Better End of Life 2022

Marie Curie policy commentary on
*Mind the gaps: understanding and improving out-of-hours
care for people with advanced illness and their informal carers*

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 come to the fore.

Patients and their carers in this situation need to be able to urgently access palliative and end of life care, perhaps including medicines, equipment and other forms of personalised care and support.

However, if their moment of deterioration occurs outside of 'normal' working hours (Monday to Friday, 9am to 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, especially in the final three months of their lives. Such visits are highly distressing for them and their families, and very expensive for our health and care system.

In this briefing, Marie Curie summarises important findings from a new research report which helps to fill a key gap in the evidence base on out-of-hours services for people with a terminal illness and their carers across the United Kingdom, and we provide commentary on its implications for policy.

Mind the gaps: understanding and improving out-of-hours care for people with advanced illness and their informal carers [1] **has been produced through the Better End of Life programme,**

a collaboration between Marie Curie, King's College London Cicely Saunders Institute, Hull York Medical School, the University of Hull and the University of Cambridge.

The research report clearly demonstrates that out-of-hours care as experienced by patients, carers and health professionals falls far short of what is needed. It also shows that we are currently not delivering high quality out-of-hours care at home for everyone who needs it, and that access to and availability of good quality palliative and end of life care at home varies widely by geographical location.

Ensuring palliative and end of life care is available quickly and easily on a 24/7 basis, in every part of the country, would bring benefits for patients and carers, and for our wider health and care system. We urgently need to address current challenges in out-of-hours care, so that the right community-based care is available at the right time, for everyone who needs it.

This is a critical moment for action to improve out-of-hours care for people with a terminal illness and their carers. As a result of our ageing population, demand for palliative care is rising rapidly. In twenty years' time there will be 147,000 more people dying each year in the UK [2], up to 90% of whom would benefit from palliative care [3]. Without action now, existing unmet demand and inequalities in access to and experience of out-of-hours end of life care will worsen.

Ensuring everyone has the best possible palliative and end of life care, on a 24/7 basis and regardless of where they live, is an urgent and important policy priority.

Mind the gaps research report: context and key findings

This new research report responds to the fact that concern about 'out-of-hours' palliative and end-of-life care was identified as the top unanswered question by patients, carers, health and care professionals in a comprehensive survey of palliative and end of life care research priorities[4].

The *Mind the gaps* report also builds on previous research such as the National Institute for Health and Care Excellence (NICE) review of out-of-hours services, models and policies [5]. From such research we know that out-of-hours health services can be complex to navigate for both patients and those caring for them. There is also a higher risk that out-of-hours professionals may not know the patient's history because they have not seen the person before or do not have access to their records.

The research report authors acknowledge that out-of-hours care challenges occur in UK health and social care systems that are facing unprecedented pressures as they recover from the Covid-19 pandemic. This has exacerbated many of the inequalities that health care systems have a statutory duty to address. Across the UK there is also a growing focus on the importance of integrated and comprehensive palliative and end of life care being accessible and available at home 24 hours a day, seven days a week to all who need it[6 7 8 9].

For people living with advanced illness, care during the out-of-hours period is provided by a number of different health and care professionals; both those who provide general health and care (such as general practitioners, and district nurses or community nursing teams) and those who specialise in palliative and end of life care. The research report considers both general and specialist care, and how they work together.

Gaps in access to out-of-hours palliative and end of life care were explored through two main data sources. The first was data on out-of-hours emergency department attendance among people who are in the last year of life.

The second was interviews with health professionals with commissioning or leadership responsibility for, or detailed knowledge about, out-of-hours services across the UK. The interviews focused on aspects of out-of-hours care that had previously been identified as important by patients, carers and professionals [10]. These aspects and an independently facilitated workshop involving patients and carers informed the analysis and led the researchers to focus on the following questions:

- How do patients and their informal carers (whether family or friends) get help out-of-hours?
- Who sees the patient out-of-hours, especially if they need a medicine prescribed or administered?
- Can patients and informal carers access care and equipment out-of-hours?
- Can patients and informal carers access specialist palliative care out-of-hours, if needed?
- Do services work together out-of-hours?

The research report describes significant disparities in access to out-of-hours care, high use of emergency department attendance, and a large gap between the out-of-hours care people experience and that which ought in theory to be available to them.

Key findings from the research report

The research report uncovered considerable variation and gaps in out-of-hours care in the 60 areas surveyed across the UK:

- 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. It is also more common among people living in the most socioeconomically deprived areas.

- Not all areas have a designated telephone line for out-of-hours palliative and end of life care support; 27% of areas had no designated telephone line while 42% had only partial coverage.

- Access to medicines out-of-hours can be complicated and time consuming; only 25% of areas had a pharmacy open throughout the night that was able to dispense palliative medicines. 68% of areas only had partial availability of healthcare professionals able to administer palliative medicines at night.

- Equipment is hard to access; 52% of areas had only partial or no access to equipment out-of-hours.

- Care packages are often delayed or unavailable.

- Much out-of-hours care relies on stretched community nursing services.

- There are significant gaps between what is theoretically in place and what is actually experienced by patients and informal carers.

Lived experience of minding the gaps in end of life care

Darren, 54, shares his experience of caring for his dad at the end of life.

My dad died of mesothelioma which is a cancer caused by asbestos exposure – he worked as a painter and decorator.

When he was diagnosed, I asked the specialist clinician what happens next and who I should contact. She said, "In an ideal world, we would now take over your dad's care until he dies, but that's not the way the system works."

I had to contact my dad's GP first, she explained, who would contact the district nursing team, who would then contact the palliative care team.

My dad didn't need palliative care at that point, but I contacted the GP to make a [care] plan so that, when the time came, everything would be ready. Or so I thought.

I didn't hear back from the GP until it was too late. It turned out that nobody had contacted the district nurses or the palliative care team. My dad was at home without the care he needed.

I spent a lot of time on the phone, trying to get someone to come out and see my dad. When the district nurse eventually came, she was shocked at how unwell he was and said she'd make sure the GP knew he needed help. But again I didn't hear from anyone until I called back myself.

My dad wanted to die at home. That was the plan we'd agreed with the GP. But he ended up being admitted to hospital.

Nobody in the hospital knew what was going on and his pain wasn't being managed properly. I came in one day to find him in a chair with a pillow over his head, screaming into it.

The on-call registrar told me he'd been prescribed hourly morphine top-ups as needed. But when I asked a nurse about it, she wasn't aware.

The registrar had also said she'd contact palliative care. But I didn't feel like I could trust what I was being told by then. Nobody was communicating properly. So I called palliative care myself, and only then did things start to change.

My Dad went into a hospice. He was there for four days before he died. He should've been in there for a week – they said the delay was because of Easter, but that's not good enough. You can't choose when you become terminally ill.

As far as I can see, the system doesn't work. My dad fell through the cracks. If he hadn't had me advocating for him, I don't know what would have happened.

If there was a dedicated helpline, it would be so much easier. The way it works now makes it impossible to check on the progress of anything or find out who you need to speak to.

The actual dying part wasn't scary. In the last 48 hours, Dad was comfortable in the hospice. But in the weeks leading up to that point, he was in extreme pain and without dignity. That shouldn't happen to anybody.

Policy implications of the research report

1. People who are dying at home need a single point of access to palliative and end of life care out-of-hours

"We had a number for the district nurses and one for the hospice who provided the palliative care. But they were both 9 to 5 which is no good at 1 o'clock in the morning. Who do you phone?"

- Tracey, who cared for her dad Michael

The *Mind the gaps* report shows that emergency department attendances increase rapidly during the final three months of life. Although the medical needs of people with a terminal illness will inevitably increase in their final year and months of life, attending emergency departments in order to have those needs met is both extremely distressing for patients and their carers, and very expensive for our health and care system.

Out-of-hours visits to emergency departments increased more than in-hours visits during the last months of life [11]. This suggests a particular problem with gaps in accessible and high-quality alternative services during nights, weekends and bank holidays. People with a terminal illness and their carers would not always need to visit their local emergency department if they could quickly and easily access the palliative and end of life care they need in community settings during these hours.

The research report suggests that existing telephone lines giving access to general NHS services out-of-hours, such as NHS 111 or NHS 24, do not always meet the needs of terminally ill people and their carers. Patients and carers can experience long waiting times and difficulty in being connected to the local services and support they need. The most recent figures (June 2022) show that the average waiting time when contacting NHS 24 in Scotland for example is

just over 22 minutes. Even when a call has been answered by either NHS 111 or NHS 24 there may be further delays waiting for a clinical advisor.

A single point of access for local palliative and end of life care services such as a designated telephone advice line for people in need to call could help prevent distress and reduce pressures on the system arising from emergency department admissions at the end of life. The research report, however, found designated palliative and end of life care phone lines are not available in over a quarter of the areas they surveyed. Even where they are available, 42% only cover part of the out-of-hours period or were limited in other ways such as only being available in part of the local area (Figure 1).

The research report also found that single point of access phone lines are often only open to people who have already been referred for palliative care. Whilst restricting access may be intended as a logical response to the need to manage demand for a service with limited funding, in this instance it risks compounding wider inequalities in access to health services. Individuals who find it difficult to access health services throughout their lives are less likely to be identified early by a health professional as having palliative care needs, and then find themselves unable to self-refer into these services when in crisis at the end of their lives.

Improving access to out-of-hours care has been acknowledged as a policy priority in all four nations of the UK. NICE guidelines have consistently emphasised the importance of an out-of-hours designated palliative and end of life care advice phone line as one of the three pillars for equitable
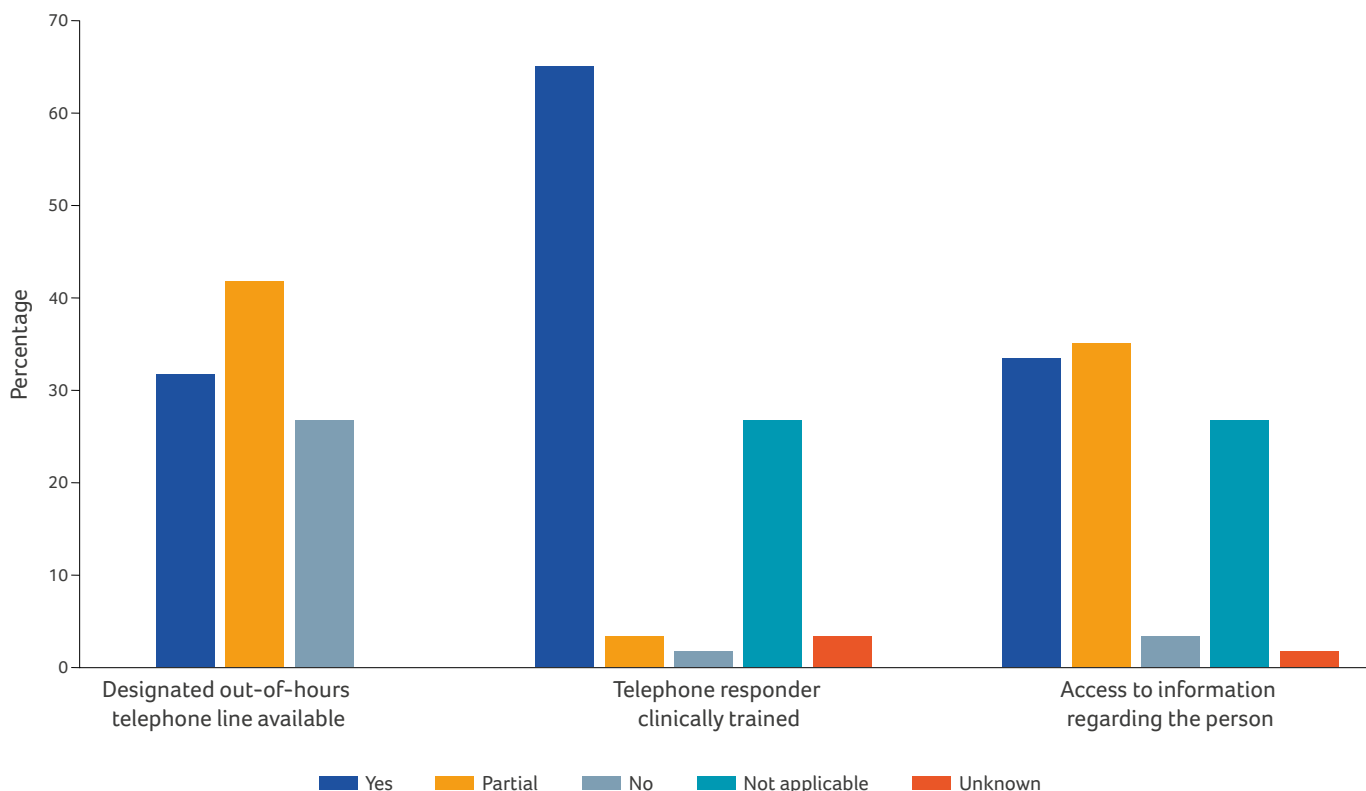
Figure 1: Provision of out-of-hours designated telephone services in the 60 UK areas surveyed (Source: Pask et al, 2022, p.13).

access to out-of-hours care and support [12] [13]. The recent statutory guidance for Integrated Care Boards (England) on palliative and end of life care emphasises that out-of-hours access must include people who are not on the palliative and end of life care register [14]. The Scottish Government has also emphasised the need for 24/7 telephone support, though for the moment this only applies to care homes [15].

The research report shows that much more work is needed to make a reality of the vision set out in policy of a designated single point of access phone line being available to everyone with palliative and end of life care needs.

Recommendation:

Every part of the UK should have a designated 24/7 palliative and end of life care phone line staffed by professionals with specialist palliative care expertise who can provide advice, guidance and support to access local services. This service should be available to all people with a terminal illness, their carers and health and care professionals.

Designated 24/7 telephone advice lines providing a single point of access can support better outcomes.

CASE STUDY 1 – IMPaCT

The Integrated Mersey Palliative Care Team (IMPaCT) was established in 2020 to ensure seamless provision of end of life care in the Liverpool area. The service is comprised of Marie Curie, Woodlands Hospice, Liverpool University Hospitals Foundation Trust and MerseyCare NHS Trust.

Before the IMPaCT service, palliative and end of life care was fragmented and difficult to navigate (Figure 2). This was resulting in more hospital admissions in the last days of life than the national average, fewer people dying at home and a smaller proportion of people on the GP palliative and end of life supportive care register.

The IMPaCT service started by creating two specialised palliative and end of life care hubs and streamlining key processes such as sharing clinical information. However, a key factor in the success of the service is having a single point of access and referral to services through a designated palliative and end of life care phone line. Crucially, this is available 24/7 to patients with a diagnosis of a life-limiting, progressive disease, or those in need of palliative care assessment.

The benefit to patients and carers is that there is one number that they can call where whatever care and support they need can either be provided directly or arranged quickly. This is made possible because of the underlying collaboration that allows services to work seamlessly around the needs of the patient and where all the health and care professionals involved know and understand the contribution of their partners in the IMPaCT service.

Both staff and patients value the ability to provide an integrated service where patients and carers can feel that they are known and supported whenever their needs arise. The success of the service can be seen in a 12% reduction in the number of people dying in hospital in the 6 months to March 2021 compared to the same period a year earlier. There was also as reduction in hospital admissions: 30% of patients needed no hospital admissions in the last 90 days of life compared to 9% previously.

Figure 2: Illustration of move from fragmented to integrated palliative and end of life care service with single point of contact (Source: Marie Curie, 2022).
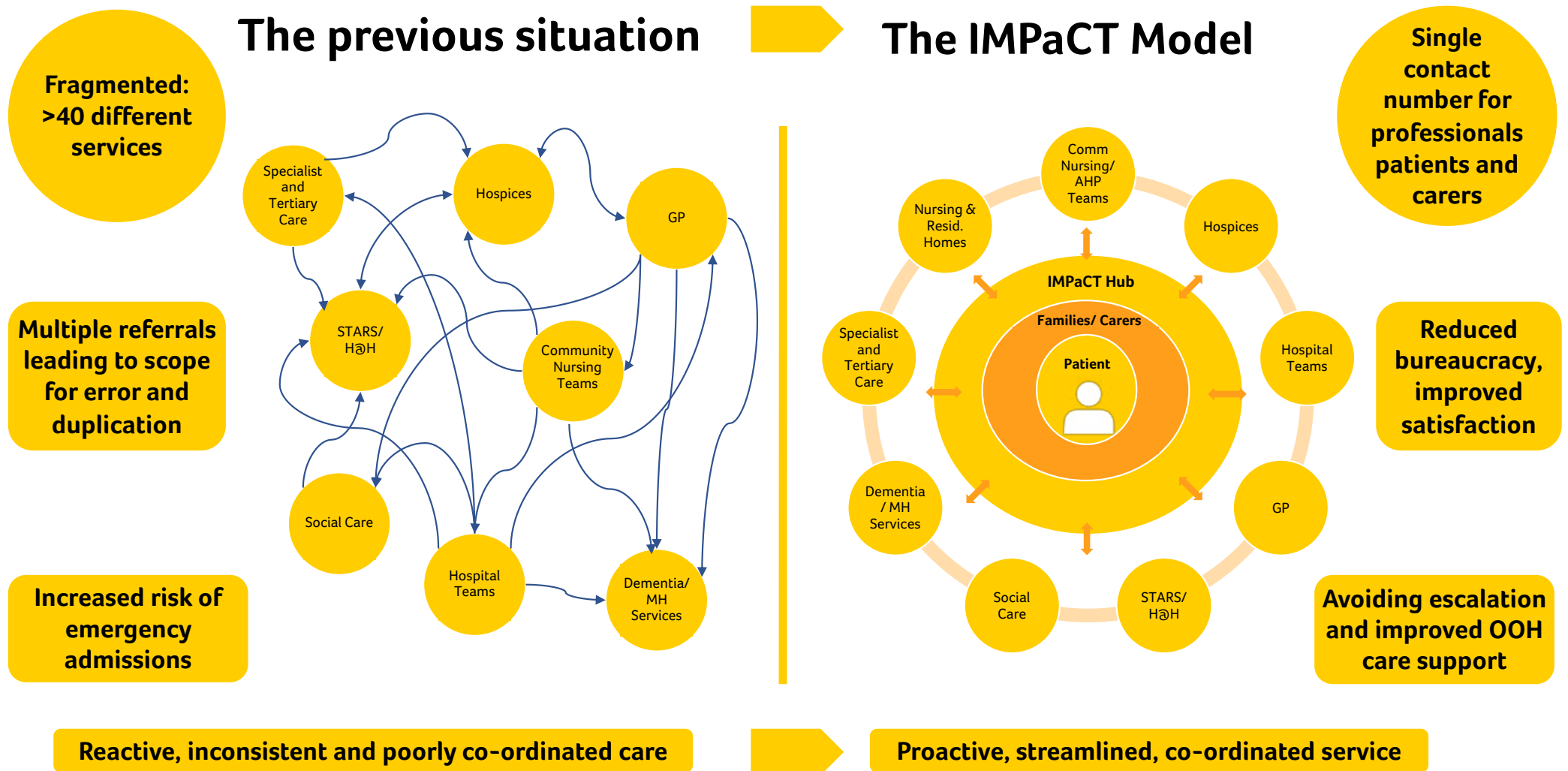
* See page 22 for explanation of abbreviations

CASE STUDY 2 – 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 and the East of England Ambulance Service.

A working group including representatives from NHS 111, out-of-hours services, ambulance service, adult hospices, acute and community trusts, and the Clinical Commissioning Group met throughout the Covid-19 pandemic to develop this innovative telephone advice line. The service is accessed by calling NHS 111 option 3, rather than a dedicated telephone number. The telephone line is staffed 24/7 by 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.

During the first six months of operation, and before it was fully 24/7, 1,164 calls from patients or their carers/relatives were received. 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 symptom control, sudden deterioration in condition, or for advice about or access to medication.

The 24/7 palliative and end of life care telephone line is also used by health and social care professionals including paramedics, district nurses and community nurse teams and nursing/residential homes. This took the total number of calls to 1,692. 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 148 avoidable hospital admissions were prevented during the first six months of operation.

Key elements of a 24/7 palliative and end of life care single point of access phone line

From these case studies and the *Mind the gaps* research report we can identify a number of features of a single point of access telephone advice line that are likely to improve access to out-of-hours care, improve patient and carer experience and reduce unnecessary hospital admissions:

• Designed around a comprehensive assessment of the palliative and end of life care needs of the whole population

• Provides a single point of access for advice and connection to local health and care services for everyone with a terminal illness (even if not known to the palliative care team), their carers and health and care professionals

• Fulfils a care co-ordinating role including onward referral on behalf of both patients and health and care professionals

• Accessible 24/7 to cover all out-of-hours periods and for all people with a terminal illness regardless of whether they are on the end of life care register or known to specialist palliative care services

• Has call responders who are sufficiently qualified and experienced in order to advise other health and care professionals and provide the care and support people with a terminal illness and carers need. The team should also include professionals who can prescribe medication.

• Onward referral out-of-hours includes ready access to a rapid response service to provide support to people dying at home and their carers

• Sustainable and long-term funding model that does not depend on fundraising by charitable hospice providers

• Integrated IT systems and access to patient records requires appropriate governance processes to enable rapid resolution of any barriers or issues that emerge

• Model responds to patient and carer experience to understand gaps in provision, accessibility and as part of continuing service improvement.

Outcome indicators of such a service could include:

1. Reduction in avoidable emergency admissions in the last 90 days of life

2. More people able to die in their place of choice with appropriate levels of support, including at home if that is their preference

3. An increase in the proportion of people on the palliative and end of life supportive care register. This should help create the context for more people to be offered conversations about what matters most to them personally for care at the end of their lives and for their needs, wishes and preferences to be recorded and shared with professionals involved in their care.

2. People dying in deprived areas should not have to rely on emergency departments for their end of life care out-of-hours

Everyone should have the best possible end of life care, regardless of where they live and their background and social characteristics.

Palliative and end of life care services including out-of-hours care are subject to the equalities duties and requirements that apply in each of the four nations. In England, for example, new guidance requires commissioners to address health inequalities for palliative and end of life care by improving equity of access to services and reducing inequity of outcomes and experience [16].

Emergency admissions towards the end of life are disruptive and can be distressing, impacting on a person's quality of life[17]. They are also expensive; the total cost of emergency admissions in the last 12 months of life were estimated to exceed £1.2 billion in 2018/2019 [18].

It is therefore concerning that the research report showed that out-of-hours emergency attendances in the last year of life were higher for people living in more deprived areas compared to people living in the less deprived areas across the UK [19], with evidence of a gradient from most deprived to least
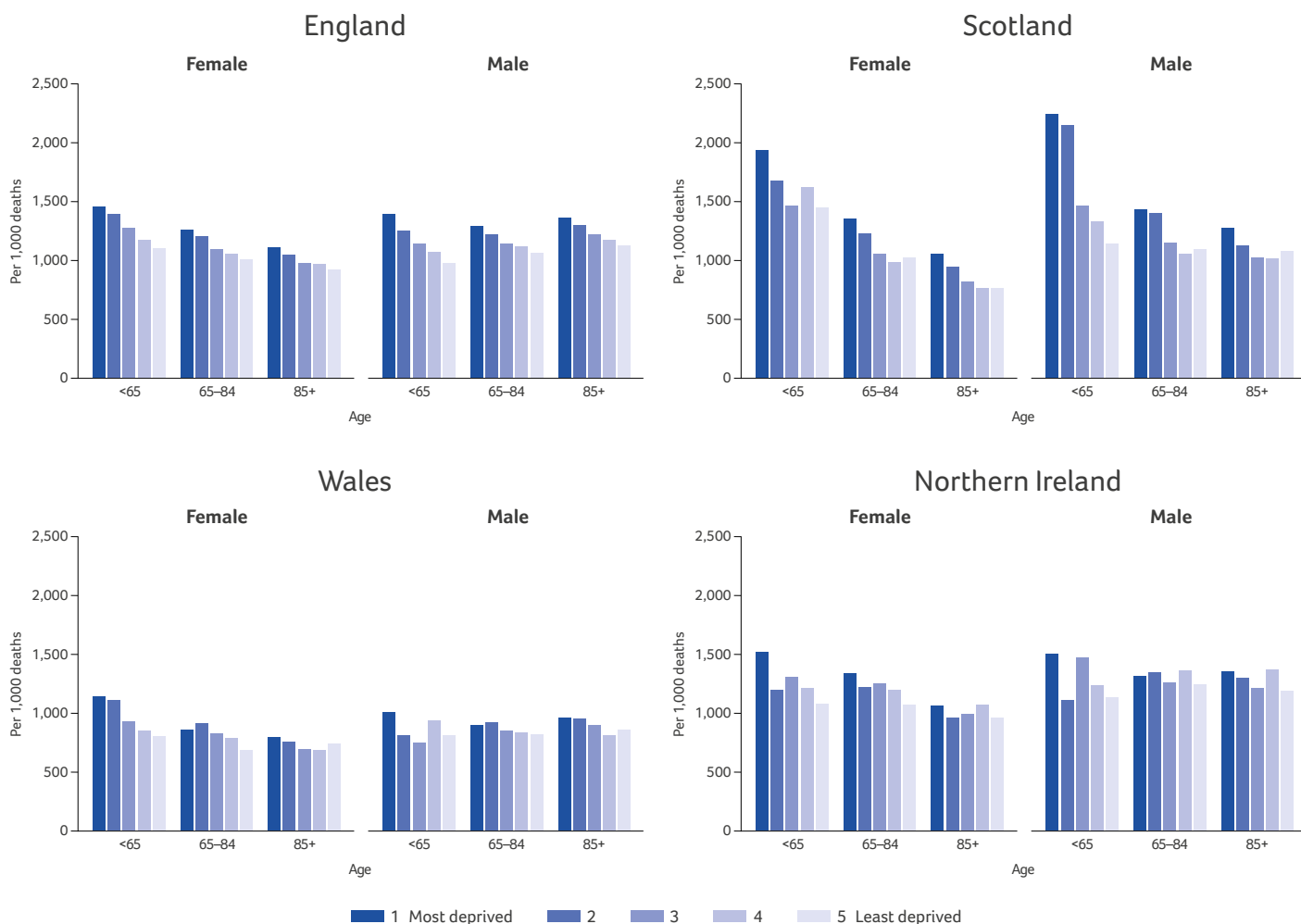
Figure 3: Rate per 1,000 deaths in 2020 of out-of-hours Emergency Department attendance for people in the last 12 months of life, by age, sex and deprivation quintile (Source: Pask et al, 2022, p.9).

deprived groups (Figure 3). This effect is most clear in England where the number of attendances is higher.

Inequality of access to out-of-hours care must be viewed in the context of wider inequalities in access to palliative and end of life care. People living in the most deprived areas have less money spent on their care in the final year of life[20]. Professionals in socially deprived areas may have less time to talk and not be as responsive for requests for help [21]. Patients and carers from less deprived groups have been found to be more vocal in requesting care and support [22].

People living in deprived areas are also less likely to be able to realise a preference for home as the place of care at the end of their lives, or believe that they have sufficient support to care for someone dying at home [23][24]. Poor housing can make care at home more difficult to achieve [25] while the geographic distribution of hospices means that both rural and more deprived areas have been comparatively underserved [26].

Certain groups face particular barriers in access to palliative and end of life care, including people living in poverty, alone or with dementia – as well as people with learning disabilities, people who are homeless or poorly housed, people in prison, ethnic minority groups and LGBTQ+ people [27][28]. For many individuals, this intersects with socio-economic deprivation.

Involving a diverse range of people with lived experience of dying, death and bereavement in the design and delivery of palliative and end of life care services is a vital first step towards addressing inequalities in access to and experience of services in community settings out-of-hours. They should be involved in assessment of local population needs, service development and monitoring and evaluation in order to improve understanding of gaps and inform commissioning. Involvement of people with lived experience should seek to ensure the specific needs of individuals are addressed, as well as the needs of underserved groups.

There is good data available on inequality of access to palliative and end of life care in hospitals, for example through the National Audit of Care at the End of Life which reviews case notes alongside demographic data about patients [29]. The lack of comparable data for community settings that enables analysis of variation in patient and family experience is a significant barrier to effective targeted action to address inequality of access to out-of-hours care.

Recommendations:

- The National Audit of Care at End of Life should be extended to include nursing and residential homes, as well hospital settings, so that equivalent insight into experiences of end of life care can be used to inform future design and delivery of services in all settings. A similar audit should be established in Scotland.

- Local and national service design and delivery should be shaped by the diverse voices of people with lived experience of dying, death and bereavement – including those living in deprived areas and who are underserved by existing services.

3. People dying at home need easier and faster access to medicines out-of-hours

"It was very difficult to get medication. Honestly, I sometimes was on the phone to the pharmacy 20 times a day, and when you're trying to care for somebody as well... I just felt so stressed."

– Hayley, who cared for her husband Matt

Medicines are vitally important for managing pain and other symptoms experienced by people with a terminal illness, especially in their final year and months of life. When symptoms change rapidly out-of-hours they may need medicines to be prescribed, collected from pharmacies or administered (for example injections). The research report showed that while all three steps in accessing medication were available in theory in all the areas surveyed, in practice they were often only partially available, difficult to access or involved long waiting times [30].

The research report identified a number of reasons why ensuring access to medicines is often challenging in practice, particularly at night and in rural areas with long travel times. Insufficient staff to cover out-of-hours demand, particularly home visits, was a significant factor. Community pharmacies did not always stock the right palliative medicines, with fewer open at night compared to bank holidays and weekends. While anticipatory prescribing can help to alleviate these challenges, it depends on early recognition of needs which was often not happening.

Good symptom control through access to medication helps avoid unnecessary patient and carer distress and reduces unplanned and emergency use of services [31]. Workforce pressures that constrain out-of-hours prescribing and administration are exacerbated by underdevelopment of nurse prescribing. Less than half (42%) of specialist nurses and only a quarter (27%) of generalist community nurses are trained to prescribe [32]. All prescribers working in the community need access to electronic prescribing systems and electronic patient records.

The potential of community pharmacies to support improved out-of-hours access to palliative care medicines is recognised in the NHS Long Term Plan

and is being addressed through the community pharmacy contractual framework. This will be supported by the development of new Daffodil Standards for quality palliative and end of life care by the Royal Pharmaceutical Society with Marie Curie. Stocking standard palliative care medications in community pharmacies is also vitally important.

Difficulties in obtaining medications can be reduced through anticipatory prescribing of medicines that are likely to be needed. Clear guidance from NICE [33] and Healthcare Improvement Scotland sets out how this should be done well [34]. Where appropriate, this can be complemented by anticipatory dispensing such as the use of 'just in case' boxes, which ensure there is a supply of drugs in the patient's home when needed.

This depends on early recognition of palliative care needs and regular reviews of medication. Sufficient continuity of care is needed to enable changes in patients' conditions to be reliably recognised.

The research report suggests that much more work is needed to realise the ideal of prompt and easy access to medicines for pain and symptom control by everyone with a terminal illness and their carers. Building on existing initiatives, action is needed to increase the number of professionals who are qualified and permitted to prescribe palliative care medicines and to ensure that they are made available in local pharmacies in every part of the UK.

Recommendations:

• The proportion of district and community nurses able to prescribe medicines should be increased through a significant expansion in provision of funded clinical training and continuing professional development.

• Community pharmacy services should be commissioned to provide a standardised set of palliative care medications and make them consistently available 24/7.

4. Better sharing of electronic records is vital for delivering personalised end of life care out-of-hours

"John felt relieved when his Care Plan was made with the GP. But I only found out after his death that the hospital don't allow ward doctors access to this online – only the palliative care team. The very people who treated him couldn't access it."

– Frances, who cared for her husband John

Access to up-to-date shared electronic medical records gives staff providing out-of-hours care the information they need to provide the most appropriate care safely, quickly, and in a way that meets individual patient preferences.

Advance Care Planning (ACP) – known as Anticipatory Care Planning in Scotland and Advance and Future Care Planning (AFCP) in Wales [35] – enables individuals to discuss their needs, wishes and preferences for their future care with professionals involved in their care and with their carers if they wish to. When documented, this should form part of their electronic medical record.

A recurrent theme of the research report was that access to out-of-hours care was restricted for patients not already known to services or on the end of life care register. Patients and carers reported experiencing distress from care that was "too little, too late". Provision of anticipatory medication was also less likely without early recognition of deteriorating health and proactive discussion of care preferences. In this context, better ACP could help ensure a person's needs are recognised earlier and thus be a crucial first step towards them accessing services that can respond to out-of-hours needs.

The prevalence of ACPs among patients with advanced age admitted to hospital remains low at 9.5% for patients aged over 80 [36]. This is despite national guidance and evidence that it improves satisfaction with end-of-life care [37], reduces avoidable emergency admissions in the last months of life [38] and increases patients' chances of dying in their preferred place[39].

One reason for the low prevalence of ACP is a lack of confidence and skills among some health and social care staff in initiating conversations [40] [41].

Without ACPs, the need for out-of-hours care is both more likely and less easy to meet. Anticipatory prescribing is less likely to have been put in place by a health professional and the referral to specialist palliative care services that enables access to them is less likely to have been made. However, even if there has been an ACP conversation, the record of it then needs to be accessible to staff via technology with access permissions in place for those making treatment decisions.

The benefits of ACP have been recognised in all four nations with clear principles and guidelines being published with supporting resources and training [42] [43] [44] [45].

In reality, however, inadequate training and time pressures on staff present challenges in delivering ACP, as shown during the Covid-19 pandemic where Marie Curie found that ACP conversations often did not take place or were hurried. They also focused more narrowly on medical needs or on what treatments patients did not wish to receive (such as resuscitation) instead of addressing all the holistic needs of a person with a terminal illness and their carers [46] [47] [48].

The research report found that there was partial or incomplete access to a shared health record providing clinical information about the person needing out-of-hours help (if already referred to specialist palliative care services) in about two thirds of the areas surveyed. Records were not, however, always fully integrated with multiple systems used. The accuracy and speed of information flow between settings was also variable so that records do not always include the most recent information. This is a particular problem for patients recently discharged from hospital.

Efforts have been made in recent years to introduce policies to improve access to shared electronic patient records, with mixed results. The commitment that digital records such as the Electronic Palliative Care Co-ordination System (EPaCCS) would be in use across England by 2020 has not been met [49]. The current aim is to have "shared care records for all citizens by 2024 that provide a single, functional health and care record which citizens, caregivers and care teams can all safely access" [50] [51] [52]. In Scotland Key Information Summaries (KIS) for people with a terminal illness have been more successfully adopted [53].

Implementing improved access to shared health records also depends on appropriate technical and governance solutions. One such example of good practice is provided by Cheshire's EPaCCS digital road map [54]. This took a whole systems approach that sought to make the most of what was already in place, was co-produced with patients and staff, and committed to learning from best practice with a strong shared vision.

Such initiatives depend for their success on long-term resourcing to both establish, maintain and use patient care records well. As with other health and care initiatives, the potential to incentivise action through commissioning frameworks or Quality and Outcomes Framework (QOF) payment incentives should be actively realised.

Recommendations:

- All health professionals should be funded to receive training in and have time to follow clear national guidance on advance or anticipatory care planning.
- Electronic care co-ordination systems should be resourced in ways that incentivise their sustained use and sharing. Progress on the use and availability of shared records, including advance care planning, should be audited regularly.

5. The workforce delivering end of life care out-of-hours in community settings needs more of the right people with the right skills

"Sometimes it would take up to three hours for a district nurse to arrive. When I complained about this, I was told there were only two nurses covering the whole of the south side of Glasgow at night-time. It's sickening to think that such a large population is covered by a team of two."

- Patricia, who cared for her dad Joseph

"You never saw the same district nurse twice. So nobody saw a deterioration with my dad apart from me because I was there all the time."

- Tracey, who cared for her dad Michael

For a person with a terminal illness and their carers to have a good experience of care, workers in different parts of the health and care system will need to be recruited and retained in sufficient numbers, have appropriate training, and work in a 'joined-up' way to deliver personalised care.

People with a terminal illness are likely to depend for their palliative and end of life care on a combination of generalist services provided by GPs, district nurses and community nursing teams, as well as specialist services such as palliative care nurses and allied health professionals employed by charitable hospices to work in community settings. Individuals may also depend on social care workers, especially if they live alone and do not have friends or family caring for them.

The research report shows that access to specialist palliative care nurse advice or support by phone or video-calls was widely available out-of-hours, but only for patients already known to specialist palliative care services. Home visits were available or partially available in 73% of the areas surveyed during weekends and bank holidays. They are much less common overnight; in 80% of areas this service is not provided at all (Figure 4).
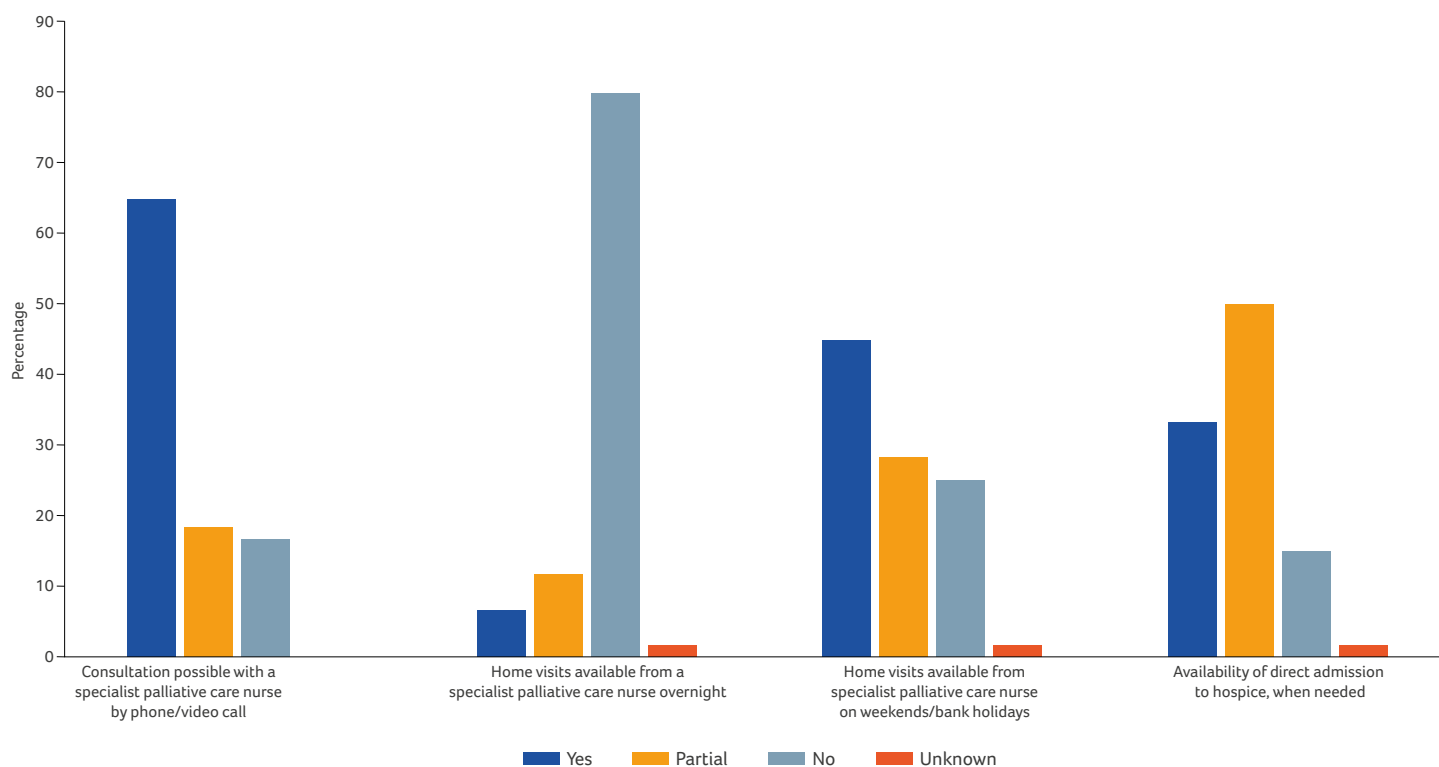
Figure 4: Responses about out-of-hours access to specialist palliative care in the 60 UK areas surveyed (Source: Pask et al, 2022, p.17).

District nurses and community nursing teams play a vital role in providing out-of-hours care. This includes the emotional aspects of care and support, monitoring symptoms, prescribing and administering medications and 'hands-on' care. Workforce pressures, however, limit the care they can provide and its availability [55]. Over 75% of district/community nurses, for example, currently report insufficient staff to meet the needs and dependency of their patients [56].

Workforce pressures make covering out-of-hours rotas difficult in community settings. Pressures on palliative and end of life care reflect wider pressures in primary and community care. There are currently 1,857 fewer fully qualified full-time equivalent GPs than in 2015 [57]. As a result of this, the average number of patients each GP is responsible for has increased by around 300 (16%) since 2015. Since 2010, the number of district nurses has fallen by 48% in England [58].

Workforce pressures affecting palliative and end of life care are worse in some areas than in others. GP shortages, for example, are higher in some coastal towns with older populations and in more deprived areas [59].

Nurse recruitment is improving with increased numbers of district nurses entering educational programmes in both Wales and Northern Ireland and the early indications of increased numbers in England [60]. However, nurse recruitment is yet to have a clear impact on overall vacancy rates [61] with over one in ten posts in England currently unfilled [62]. An ageing workforce is one factor, with 40% of practice nurses now aged 55+ [63].

The legacy of the Covid-19 pandemic, alongside increased numbers of people dying at home with more complex needs, is increasing the pressure on staff, including those working in community settings out-of-hours. The time taken to build relationships with patients and their carers is becoming less [64]. Low morale, exhaustion and increased cost-of-living pressures are also hindering recruitment and retention [65].

The social care workforce is also experiencing a significant crisis in recruitment and retention. There are currently around 165,000 vacant social care posts and the number of vacancies has increased by 52% since 2020/21. The estimated staff turnover rate in adult social care is 28.5% [66].

National initiatives addressing pay and conditions to support recruitment and retention in different health and social care professions are vitally important as are improvements to career pathways. Ensuring every health and social care worker has training in palliative and end of life care and opportunities to learn and work more efficiently by operating across organisational boundaries would also make a positive difference.

Generalist health and care workers often do not have the skills and training to provide palliative and end of life care out-of-hours [67]. Experience during the Covid-19 pandemic demonstrates that specialist workers can play an important role in upskilling and educating workers in other parts of the health and care system in palliative and end of life care [68].

Within multi-disciplinary teams that can respond to the more complex needs of patients, the contribution of Health Care Assistants is recognised as important for patients but often undervalued in policy [69] [70]. Better use of this resource and that of care workers could also result from improved training, support and supervision to help them meet non-medical end of life care needs.

Working across organisational boundaries (health, social care and voluntary sector) can enable workers to build capacity, skill and expertise in ways that extend beyond formal training, and also achieve efficiency gains. Increasing opportunities for continuing professional development for palliative and end of life care staff can also have a positive impact on retention rates. For example, a rotation scheme to enable community nurses to experience palliative and end of life care and access training in use of digital tools and virtual consultations could bring benefits both to the nurse's career and for patient care.

Alongside this, the use of technology and new service models can reduce the time demands on staff and thus help alleviate workforce pressures in out-of-hours services. For example, virtual wards with remote monitoring can help to manage demand for home visits and provide a mechanism for accessing specialist advice. Their potential to complement Hospice at Home and Rapid Response services is recognised in guidance that is currently being drafted by NHS England [71]. There are also very practical benefits from better use of technology such as nurses not spending time driving to get prescriptions when electronic prescription systems could be used.

Recommendations:

- Governments should publish annual, independently verified projections of future demand for the palliative and end of life care workforce and ensure a properly resourced plan is in place for meeting this demand — both now and over the long-term.

- Palliative and end of life care training should become a compulsory part of training and continuing professional development for all health and care workers, not just those in regulated professions.

Conclusions

Too many people are currently let down by inadequate provision of out-of-hours care and support at the end of their lives. They struggle to access the medication and other services they urgently require to prevent a crisis-driven visit to their local emergency department.

Mind the gaps: *understanding and improving out-of-hours care for people with advanced illness and their informal carers* is an important new research report. It helps to fill the gaps in evidence about out-of-hours palliative and end of life care services in the UK today, and highlights the very real impact that this is having on people with a terminal illness and their carers.

In this briefing, Marie Curie has summarised the key findings of the research report and explored five key implications for policy.

First, people who are dying at home need better access to palliative and end of life care out-of-hours. Ensuring everyone has access to a designated 24/7 palliative and end of life care telephone advice line that can connect them quickly and easily to local services would be an important step towards achieving this in practice.

Second, people dying at home in deprived areas should not have to rely on emergency departments for their end of life care out-of-hours. Extending the National Audit of Care at the End of Life to community settings and ensuring the diverse voices of people with lived experience of dying, death and bereavement in deprived areas are heard would help to drive improvements in the design and delivery of out-of-hours services that meet local population needs.

Third, people dying at home need easier and faster access to medicines out-of-hours. To achieve this, an expansion is needed in the proportion of district and community nurses who are qualified to prescribe palliative care medicines, and a standardised set of such medicines should be made available in community pharmacies on a 24/7 basis.

Fourth, better sharing of electronic records is vital for delivering personalised end of life care out-of-hours. All health professionals should be supported to engage in best practice advance and anticipatory care planning conversations and the records of these should be included in electronic records. The workforce skills, integration of services and technology should enable shared electronic records to be accessed and used well out-of-hours. The effectiveness of this should be audited.

Finally, the workforce delivering end of life care out-of-hours in community settings needs more of the right people with the right skills. Better workforce planning and investment over the long-term and ensuring palliative and end of life care is a central part of training for all health and care workers are key steps towards achieving this in practice.

Out-of-hours palliative and end of life care is an essential component of a safe, equitable and accessible health service. The changes we are calling for will help to address wider pressures on our health and care system by promoting integration, supporting the workforce, and preventing unnecessary and costly hospital admissions.

More importantly, these changes will also help to ensure that everyone at the end of life has the care and support they need on a 24/7 basis. It is what all of us would wish and hope for at the end of our own lives.

Policy recommendations

	Recommendations for improving out-of-hours care in the UK	For action by
24/7 Palliative and end of life care advice line in every area	Every part of the UK should have a 24/7 palliative and end of life care telephone line, staffed by professionals with specialist palliative care expertise, who can provide advice, guidance and support to access local services. This service should be available to all people with a terminal illness, their carers, and health and care professionals.	ICBs Health Boards IJBs HSC Trusts
Better access to medicines	The proportion of district and community nurses able to prescribe medicines should be increased through a significant expansion in the provision of funded clinical training and continuing professional development.	Governments
	Community pharmacy services should be commissioned to provide a standardised set of palliative care medications and to make them consistently available 24/7.	ICBs Health Boards IJBs HSC Trusts
A workforce that is fit for purpose	Governments should publish annual, independently verified projections of future demand for the palliative and end of life care workforce and ensure a properly resourced plan is in place for meeting this demand – both now and over the long-term.	Governments
	Palliative and end of life care training should become a compulsory part of training and continual professional development for all health and care workers, not just those in regulated professions.	Governments
Better access to shared records including ACPs	All health and care professionals should be funded to receive training in and have time to follow clear national guidance on advance or anticipatory care planning.	Governments
	Electronic care co-ordination systems should be resourced in ways that incentivise their sustained use and sharing with progress on the use and availability of shared records, including advance care planning, being audited regularly.	HEE/NHSE HEIW NES HSC Trusts

	Recommendations for improving out-of-hours care in the UK	For action by
Equitable access to palliative and end of life care services for everyone	The National Audit of Care at the End of Life should be extended to include nursing and residential homes, as well as hospital settings, so that equivalent insight into experiences of end of life care can be used to inform the design and delivery of services in all settings. A similar audit should be established in Scotland.	HQIP (England, Wales & NI) Health Care Improvement Scotland
	Local and national service design and delivery should be shaped by the diverse voices of people with lived experience of dying, death and bereavement – including those living in deprived areas and who are underserved by existing services.	ICBs Health Boards IJBs HSC Trusts

Abbreviations:

- ICB: Integrated Care Board (England)
- IJB: Integrated Joint Board (Scotland)
- HSC: Heath and Social Care Trust (Northern Ireland)
- HEE: Health Education England
- NHSE: NHS England
- HEIW: Health Education and Improvement Wales
- NES: NHS Education for Scotland

- HQIP: Healthcare Quality Improvement Partnership
- H@H: Hospice at Home
- OOH: out-of-hours
- MH: Mental Health
- AHP: Allied Health Professional
- STARS : Supportive and End of Life Care Service

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