcomes.[194]

These examples highlight the importance of conducting rigorous research and underscore that publishing negative findings is not a setback but a vital contribution to advancing evidence-based care. Such transparency helps to prevent the widespread adoption of ineffective interventions, inform future research directions and ultimately improve patient outcomes by ensuring resources are directed toward strategies that genuinely make a difference.

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