“The night times are frightening”: gaps in 24/7 community care for people at the end of life

Policy briefing, May 2025

Introduction

Terminal illness does not respect the clock. The health of a person living at home with an advanced illness can deteriorate suddenly at any time – day or night, during the week or at the weekend.

These are anxious moments for the person with a terminal illness and for family or friends who are caring for them. Pain and other symptoms may suddenly worsen, and fears about dying without dignity or the company of loved ones may surface. Patients and their carers[1] in this situation need to be able to urgently access palliative and end of life care (PEoLC), including medicines, equipment and other forms of personalised care and support.

However, if this deterioration occurs outside of ‘normal’ working hours (Monday to Friday, 9am-5pm), accessing care in or near to their own home may be neither quick nor easy – especially if they have not already been registered or referred for palliative care, or if they live in a rural or deprived area. **The out of hours period accounts for over 75% of time in every week.**

This is why people with a terminal illness often resort to visiting their local emergency department out of hours, particularly in the final three months of their lives. These visits can be highly distressing for them and their families and very expensive for our health and care system.

Previous research has already exposed considerable variation and gaps in out of hours care across the UK.[2] It has also highlighted that out of hours emergency department attendance increases in frequency as death approaches. It is between five and eight times higher in the month before death than at 12 months before death and there are around 650,000 out of hours visits to emergency departments in England by people in the final year of life each year. It is also more common among people living in the most socioeconomically deprived areas.

This new research has sought to map the gaps in out of hours care available for people at the end of life across England.

Our findings highlight the urgent need for 24/7 PEoLC to be prioritised in the 10 Year Health Plan and for local services to be transformed, so that everyone who needs this vital care is able to receive it at the right time and in the right place.

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[1] In this report we have used the term ‘carer’ to refer to unpaid carers of people with a terminal illness.

[2] Pask et al (2022), Mind the gaps: understanding and improving out-of-hours care for people with advanced illness and their informal carers. Marie Curie Report. Available at: **www.mariecurie.org.uk/document/better-end-of-life-report-2022**

Summary

- New research by Marie Curie highlights significant gaps in access to out of hours co-ordinated care in the community for people at the end of life.
- This research is based on the results of Freedom of Information (FOI) requests issued to all 42 Integrated Care Boards (ICBs) in England, asking them about their provision of a dedicated palliative care advice phone line and urgent community response services.
- The responses we have received show that these essential PEoLC services can be patchy, particularly in the evenings, overnight and at weekends.

Access to a 24/7 palliative care advice phone line

- Access to a 24/7 palliative care advice and support telephone line for people with terminal illnesses has been recommended as a minimum service requirement for nearly two decades, but our research shows these services are still not available across much of England.
- Only 7 of the 42 ICBs in England said they have a dedicated 24/7 single point of access to PEoLC advice, guidance and onward referral, when needed, to other services.
- In many cases, even where services exist, access is not universal. 18% of the advice lines are only available for health and care professionals rather than being available to patients and carers as well. In some areas, a designated palliative care advice phone line was only available to patients already known to palliative care services.
- Most PEoLC advice lines are delivered by charitable hospices and funded by a combination of ICB and charitable funding. Given the significant current financial pressures on charitable hospices, this raises concerns about the sustainability of these services.

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ICBs in England said they have a 24/7 single point of access to PEoLC advice and guidance

Urgent Community Response services

- Urgent Community Response services – rolled out across all areas since 2022 – are seeing consistently high levels of referrals due to patients having end of life care needs. But these services are also not routinely available on a 24/7 basis.
- Previous studies have shown that significant gaps in access to 24/7 co-ordinated care in the community are resulting in large numbers of people entering a crisis at the end of life and avoidable uses of ambulances, A&E and emergency hospital admissions. This is deeply distressing for patients and families, and extremely expensive for the NHS.

The need for better community care

- Across the United Kingdom, we are currently spending five times as much on hospital care for people in the last year of life as we do on care in the community.
- The UK Government has set out its ambition to shift more healthcare out of hospitals and into the community as part of its 10 Year Plan for Health, to ensure patients and their families receive personalised care in the most appropriate setting.
- If it is to realise this ambition, then PEoLC must be a significant priority within the plan, and there must be investment in integrated models of care that shift provision from hospital to community.

Context

What are current experiences of the end of life?

Whether or not people of all ages can die with dignity – able to access the care and support they need, financially secure and able to meet their material needs, and in the place of their own choosing – is a significant marker of a civilised society. But a range of recent evidence suggests that for far too many people today, their experiences of the end of life are marked not by dignity, but by avoidable pain, inconsistent care, and significant uncertainty around where to turn for the help they need.

Recent research published as part of the **Better End of Life programme[3]** has demonstrated that whilst the number of people who need PEoLC is increasing steeply, our health and care system is already struggling to meet that demand.

The largest nationally representative survey undertaken in almost a decade (across England and Wales) of people affected by dying, death and bereavement found that gaps in 24/7 community care are preventing people from dying in comfort in home.

The survey also found that too many people were affected by pain and other symptoms. Patients and unpaid carers are suffering due to poor communication and coordination. Current workforce capacity is insufficient to meet demand for end of life care, and unpaid carers are taking on significant caregiving roles with little support.

The Health & Care Act 2022 introduced a new legal responsibility for ICBs in England to commission palliative care services that meet the needs of their local populations. But early research conducted on behalf of Marie Curie highlighted that this duty has not resulted in a greater strategic prioritisation or funding of PEoLC services.[4]

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3. Johansson et al (2024); 'Time to care: Findings from a nationally representative survey of experiences at the end of life in England and Wales' Better End of Life 2024; Available at: **www.mariecurie.org.uk/policy/better-end-life-report**
4. Marie Curie (2023); 'Palliative and end of life care in Integrated Care Systems: Exploring how Integrated Care Systems are responding to the Health and Care Act'; available at **www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2023/015529-mc-peolc-discovery-a4-report.survey.finalv1.pdf**

Sharon's story

Sharon, a retired nurse, struggled to access palliative care for her husband, Kevin who was diagnosed with a brain tumour in 2022.

"From the very beginning, Kevin's treatment was always going to be palliative. But he didn't get palliative care – he just got end of life care in the last couple of weeks.

We didn't have much support from the GP at all, and where we live is an hour away from hospital, and any support was all in the hospitals. There was nothing local for us. We couldn't drive at the time, so it was really difficult to access. ***We fell through the cracks and had to fight for everything.***

I wasn't offered any support as a carer. I could phone Maggie's but that was only phone call support. I spoke to somebody from Brainstrust – that was email support – but other than that, I just had my family. ***There was no professional support. It's terrifying to have that responsibility, to try and make a life when I didn't know what was going to happen.***

I worried all of the time. The anticipation of him having a seizure, or if you need to get hold of a GP and you can't get hold of them, was awful.

If I'd have had the palliative care team there a bit sooner, even for just the odd phone call, that would have been lovely. It would have let me build some trust and a relationship with them, so I felt more confident when things got difficult.

I have to say that I've been nursing for 40 years, and end of life care hasn't got better, which is very disappointing, scary and sad."

Unmet needs, rising fast

As our population ages more people will be living with, and dying from, multiple and complex conditions. Between 2023 and 2048 the number of people with palliative care needs in the UK is projected to increase by more than 147,000 (a 25% increase). Around one in four people currently do not get the end of life care and support they need. Yet around 90% of us will die with palliative care needs.

Every single one of us deserves to have our preferences on the care and support we receive listened to with respect. But the needs, interests and preferences of most people at the end of life are deeply neglected both in public discourse and public policy. Partly as a result of this, there are significant gaps in end of life care in all parts of the UK today. These gaps are geographical and reflect inequities in access to services for groups, such as people living in poverty, alone or with dementia, as well as people with non-cancer conditions, learning disabilities, people from ethnically minoritised groups and LGBTQ+ people.[5]

With a significant proportion of NHS costs accrued in the last year of life, the design

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[5] Hudson BF et al., (2023) Intersectionality factors and equitable end-of-life experiences: rapid review. Available at: **spcare.bmj.com/content/bmjspcare/early/2023/12/07/spcare-2023-004658.full.pdf**

and delivery of end of life care has huge implications for public spending. More people now die at home than before the Covid-19 pandemic[6] but, in general, emergency admissions to hospital and Emergency Department use increases in the final months of life[7], and frequent hospital admissions are indicative of poor care planning and poor quality of end of life care.[8]

As our population ages and a greater number of people die each year, this will place our health and care system under ever more pressure. But the funding context for end of life care is extremely uncertain. Both the NHS and charitable hospices are facing extreme financial pressures, and long term investment in the primary and community care workforce has been insufficient to meet the rising demand.[9]

Public expenditure and cost-effectiveness

Recent analysis undertaken by The Nuffield Trust and Health Economics Unit on public expenditure in the last year of life[10] highlights significant public expenditure (£22 billion in 2022) on people in their final year of life across the UK, equating to £33,960 per person.

Over half of this total expenditure – almost £12 billion – was on healthcare, but the analysis makes clear that current health spending is disproportionately distributed towards hospital care rather than coordinated and holistic care in the community. Of public funds spent on healthcare for people in their last year of life, 81% was spent in hospital, 56% was spent on emergency hospital care and only 11% on primary and community care.

Given this significant expenditure, there is an urgent need to reimagine the policy response and reshape public expenditure on this group, in particular by shifting health expenditure on people at the end of life from hospital to community settings.

A new rapid review of the evidence on cost-effectiveness of PEoLC interventions by the NIHR Policy Research Unit has identified robust out of hours care with prompt home visits for crisis care, and dedicated palliative care support lines in all areas as one of its top recommendations for change. [11]

Existing policy framework

24/7 access to support and care for people with terminal illnesses in the UK has been consistently recommended as a minimum requirement for nearly two decades. NICE Guidelines [NG142] & [NG61] say:

‘People approaching the end of their life, their carers and other people important to them should have access to:

- **a healthcare professional available 24 hours a day, 7 days a week, who can access the person’s records and advance care plan, and make informed decisions about changes to care,**
- **an out-of-hours end of life care advice line,**
- **an out-of-hours pharmacy service that has access to medicines for symptom management in people approaching the end of their life.’**

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[6] Office for Health Improvement and Disparities (2025): Palliative and end of life care profiles January 2025 update: statistical commentary. Available at: **www.gov.uk/government/statistics/palliative-and-end-of-life-care-profiles-january-2025-update**

[7] Office for Health Improvement and Disparities, Palliative and end of life care factsheet: patterns of care, England 2022. Available at: **www.gov.uk/government/statistics/palliative-and-end-of-life-care-factsheet-patterns-of-care-england-2022**

[8] Nuffield Trust (2025); ‘End of life care: We look at trends in the quality of end of life care’; Accessed on 20.01.25 at: **nuffieldtrust.org.uk/resource/end-of-life-care**

[9] Baird B et al., (2024) Making care closer to home a reality. The Kings Fund) Available at: **www.kingsfund.org.uk/insight-and-analysis/reports/making-care-closer-home-reality**

[10] Nuffield Trust, Health Economics Unit and Marie Curie (2025) ‘Public expenditure in the last year of life’ Available at: **www.mariecurie.org.uk/document/public-expenditure-in-the-last-year-of-life-report**

[11] Clarke, G et al., (2025). Costs and cost-effectiveness of adult palliative and end-of-life care. Evidence briefing summary. London: National Institute for Health and Care Research (NIHR) Policy Research Unit (PRU) for Palliative and End-of-Life Care Available at: **kcl.ac.uk/nmpc/assets/research/costs-and-cost-effectiveness-of-adult-palliative-and-end-of-life-care-evidence-briefing-summary.pdf**

Timeline of relevant guidance

2004	NICE [CSG4] recommends that general and specialist PEoLC services are available within each locality 24/7
2008	Department of Health's 'End of Life Care Strategy' recommends access to a dedicated 24 hour helpline for people on an end of life register
2011	NICE [QS13] recommends service providers ensure PEoLC is available 24/7, including through the provision of an advice line
2016	Department of Health's 'Our Commitment to you for end of life care' recommends local clinical advisory hubs to improve access to PEoLC
2019	NICE [NG142] recommends 24/7 access to a dedicated PEoLC advice line and a pharmacy with stock of palliative medicines
2021	National PEoLC Partnership Ambitions Framework includes 24/7 access to services as a foundational principle
2022	NHS England develops statutory guidance on the requirement for ICBs to commission PEoLC services, with 24/7 access as a core principle

Research findings

About this research

New research undertaken by Marie Curie seeks to build on previous findings from the Better End of Life 2022 Mind the Gaps report[12] to understand current 24/7 single point of access PEoLC advice line and Urgent Community Response services across England which may be available to support patients at the end of life during the out of hours period.

Information was gathered through a survey of all 42 Integrated Care Systems (ICS) (submitted as FOI requests to all ICBs), supplemented by a literature review and desk-based research.[13] 39 out of 42 ICBs responded to the FOI requests. Where they did not respond, relevant information was gathered through desk-based research. Requests were issued in December 2024 and January 2025.

Different types of services

As this research highlights, the provision of out of hours co-ordinated care in the community for people at the end of life is highly variable, and in many areas patchy. Where services exist, they have various models, delivered by a range of providers, and integrated with other local health and care services to greater or lesser extents. For the purposes of this research, services have been broadly categorised in the following ways:

PEoLC advice lines can enable people living at home with advanced illness and their carers to access advice and support via telephone. Experienced palliative care professionals can provide advice and guidance, as well as onward referral if needed to services such as Urgent Community Response, virtual wards, pharmacy, GP and community team, or acute/hospital. They use a local number that patients and carers need to know, and may be only accessible to those on the palliative care register. An ICS may have a number of such lines across its geography with different numbers covering different local areas. Some are fully available 24/7 and others have more limited availability and service out of hours.

Single point of access palliative care advice lines have some or all of the features described above, but they also cover the whole ICS using one number and are available 24/7. New technology can now enable access for patients and unpaid carers via NHS 111 with a palliative care option providing direct access to local palliative care professionals. This local specialist provision can then triage calls, provide advice and support, and refer people on to the right local services. They are also available to other health and care professionals such as paramedics and care home staff.

Urgent community response:
The 2-hour Urgent Community Response standard requires all ICSs to assess, treat and support people aged over 18 experiencing health and/or social care crises in the place they call home, including care homes, who are at risk of hospital admission. Since April 2022, each ICS has been required to provide a consistent service over 12 hours (usually 8am-8pm), seven days a week across its full geography. While the 12-hour coverage window is the minimum requirement, the NHS England guidance notes operating hours should be extended where demand necessitates.[14]

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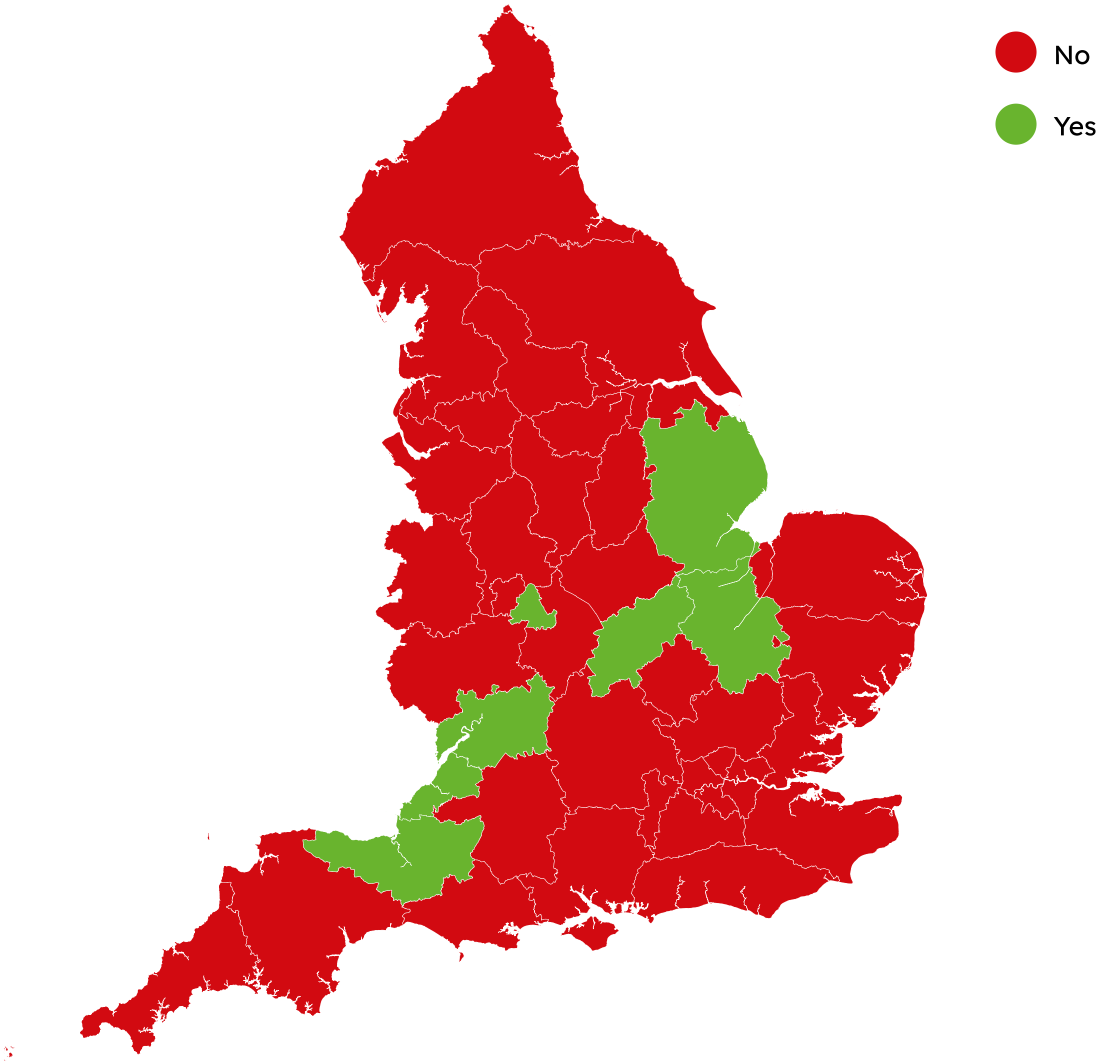
12. Pask et al (2022), Mind the gaps: understanding and improving out-of-hours care for people with advanced illness and their informal carers. Marie Curie Report. Available at: **www.mariecurie.org.uk/document/better-end-of-life-report-2022**
13. We have relied on the information provided to us through the Freedom of Information responses for the purposes of categorisation and this does not provide a comprehensive or nuanced picture of the totality of palliative and end of life care provision in each individual ICS. Some additional desk research was carried out where the FOI responses did not provide a complete picture of the relevant services available in the ICB.
14. NHS England (2022), Community health services two-hour urgent community response standard. Available at: **www.england.nhs.uk/wp-content/uploads/2021/07/B1406-community-health-services-two-hour-urgent-community-response-standard.pdf**

Key findings

- Access to a 24/7 palliative care advice and support telephone line for people with terminal illnesses has been recommended as a minimum service requirement for nearly two decades, but our research shows these services are still not available across much of England.
- Only 7 of the 42 ICBs in England said they have a dedicated 24/7 single point of access to PEoLC advice, guidance and onward referral, when needed, to other services.
- In many cases, even where services exist, access is not universal. 17% are only available for health and care professionals, rather than being available to patients and carers as well. In some areas, a designated palliative care advice phone line was only available to patients already known to palliative care services.
- Most PEoLC advice lines are delivered by charitable hospices and funded by a combination of ICB and charitable funding. Given the significant current financial pressures on charitable hospices, this raises concerns about the sustainability of these services.
- Urgent Community Response services, rolled out across all areas since 2022, are seeing consistently high levels of referrals due to end of life care needs. But these services are also not routinely available on a 24/7 basis.

Figure 1: Does the ICS have a dedicated palliative and end of life care single point of access telephone advice/support/help line?[15]



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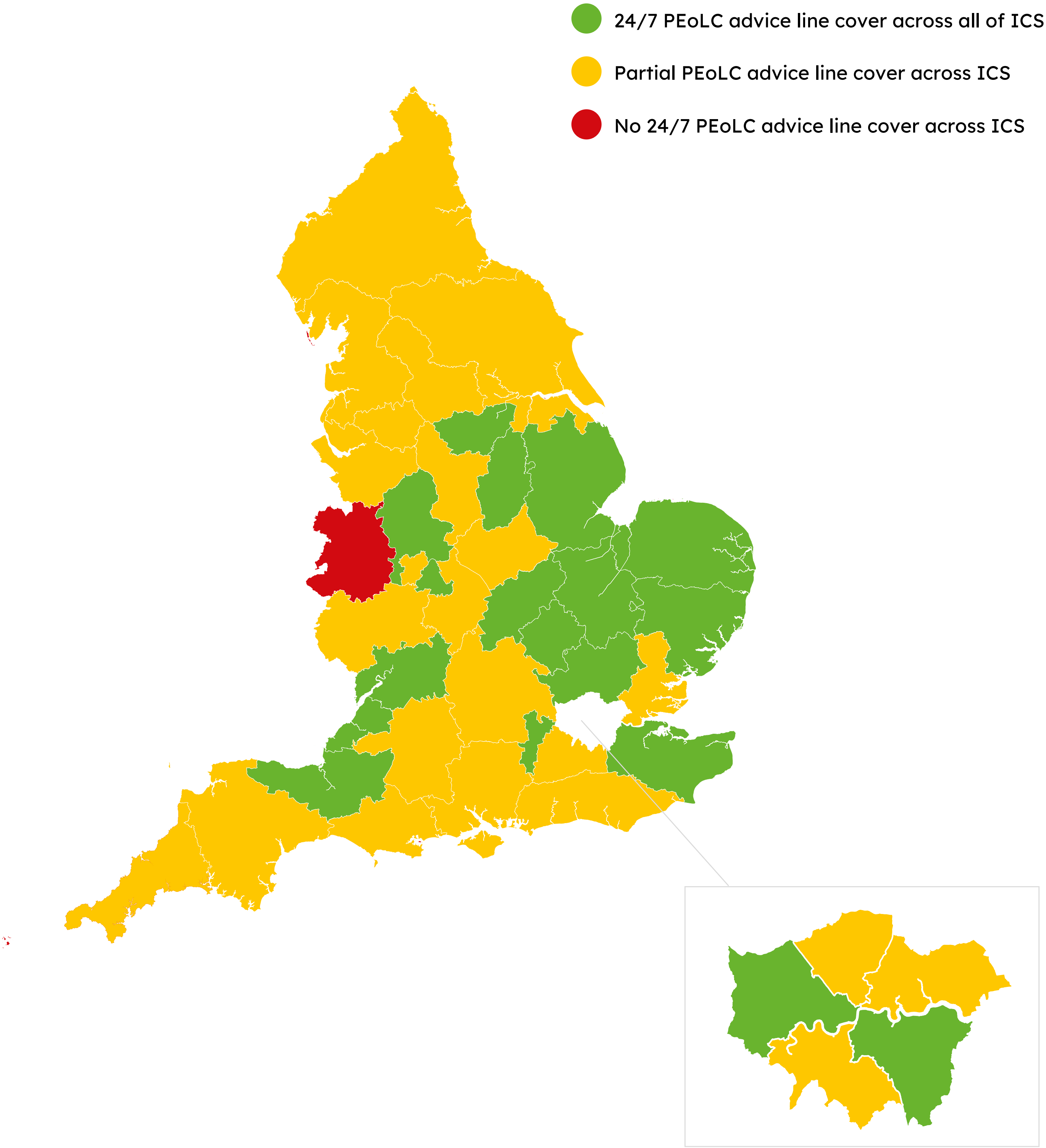
[15] A key for the numbering of ICBs as presented on these maps is provided in the Appendix, available on request.

Figure 2: Is there 24/7 palliative and end of life care telephone advice, support and guidance line service across the ICS?[16]



Note: 'Partial' means covering some of the ICS's counties or boroughs 24/7 or only being open to health and care professionals and not carers or people with a terminal illness. 'No' means no 24/7 advice line coverage in any area of the ICS.

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[16] A key for the numbering of ICBs as presented on these maps is provided in the Appendix, available on request.

Jo's story: What gaps in 24/7 services mean for patients and carers

Jo struggled to secure nighttime care for her husband Mat.

"There were a few nights towards the end where Marie Curie wasn't able to offer us night care, due to the availability of carers and the demand being so high. The nights when we didn't have Marie Curie, it was just me caring for my husband Mat, supporting him during the seizures or when he was in so much pain.

I'd be on the end of a phone, waiting for somebody to answer the out of hours service or leaving a message for someone to call me back. Waiting for someone to call back was a lonely and scary time because of the helpless feeling of not knowing what to do for the best when seeing a loved one suffering.

When I would receive a phone call I would often have to constantly repeat and retell Mat's history and diagnosis, and this was upsetting to keep reliving when all I wanted was someone to say they were on their way to see him now. We would then have to wait 1-2 hours for someone to arrive to assess Mat which seemed like hours. Unfortunately, on a couple occasions I had no one call me back at all, so on those nights I had to call 999 for a paramedic to come to the home.

The constant phone calls – trying desperately to get support for nights – left me scared and so tired and drained, even though I had to care for my husband the next day. My husband wanted to die at home and that is what I fought for him. However, the constant battle for this to happen safely for him was at times exhausting.

During the day, the support was outstanding because I would call the community nurses and the palliative nurses, and they would always call me straight back. They would visit Mat daily to administer the medication needed in his syringe drivers, they were kind, caring and so supportive to us and our family. Support from the GP was outstanding too."

The night times were so different and frightening. Often during the night when I was trying to get support, he could see how scared and stressed I was which made him more scared often telling me he was okay just to try and not make me worry. Every night I used to be thinking what might happen tonight, will Mat have another seizure? Will he be in so much pain again? Will they call me back if I need support? How long will it take for help to arrive?"

Going forward, the NHS could have a better system during the night – I know it's a postcode lottery, and different from county to county or council to council. But the care and support we had during the day was outstanding. However, at nighttime, if Marie Curie weren't there, it was a scary, lonely and a frightening time."

Palliative and end of life care single point of access and 24/7 advice lines

- Less than 17% (7 out of 42) of ICSs have a dedicated single point of access PEoLC telephone line, providing advice, guidance and onward referral to other services covering the whole ICS area.
- Less than half (18 out of 42) of ICSs have 24/7 PEoLC advice lines covering the whole ICS area.
- Half of ICSs (22 out of 42) have only a patchwork of partial coverage for PEoLC advice lines – meaning that geographically services may only cover some parts of the overall area, may be available for only some of the 'out of hours' period but not 24/7, or services are available only to health and care professionals (not directly to patients and their carers).
- 2 out of 42 of ICSs did not have any 24/7 coverage across its area.[17]

How services are delivered and accessed

- Information on 113 different designated PEoLC advice lines across England was provided by ICB respondents. Missing response data means the actual total number is likely to be much higher than this.
- We asked **'who is the contracted lead provider'** of the PEoLC advice, guidance and support lines? Of the 113 PEoLC advice lines
  - 75% were provided by charitable hospices,
  - 22% were provided by the NHS/ Community Foundation Trusts, and
  - 3% were other providers e.g. Community Interest Companies/ Independents.
- We asked **'how these services were funded'**? Respondents provided information on 69 PEoLC advice lines. Of these:
  - 40% were funded by the ICB
  - 54% were funded through a combination of ICB and charitable funding
  - 6% where funded by charitable funding.
- We asked **'Is the service available to patients and carers'**? We also asked **'Is the service available to health and care professionals'**? Of the 113 designated PEoLC advice lines:
  - 82% were available for patients, carers and health and care professionals.
  - 18% were available for health and care professionals only
- In some areas, a designated PEoLC advice phone line was only available to patients already known to palliative care services, which is concerning given high levels of unrecognised palliative care needs. In only 29% of services the respondent noted that the person did not need to be known by the service before calling the PEoLC advice line.
- We asked **'what are the hours and days of operation of the service'**? Of the 113 designated PEoLC advice lines:
  - 76% said that people could access support 24/7 via the advice line.
  - However, some respondents said the service had 24/7 PEoLC advice line coverage but these advice lines operated 9am-5pm and then switched to a single phone line connecting to the hospice Inpatient Unit (IPU) or callers were given another number in order to contact the IPU outside of those hours. This model carries more risk that calls may be dropped or unanswered due to capacity.

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[17] Reported at time of request (10th December 2024). Subsequent research has indicated that Cornwall and Isles of Scilly ICB are in the process of implementing a new single point of access service.

Urgent Community Response Services Findings

- All 42 ICS areas have an Urgent Community Response service.
- 39 out of 42 ICSs (93%) provide the required 12 hours (usually 8am-8pm) of service provision, 7 days a week across all their boroughs or counties.
- 3 out of 42 (7%) ICSs have areas in their ICS that provide 10 hours (8am-6pm), 7 days a week.
- Across England, end of life support is consistently the second highest known reason for UCR service callout across ICSs each month.[18]
- 50% of ICSs are providing extended hours Urgent Community Response service provision across part or all of their counties or boroughs.
- 2 out of 42 ICSs (5%) have 24 hour Urgent Community Response service coverage, 7 days a week, with 11 out of 42 of ICSs (26%) providing 24 / 7 coverage across some of their boroughs and counties.
- 5 out of 42 ICSs (12%) offer extended hours (8am-10pm) across the entire ICS.

Best practice service model: Cambridgeshire and Peterborough Palliative and End of Life Care Hub

The Cambridgeshire and Peterborough Integrated Care System Palliative Care Hub was launched in April 2021. It is operated by Arthur Rank hospice charity in partnership with Herts Urgent Care (HUC) and the East of England Ambulance Service NHS Trust. It serves a population of c.950,000, including a mix of rural and urban areas. The Hub supports a region of disparate deprivation levels, with Peterborough ranking as the 51st most deprived local authority in England compared with Cambridgeshire as the 132nd. In 2021, the Hub was awarded the Health Services Journal Award for Primary Care Innovation of the Year.

A working group including representatives from NHS 111, out of hours services, the ambulance service, adult hospices, acute and community trusts, and the Clinical Commissioning Group (now Integrated Care Board) met throughout the Covid-19 pandemic to develop this innovative telephone advice line.

The service is accessed by calling NHS 111, selecting the palliative care option and being placed in direct contact with an Arthur Rank hospice palliative care professional. The advice line is staffed 24/7 by band 7 palliative care Clinical Nurse Specialists who provide advice, guidance, support and signposting to other services. It is available to patients, carers, GPs, or other health and social care professionals. Patients do not need to be known by specialist palliative care services to access the line.

The aim of the Hub is to ensure that people facing life-limiting illness and, those who are at the end of life, are able to access the support they need, when they need it. **The phone line seeks to enhance quality of life, enable a more positive experience of care and support, reduce avoidable hospital admissions and give patients more choice in accessing their preferred place of care.**

The Hub sought to deliver these benefits by making a number of system level changes to achieve simplified pathways for referral and advice. Partnership working and collaboration has been key to the success of the project. Alongside Arthur Rank hospice, partners include Sue Ryder Thorpe Hall hospice, the ambulance service, Herts

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[18] NHS England, Urgent Community Response Monitoring Dashboard.

Urgent Care (who run the NHS 111 service and GP out of hours service), GPs and primary care networks. It was helpful that NHS 111 was already routing patients with mental health needs direct to a local mental health service, as this provided a model for this hub to follow

During the first 30 months of operation (April 2021 to December 2023), 6,688 calls regarding 4,943 patients were received. The majority of calls (60%) came from patients or their carers/relatives. Half of patients had cancer, around a third had non-malignant disease, and 16% had both. The calls came disproportionately from more deprived areas of Cambridgeshire and Peterborough and roughly half the patients were not previously known to a specialist palliative care service. The main reasons for calling were pain, symptom control, sudden deterioration in condition, notification of a death, or for advice about or access to medication.

The 24/7 PEoLC telephone line is also used by health and social care professionals including GPs, hospice at home staff, ambulance clinicians, district nurses and community nurse teams and nursing/residential homes. Access to specialist palliative care advice supported them in making important care decisions such as whether admission to hospital was needed.

An indication of how the telephone line functions as a single point of access that can co-ordinate care is that, on average, each call to the line triggers two further calls from the clinical nurse specialists who answer the phone to those who can provide the support or care that is needed. **A key outcome of this is that 410 avoidable hospital admissions were prevented during the first 30 months of operation**, enabling an average of 13 patients per month to remain in their preferred place of care/preferred place of death. This has led to a reduction in calls to primary care and GP out of hours services, as 62% of calls received by the Hub would routinely have been managed by these services. Using data from SystmOne and national NHS costs data, net efficiency to the local system is estimated to be £944,790 since the service began (approximately £412,849 per year).

A number of options are now under consideration for enhancing the Cambridgeshire and Peterborough Palliative and End Of Life Care Hub. One key potential next step is training up the Clinical Nurse Specialists to become independent prescribers. This could reduce pressure on primary care and GP out of hours services further, as recent data analysis has shown that 53% of calls to the Hub were related to prescribing issues.

Other options for further developing the service include:

- better use of technology such as ‘talk to text’, immediate translation and video calls to make the service even more accessible
- independent prescribing online
- accessing 111 and the ambulance service ‘stack’ to pull out appropriate patients for management by the Hub
- creating and managing an integrated care system-wide PEoLC register
- proactively engaging with emergency departments and primary care to identify frail patients nearing the end of life and carry out advance care planning
- establishing a rapid response service
- improved data collection
- auditing prevented hospital admissions to understand for how long they were avoided
- reviewing service level data to inform plans for future service development
- and exploring whether assistance can be given for verification of expected death as a way of further reducing pressures on out of hours services.

Policy recommendations

As the Department for Health and Social Care develops its new 10 Year Health Plan, it is crucial that palliative and end of life care is recognised as a vital part of our health and social care system and made a priority within the plan.

We also need to see urgent investment at the 2025 Spending Review into innovative models of care, which shift provision of care for people at the end of life from the hospital into the community. Without these changes, the UK Government will not be able to achieve its ambition of building an NHS fit for the future by providing more care in the community, making greater use of technology, and building a more preventative health service.

Janice's story

Janice's mother received poor end of life care at her care home.

"My mother was living in a care home when she passed in December 2023. She was suffering from dementia and terminal metastatic cancer, amongst other illnesses. Like many people, I thought (somewhat naively in retrospect) that being in a care home she would receive adequate palliative care and, when the time came, end of life care. Unfortunately, that was not the case.

I truly believe that if my mother had been provided with adequate, specialist palliative and/or end of life care, it would have helped her enormously – physically, psychologically, and emotionally, and she would have been far more comfortable towards and at the end.

I believe that it would also have helped her family, including myself, in caring for her during this time. In the event, I have been left feeling eternally frustrated, helpless, and very saddened - heartbroken even - that I was not able to help my beautiful, kind, and courageous mother when she needed that help the most.

National policy should be changed urgently so that all terminally ill people have a mandatory right to adequate, specialist palliative or end of life care – in whichever setting they feel is right for them.

A helpline providing urgent palliative and end of life advice for staff and families should also be made readily available for anyone needing it."

Responding to gaps in 24/7 community services for people at the end of life

The NHS 10 Year Health Plan should commit to creating a universal gateway to 24/7 PEoLC advice, guidance and support by dialling 111 and selecting the PEoLC option.

Every part of the country should have a 24/7 single point of access PEoLC telephone advice line, accessed via 111, staffed by palliative care specialists who can provide advice, guidance and support to access local services. Alongside providing a universal gateway for palliative care needs, this could also help manage demand for Urgent Community Response services where end of life care needs are consistently one of the most frequent reasons for referral.

Making palliative and end of life care (PEoLC) a priority for health reform

There has not been a national strategy for PEoLC in England since 2008, highlighting a lack of national leadership, prioritisation and oversight. In order to address this gap, the Government should:

Develop a national strategy for improvement of PEoLC, with targets for improving the availability, quality and distribution of integrated health and care services for everyone with palliative care needs in local populations. This strategy should aim to achieve 24/7 delivery of co-ordinated and quality PEoLC services for everyone through a national service specification that supports ICBs to deliver in full on their legal duty to commission palliative care services in the Health & Care Act.

Improve quality standards for PEoLC services by introducing minimum standards which must be met in all localities. These should build on the Ambitions Framework for PEoLC and provide a basis for regular auditing of the accessibility, quality and sustainability of end of life care services.

Improve data collection on PEoLC. Limited data on activity, quality and spending in community PEoLC and hospice services hinders achieving greater equity in provision and service improvement and innovation across the UK. Improved data collection and publication would assist providers, commissioners and policy makers to make more informed and evidence-based decisions about future support for people at the end of life.

Ensure palliative care is at the centre of plans for Neighbourhood Health Centres and virtual wards, by ensuring palliative care specialists are part of multi-disciplinary teams in neighbourhoods and virtual wards, and that both models draw on innovative emerging new approaches to integrated PEoLC in community settings.

Targeting a long term shift in expenditure at the end of life from hospital to community

There must be a clear long term ambition to shift health expenditure on people at the end of life from hospital to community settings, supported by appropriate targets. For example, a long term target to reduce hospital expenditure on people in the final year of life by 20% (£1.9billion) and a corresponding increase in expenditure on community based (community/GP/hospice) health services over a 10 year period would represent a doubling of current expenditure on community services.

In order to enable a long term shift in expenditure, the UK government should introduce a new PEoLC Transformation Fund to drive long-term improvements in access, quality and sustainability of PEoLC by incentivising the adoption and scaling of innovative models of community PEoLC care. These models have the potential to enable the shift from hospital to community, reduce the significant inequities in access, and support service innovation to improve quality and cost effectiveness.

Funding and workforce

The Government should plan and resource a workforce that can respond to increased future need for PEoLC, especially in community settings. Workforce planning must focus on investment in the GP, district and community nursing and specialist palliative care workforce that is needed to achieve the shift from hospitals to community. We must ensure parity of esteem between the NHS and charitable hospice workforce in pay and conditions, alongside full alignment of skills training and professional development to enable 'one workforce'. PEoLC should become a compulsory part of training for all health and care professionals as all of them will likely need to care for someone through the end of life during the course of their career.

A new funding solution for PEoLC is needed which ensures commissioning contracts cover the full operational costs of those services, including the clinical workforce, to reduce reliance on charitable fundraising and improve financial sustainability. This should include provision for ensuring that charitable hospices providing services are compensated for changes to national policy which directly affect them such as increases in NHS staff pay and conditions and the minimum wage. It should also ensure that contracts are commissioned over a medium-term time frame to improve financial sustainability.

For more information please contact

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