Better End of Life 2024

Time to care in England

Implications for England of 'Time to care: Findings from a nationally representative survey of experiences at the end of life in England and Wales'

Policy summary
September 2024

Marie Curie

1 Introduction

This is a critical time to improve palliative and end of life care. Too many people are dying without the care and support they and their unpaid carers need.

The number of people in England who need palliative and end of life care is increasing as our population ages and people live longer, often with multiple and complex conditions. [1] Up to 90% of deaths would benefit from palliative care, the need for which is expected to increase by 26.5% by 2048. [2]

More people now die at home, but hospital emergency service use in the final months of life is increasing. [3] With around a third of NHS costs accrued in the last year of life, the design and delivery of end of life care has huge implications for public spending. [4] 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. [5, 6]

Integrated Care Boards now have a legal duty under the *Health and Care Act 2022* to commission palliative care services that meet the needs of their local populations. The statutory guidance requires them to address inequity of access and provide safe, personalised, high-quality palliative and end of life care with sufficient workforce in all settings. This includes 24/7 access to services.

This briefing highlights key findings and policy implications from the largest nationally representative survey of people affected by dying, death and bereavement since 2015.

The survey reveals significant barriers experienced by people seeking to access the end of life care they need. But it also shows that good care is possible and the models of good practice in this briefing illustrate how the challenges can be overcome.

Without urgent action, gaps in access to palliative and end of life care will only grow. There is currently no realistic national or local plan to address the scale of this challenge.

We are therefore calling on the new Government to urgently act to make the policy changes needed so that everyone affected by dying, death and bereavement receives the best possible care, both now and in the future.

2 Post-bereavement survey

This briefing presents key findings from important new research into the experiences of people affected by dying, death and bereavement in England and explores their policy implications. It includes lived experience testimony from Kate, who cared for her father at the end of his life, and four innovative models of good practice.

'Time to care: findings from a nationally representative survey of experiences at the end of life in England and Wales' fills gaps in research evidence on the outcomes and experiences for people at the end of life. It uses a similar methodology to the Office for National Statistics (ONS) VOICES survey [7] which ran annually between 2011 and 2015.

The ONS disseminated the '*Time to care*' post-bereavement survey in 2023 to a nationally representative sample of people who had registered the non-sudden death of a family member in the prior six to ten months. The England sample was 1,500 people and 606 responses were received.

A Patient and Public Involvement (PPI) group with lived experience of advanced illness and caring for family members towards the end of life informed the design, administration and analysis of the survey. This included identification of important messages and the selection of illustrative quotes, some of which are included in this briefing.

This research was funded by Marie Curie as part of the Better End of Life programme which is a collaboration between Marie Curie, King's College London's Cicely Saunders Institute, Hull York Medical School at the University of Hull and the University of Cambridge.

The full research report is available at: mariecurie.org.uk/policy/better-end-life-report

Key findings

Too many people die in pain and without the support they need for their symptoms

- More than one in three people were severely or overwhelmingly affected by pain (34%) or breathlessness (40%) in their final week of life.
- Almost two thirds (64%) of unpaid carers felt anxious most or all of the time about the person's illness or treatment and more than a third (38%) reported that the person who died felt depressed most or all of the time during their final week of life.
- Barriers to accessing palliative care medicines were common, particularly 'out-of-hours'.
- People who were financially worse off were more likely to be affected by severe and overwhelming symptoms.
- Inequalities in access to palliative care persist, particularly for older people and those with a non-cancer diagnosis.

Gaps in 24/7 community care prevent people from dying in comfort at home

- Most end of life care occurs in the community: 64% of people spent most of their last three months of life in a private home; 24% in a care home and 7% in hospital.
- Difficulty accessing health and care professionals in the community was common.
- Emergency service use in the final three months of life was high, with 61% of people who died using an ambulance and 53% visiting A&E at least once.
- One in seven people (15%) who died in hospital had been there less than 24 hours.
- Over a third (37%) of people who died in hospital had no friends or family present.

Patients and unpaid carers suffer when communication and coordination are poor

- Half of respondents (50%) were unhappy with at least one aspect of the care the person who died received. One in nine people (11%) made a formal complaint.
- Fewer than half of the respondents (42%) said they'd had a key contact person to co-ordinate care. The lack of co-ordination created challenges in knowing who to contact for help or what was available.
- Recognition of palliative care needs was often considered too late. Healthcare professionals had discussed death and dying with just one in three (37%) of the people who died, though these conversations were more likely to have happened with the person's family (66%).
- One in four people who died (25%) either probably or definitely did not know they might die because of their illness.

Workforce capacity is insufficient to meet demand for end of life care

- Staff across health and social care settings often did not have enough time to provide adequate care for dying people.
- Most people who died had contact with health and care professionals in the community, most often from GPs or district or community nurses. Despite this, nearly one in five people (19%) who died had no contact with a GP in the last three months of life.
- Almost half of respondents felt health care professionals mostly listened or provided sufficient help. Lack of communication was a common source of frustration.

Unpaid carers take on significant caregiving roles with little support

- Most respondents undertook essential caregiving roles but many felt unprepared, lacking the knowledge, skills, and access to professional support needed.
- Of respondents still in work, 12% took between 31 and 90 days paid or unpaid leave, while 5% quit or changed their jobs (including retiring early), to care for their loved one.
- One in six respondents (15%) met the criteria for 'disturbed grief' – with bereaved people who are younger, female, or the spouse of the person who died, as well as those who had a poor experience of care, most at risk.
- Most (71%) of those who met the criteria for disturbed grief had not accessed bereavement support.

3 “We didn’t have enough support when dad was dying”

Kate shares her experience of caring for her dad at the end of life.

My father got diagnosed with prostate cancer when he was very poorly and experienced a lot of difficulties with his end of life care. He made it clear he wanted to die at home, but there was no coordination.

We had to keep going up to A&E, which was awful because he was so uncomfortable. We tried to set him up having care at home, we tried to say, “Look, why does he have to spend all this time waiting, distressed and in pain?”. We got told that care at home would be sorted, but it never happened.

Every week his trips to A&E became more frequent. Once, me and my mother arrived to find my dad so thirsty and completely dehydrated. It got really dire when his catheter blocked. It was like, “Here we go again.” The whole trauma. In the end, for the first time ever he said, “I don’t want to be here by myself.”

It was just so chaotic. If it was a weekend, there were never enough staff there, just the on-call people. We had to do the running around ourselves. It was the same when trying to get the community nurses to come out. It was so hard to get hold of them.

We started a petition for Dad to have better care. Dad even wrote an article about what would be helpful as a patient – having somebody to support you, that you could contact easily. Care that was fully joined up.

We were fortunate that we had a family friend at the time who was a nurse. She stayed with us because we didn’t have any painkillers or anything. We were just given the prescriptions.

Me and my sister would drive huge distances late at night, completely exhausted, trying to find a chemist that could dispense the drugs. Nobody came out to deliver them or administer them or call in to the house or co-ordinate anything.

I don’t think Dad was ever comfortable, but he masked it. It was awful. I was struggling managing work and running to and from the hospital. Between me and my sister, one of us would always be there helping out.

I honestly don’t know to this day whether there were things my dad could have had to make the whole process easier on him and easier on us, because nobody really ever came to the house.

When Dad passed away he needed a top up of pain medication, we could tell he was in agony. We gave him the top up and we all stayed around him. We made the room comfortable with lights, candles and things and we just talked to him and played the classical music he liked.

Dad died at home, which was what he wanted. But we managed that purely because we had a family friend who was a nurse who knew what to do and what to expect.

4 Implications of this research

4.1 Too many people die in pain and without the support they need for their symptoms

Being free of pain and other symptoms such as breathlessness and nausea is most people’s top priority for their last year of life.[8] While people with a terminal illness will experience a range of symptoms, it should be possible to alleviate them with timely care, treatment and support so that they are more manageable.

There are significant barriers to achieving this including a lack of support in managing psychological symptoms, poor access to medicines and inequities in access to specialist palliative care.

> **“[Name] struggled with the prospect of death understandably but after time this eased and she was at peace. The fact that they were able to relieve her pain helped considerably.”**
>
> Died from a heart condition

The survey provides a snapshot of symptoms and concerns affecting the people who died in their last week of life. Although it does not show whether these were resolved or improved, it does indicate the types of care and support that are needed.

In their last week of life:

40% were severely or overwhelmingly affected by breathlessness

38% felt depressed most or all of the time

34% were severely or overwhelmingly affected by pain

It is not just patients who are affected: almost two thirds of unpaid carers felt anxious most or all of the time about the person’s illness or treatment.

People who were financially worse off, and people who died in hospital rather than at home or in a care home, were more likely to be affected by severe or overwhelming breathlessness. This may reflect that people with distressing symptoms are more likely to be admitted to hospital. One in seven people (15%) who died in hospital had been there less than 24 hours, suggesting an unplanned or emergency admission.

Better access to mental health support

The prevalence of psychological symptoms revealed in the survey responses is supported by other research.[9] For example, approximately 60% of people referred for hospice care in the UK have psychological support needs, yet only 19% of hospices have access to an in-house clinical psychologist.[10, 11] Depression is under-recognised and under-treated amongst people needing palliative care.[12]

Better access to mental health support within existing palliative care services is urgently needed. Training should equip all health and care professionals to fulfil the requirements of parity of esteem of mental health in palliative and end of life care.

The National Institute for Health and Care Excellence (NICE) guidance that addresses psychological support for people with advanced illness was published 20 years ago and focuses only on people with cancer.[13] This should be updated and expanded to include psychological support for everyone with advance illness, irrespective of their diagnosis.

Better access to medicines

Medicines are vitally important to manage pain and other symptoms at the end of life. Survey responses reflected existing research evidence about difficulties accessing medicines, particularly overnight and at weekends.[14]

> **“We were told the GP would visit in 1 hour to sort out my brother’s medication, but it took them 7 hours to arrive. […]”**
>
> Died from cancer

Not every community pharmacy stocks palliative care medicines and those that are open out-of-hours may be some distance away, particularly in rural areas. Community pharmacy services should be commissioned to provide a standardised set of palliative care medicines and make them consistently available 24/7.

Anticipatory prescribing enables palliative care medicines to be kept in the patient’s home in anticipation of crisis situations during the last few days or weeks of life. This works in many contexts and can prevent unplanned A&E visits and hospital admissions.[15] Making this approach work well depends on early identification of the medicines a patient might potentially need and availability of staff to administer injectable medicines.

Where anticipatory prescribing is not in place, the carrying of end of life drugs by emergency paramedics is helpful. These ‘just-in-case’ medicines should be more widely adopted by ambulance services.[16]

Patients will also need new prescriptions as they approach end of life. With current workforce pressures, and given the time-sensitive nature of prescriptions for many palliative medicines, upskilling other health care professionals to become independent prescribers is vitally important.

Only a quarter (27%) of community nurses and less than half (42%) of specialist nurses are currently trained to prescribe.[17] Conservative estimates indicate that nurse specialist prescribing services for palliative care patients could cost £30m less than GP prescribing over a five year period.

The proportion of district and community nurses able to prescribe medicines should therefore be increased through an expansion in both funded clinical training and continuing professional development.

More equitable access to specialist palliative care

Palliative care prevents and relieves suffering through the early identification, and correct assessment of pain and other problems, whether physical, psychosocial, or spiritual. GPs, district and community nurses and other healthcare professionals play an important role in the delivery of palliative and end of life care, while palliative care specialists are trained to care for those with more complex needs.

Those who received specialist palliative care were positive about the experience with 59% rating it very good or excellent. However, care from specialists such as palliative care doctors or ‘hospice at home’ teams was only received by 28% of those who died at home, 21% of those who died in hospital and 12% of those who died in care homes.

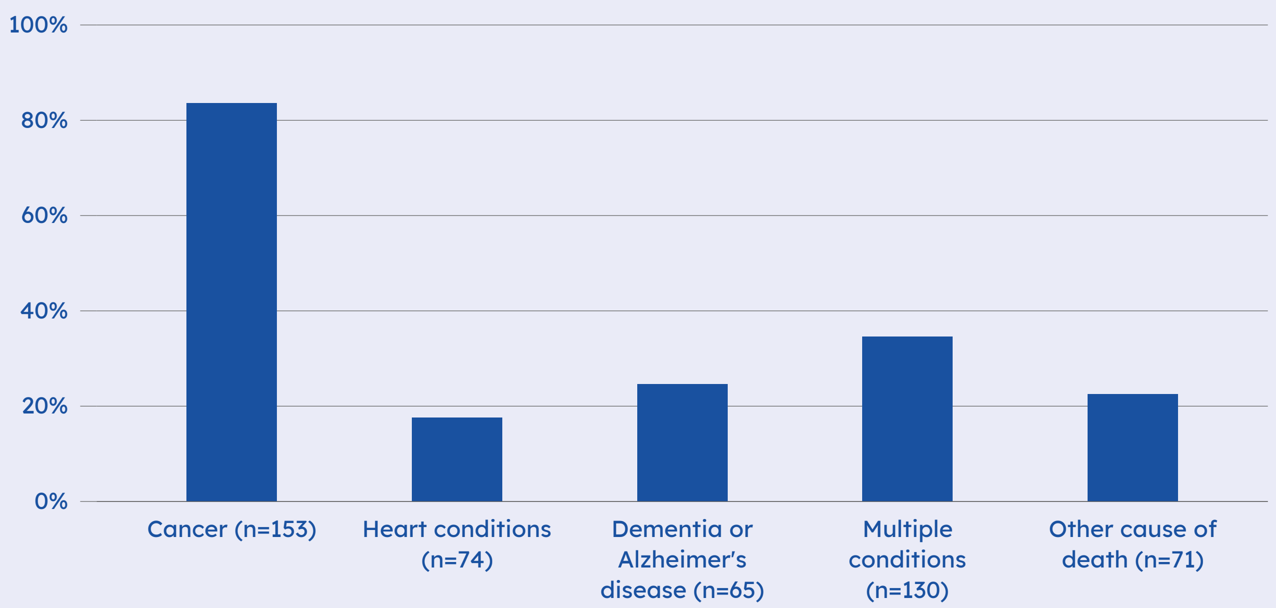
> **“Our ‘hospice at home’ support was amazing. They sorted everything and treated my Dad with dignity. Any request was supported. They were also a huge help to me. In particular the night sitting service was a huge help when I was exhausted. I could have hugged the nurse when she arrived.”**
>
> Died from cancer

People aged 85 or over and those who died from conditions other than cancer were least likely to receive specialist palliative care, despite evidence that symptom burden is similar across different conditions. 83% of those whose cause of death was cancer accessed specialist palliative care, but this was true for only 25% of those who died from dementia or Alzheimer’s disease and 30% of those who died from a heart condition. While people who were financially worse off were more likely to experience overwhelming or severe symptoms, they did not access higher levels of specialist palliative care.

> **“It is better to die from cancer in this country than dementia. There needs to be more coordinated support and care for sufferers of dementia and their families; the practical support you need has to be paid for privately.”**
>
> Died from dementia or Alzheimer’s disease

Action is needed at a national policy level and across each Integrated Care System to deliver on the commitment to reduce inequities in access to specialist palliative care.[18, 19] This should be part of a national end of life care strategy, supported by a delivery plan.

Figure 1. Receipt of care from palliative care specialists (in any setting) in England during the last three months of life across the five most common causes of death



(Source: Johansson et al., 2024, p. 79)

4.2 Gaps in 24/7 community care prevent people from dying in comfort at home

The survey findings show that the majority of end of life care happens in the community. In the last three months of life, 64% of people who died spent most of their time in a private home; 24% in a care home and 7% in hospital.

GPs, district and community nurses, and healthcare assistants play a critical role in caring for people at the end of life in the community. However, almost one in five people (19%) who died had no contact with a GP either in person or over the phone in their final three months. Difficulties accessing GP services were widely reported.

> **“You had to telephone at 8am, but either there were no appointments or you just got cut off.”**
>
> Died from multiple conditions

> **“Weekends felt more difficult; GPs’ [care] is good but that is Monday – Friday.”**
>
> Died from other condition

When people cannot access the care they need in the community, they often have to use emergency and hospital services. Emergency servive use was high, with 61% of those who died using an ambulance in the last three months of life, and over half (53%) visiting an A&E department once or more. Many experienced long waits for ambulances to arrive, or spent hours waiting to be seen in A&E.

> **“The ambulance took about 7/8 hours, and then she was sitting in the ambulance for around 5/6 hours in the cold weather. Mum wasn’t explained about what was happening in hospital, she was upset and confused when she came home.”**
>
> Died from a heart condition

Though many people say they wish to be cared for and to die at home, this does not always equate to a good end of life experience. Multiple factors can affect this including the availability of community health and care services, family and friends’ ability to meet the person’s needs, and conditions inside the home.[20, 21]

Nearly all survey respondents (93%) whose relative died at home felt this was the right place, compared to 91% for those who died in a hospice, 79% for those who died in a care home and 63% for those who died in hospital. This reflects the fact that preferences may change as needs develop and, for some, home may become no longer an appropriate or viable option.

> **“We knew her wishes were to die at home but this couldn’t be managed safely.”**
>
> Died from dementia or Alzheimer’s disease

> **“Originally, she wanted to die at home but became so poorly and the hospice were so good that she felt safe and secure with them so wanted to end her life there.”**
>
> Died from cancer

While some survey respondents identified examples of positive end of life experiences in hospitals, others felt that hospitals did not provide the appropriate environment for their loved one. Over a third (37%) of people who died in hospital had no friends or family present.

> **“The [hospital] nursing staff were exceptional: thoughtful, sensitive, attentive, constant, despite being run off their feet. ”**
>
> Died from dementia or Alzheimer’s disease

> **“My father died on a busy ward with a very noisy and disruptive man in the bed next to us. Although the curtains were closed it was not a peaceful, respectful or appropriate way to end your life. I wanted to take him home but unfortunately he was too unwell to move.”**
>
> Died from other condition

24/7 access to palliative care in every local area

Accessible and effectively resourced primary and community care services support the health and wellbeing of patients and carers, help meet their priorities for place of care and place of death, and contribute to preventing avoidable hospital admissions at the end of life.[22] For this to happen, community services must be commissioned to meet local population needs, 24 hours a day, seven days a week.

The difficulties people have accessing services, medication, and equipment, particularly during the out-of-hours period, cannot be addressed without sufficient workforce to cover these periods. The capacity of district nursing and community clinical nurse specialists must therefore be increased to meet local population needs.

The NICE quality statement for palliative and end of life care emphasises the importance of a 24/7 single point of access to co-ordinated care, medication, and advice about end of life care.[23] A palliative care advice phone line is highlighted as one of the three pillars for equitable out-of-hours care.

The statutory guidance on Integrated Care Boards (ICBs) duty to commission palliative care requires that access to this advice line must include people who are not already on the palliative and end of life care register.[24] This is important as restricting access compounds wider inequalities in access to health services.

Research shows that not every area has a 24/7 single point of access.[25] ICBs should therefore ensure that every area has a 24/7 palliative and end of life care telephone advice line, staffed by professionals with specialist palliative care expertise, who can provide advice, guidance and support to access local services.[26]

4.3 Patients and unpaid carers suffer when communication and coordination are poor

Integrated care that is coordinated, collaborative and person-centred can contribute to the safety of care for people with advanced illness.[27] This helps to address risks associated with multiple referrals, handovers and discharges as responsibility for a person's care passes from one professional or service to another.

Research into how patients with advanced illness understood harm identified symptom management, moving between health care practitioners and settings as their condition and care needs changed, and poor communication with and by health professionals as risk factors. Patients also articulated safety in terms of expectations of teamwork, agency and whether clinicians listened to and acted on concerns.[28]

In this context, survey respondents' concerns about communication and being listened to can be seen as a patient safety risk.

Half of all the survey respondents in England reported that they were unhappy with one or more aspects of care their family member received, and one in nine made a formal complaint. Issues that led to complaints included poor or absent care or long waits, disagreement with discharges or assessments, and communication or information sharing failures.

> **"Accessing all NHS services during the last 2 months of mum's life was very challenging. We couldn't get the services needed at the time needed, and the quality of her life was impacted. Although I had power of attorney for health and welfare for Mum, it was difficult to co-ordinate care. While working full-time, I had coordinated all health appointments, care provision and emergencies. Communication between the relevant organisations was poor or non-existent."**
>
> Died from a lung condition

With many different professionals and services involved, it was distressing and overwhelming for patients and their carers when care was poorly coordinated. Significant caring and administrative responsibilities fell to family and friends, who often felt unprepared and unsupported. Fewer than half (42%) of survey respondents in England said they had a key contact person to co-ordinate their care.

> **"It was hard to get any clarity as we were speaking with different doctors, whoever happened to be around when we visited. We tried to arrange an appointment for a proper conversation but this didn't seem possible. A consistent point of contact with the opportunity to sit down and talk would have helped."**
>
> Died from a heart condition

Earlier conversations about end of life care

Not being aware that the end of life is approaching can affect care choices or mean that resources and support are not put in place which result in lasting impacts on carers.

> **"My mum chose to go to hospital, rather than a hospice or stay at home because we were led to believe she would get better. […] Our choices would have been so different, if only someone spoke to us about it."**
>
> Died from other condition

Though not everyone will want or be able to have conversations about their end of life wishes, all should be offered the opportunity. More than one in three respondents (37%) said healthcare professionals had discussed death and dying with the person who died, while one in four (23%) were unsure. These conversations were more likely to have happened between healthcare professionals and the person's family (66%).

> **"This was always a very open discussion with mum and family and healthcare professionals. …. Mum was very lucid to the end so also very aware and accepting of her situation."**
>
> Died from multiple conditions

> **". . . I'm unsure if my mother wanted to know how long she had left to live, she never wanted to discuss it with us. Doctors did discuss it with us and were professional in every way."**
>
> Died from cancer

Advance care plans and shared care records

Sensitive communication taking place between staff and the dying person and those identified as important to them is a recognised priority.[29]

Everyone with palliative care needs should be supported to participate in Advance Care Planning (ACP), allowing them the opportunity to discuss their needs, wishes and preferences for care at the end of life.[30] These preferences should be recorded and regularly reviewed.

While the National Audit of Care at the End of Life (2023) found 10% of cases had no documented discussion with the patient about the possibility they may die,[31] survey respondents' perceptions were lower. They show one in four people (25%) who died either probably or definitely did not know they might die because of their illness. More than one in three respondents (37%) said they only became aware that their loved one was dying in the last month of their life.

Despite national guidance and evidence that ACP improves satisfaction with end of life care,[32] reduces avoidable emergency admissions in the last months of life[33] and increases patients' chances of dying in their preferred place, prevalence remains low.[35] ICBs should therefore commission services that offer everyone the opportunity to set out their wishes for the end of their life and ensure these plans are shared and followed by health and care providers.

One reason for low prevalence of ACP is a lack of confidence and skills among some health and social care staff in initiating conversations.[36] It is therefore vital that health and care professionals have the time and skills required to facilitate ACP. All health and care professionals should be funded to receive training in, and have time to follow, clear national guidance on ACP.

Electronic care coordination systems can support ACP by incorporating needs and preferences within care records, which can then be shared amongst all those involved in a person's care with their consent. Electronic care coordination systems should be resourced in ways that incentivise their sustained use and sharing with progress on the use and availability of shared records, including ACP, being audited regularly.

4.4 Workforce capacity is insufficient to meet demand for end of life care

Survey respondents reported that staff across health and social care settings did not have enough time to provide care for dying people, or that support was not available for as long or as frequently as needed.

> **"Although my father was looked after and contacted regularly, we never felt that we could approach hospital staff and when we did it always seemed to be a problem, they were far too busy and just didn't have the time [they wanted] to dedicate to patients in their care."**
>
> Died from a lung condition

This may contribute to respondents reporting considerable variation in satisfaction. 54% of respondents rated their GP as good, very good or excellent whilst 21% rated their GP as poor or very poor. 62% rated their district nurses as good, very good or excellent whilst 9% rated them as poor or very poor.

> **"I believe that the medical profession, being under severe pressure, were not able to offer my mum and her carers the support they need."**
>
> Died from dementia or Alzheimer's disease

Workforce pressures are well-evidenced across health and social care. GPs, nurses and healthcare assistants provide the majority of palliative and end of life care, often alongside a range of other services. While the number of people needing palliative and end of life care has risen steeply in England in recent years, the average number of patients each full-time equivalent GP is responsible for now stands at 2,298, a 19% increase since 2015.[37]

Workforce pressures affecting palliative and end of life care are worse in some areas than in others with GP shortages, for example, being higher in coastal towns[38] with older populations and in more deprived areas.[39] Workforce pressures on palliative care in the community are also exacerbated by the decline in district nurse numbers (down 47% in England since 2009).[40]

Both GPs and nurses are aware of the impact of workforce pressures. The Royal College of General Practitioner's recent survey of GPs found that 56% say they don't have enough time to adequately assess and treat patients during appointments and 57% don't have enough time during appointments to build the patient relationships they need to deliver quality care.[41] Similarly, over 75% of district and community nurses report insufficient staff to meet the needs and dependency of their patients.[42]

> **"A good death will never be achieved whilst there is a lack of care in the NHS, overworked, badly paid and understaffing in care homes and allowing people to be within hours of death before they are admitted to a hospice for palliative care."**
>
> Died from dementia or Alzheimer's disease

These pressures are linked to workforce growth and investment that is not aligned to the vision of delivering more and better care in communities. Since 2016, Community Trusts have seen half the level of funding growth as acute hospital trusts while the proportion of Department of Health and Social Care spending on primary care has fallen.[43]

The survey findings and other research[44] clearly indicate that equitable access to palliative care in community settings requires investment in primary care services and community nursing teams.

Better workforce planning, resourcing and training

The NHS Long Term Workforce Plan sets out the actions to be taken to address the systemic workforce issues facing the NHS.[45] However, the plan does not reflect the specific requirements of specialist palliative care, which is largely provided by charitable hospices, or the contribution of social care to the end of life care workforce.

Future workforce planning must take account of the significant increase in need for palliative care projected for the coming decades and the continuing trend of more people wishing to die at home.

The Government should therefore publish, at least every two years, independently verified projections of future demand for the palliative and end of life care workforce, including specialist palliative care, and ensure a properly resourced plan is in place for meeting this demand.

While staffing pressures can compromise care and, as the survey shows, are highly visible to patients and their families, the skills and supporting infrastructure that enable more integrated working are also essential. Palliative and end of life care training should therefore become a compulsory part of initial training and continuing professional development for all health and care workers, not just those in regulated professions.

4.5 Unpaid carers take on significant caregiving roles with little support

Unpaid carers – typically family and friends – play a critical role in end of life care, yet their needs are often not properly identified or met. Most of the survey respondents had been involved in caring for the person who died: 61% helped them get to appointments or treatments, 62% helped with medical procedures, and 78% spent time 'on call', typically for more than 50 hours per week.

> **"We met lots of lovely staff (dementia support, cancer nurse at GP etc) but they all just gave us contact details of people I could approach for support and I was already so busy organising shopping, appointment[s], medication, carers, all at a distance. I really felt like screaming!"**
>
> Died from cancer

Many respondents said they felt that they lacked the knowledge and skills to provide care and navigate services but were unable to access sufficient support. Poor communication from professionals and care coordination were a significant cause of distress. In many cases carers were themselves frail or in poor health, particularly where the person who died had a diagnosis of dementia.

> **"It is quite shocking that a 97-year-old man should have to carry the sole burden of a 90-year-old wife with Alzheimer's. No care was available to my father. He was isolated and lonely."**
>
> Died from a heart condition

As well as being emotionally and physically difficult, caring for a relative at the end of life can also have a financial and professional impact. Of those respondents still in work, 12% took between 31 and 90 days paid or unpaid leave in the final 3 months before death, while 5% quit or changed their jobs (including retiring early) to care for their loved one. Others reported a cut in wages as they reduced their hours to provide care.

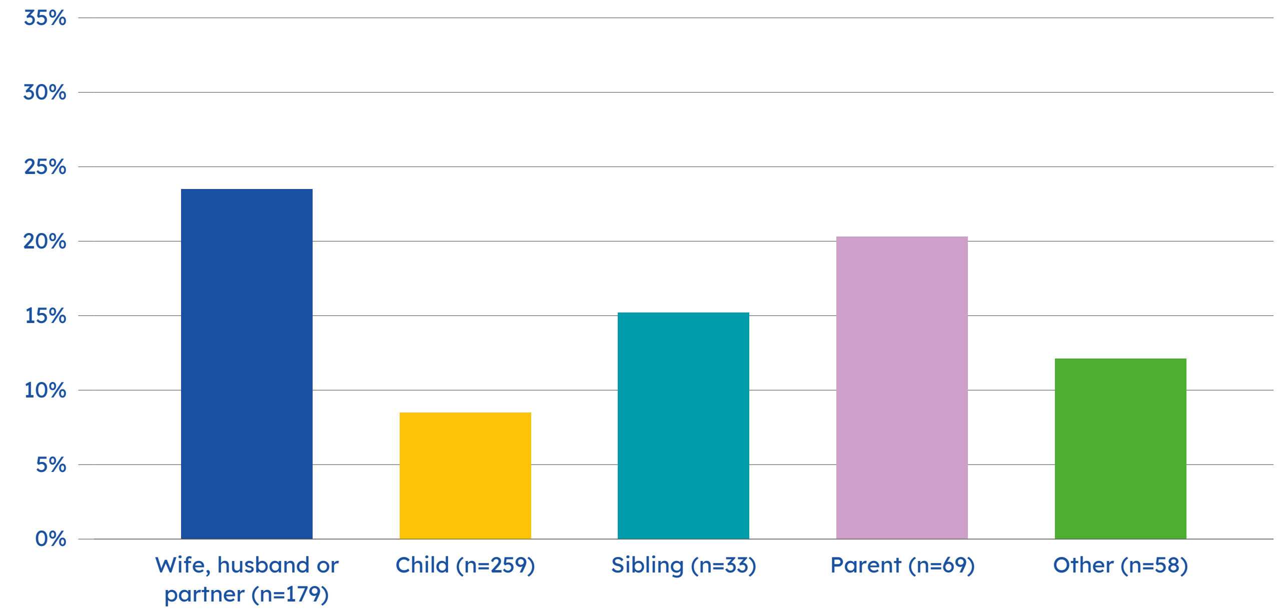
> **"I live 4 and a half hours drive from my parents and from May to December all barring a couple of weeks worked 2 days at work, travelled to my parents, gave 24-hour support for 5 days and drove back to go to work. There is no support mechanism in place, now that retirement age [state] has increased, for children to support their parents without financially affecting themselves."**
>
> Died from a heart condition

> **"My brother sacrificed four years of his life and eventually lost his income… Mum wanted to remain in her own home but she needed 24/7 care […] I am convinced that the impact of [his] sacrifice will continue to have detrimental effects for years to come."**
>
> Died from dementia or Alzheimer's disease

People with disturbed grief are not adequately supported

For some people, bereavement can result in disturbed grief: a debilitating and persistent grief response that causes psychiatric distress. 15% of respondents met the criteria for disturbed grief. This was more common among respondents who were younger, female, or the spouse of the person who died.

Figure 2. Prevalence of disturbed grief among respondents in England according to their relation to the person who died



(Source: Johansson et al., 2024, p.90)

Respondents who were unhappy with aspects of care or felt healthcare professionals had not listened to them or communicated well also had higher levels of disturbed grief.

> **"We were always dismissed in talking to the consultants during round wards […] He was discharged from a respite hospital with no care, no assistance or plan. Essentially in my eyes sent home to die alone."**
>
> Disturbed grief indicated

Most respondents (71%) who met the criteria for disturbed grief had not accessed bereavement support, suggesting significant unmet need.

> **"Since the loss of my husband, I have applied for bereavement counselling but have heard nothing apart from a letter saying I would hear 'soon'. This was received about 6 weeks ago. If it was not for my dog (now my support dog), I would not be here to complete [the survey]."**
>
> Disturbed grief indicated, no bereavement support

Better support through caring and bereavement

Identification of carers is a significant barrier to carers accessing the support they need and are eligible for in their caring role, whether physical, emotional, digital, or financial.

Given the extent to which care relies on the contribution of unpaid carers, and recognising their statutory duties under the Care Act, Local Authorities must ensure every carer is offered a Carer's Assessment at least annually, with prompt follow up after initial invitation and whenever their caring responsibilities change. This should include digital and financial needs assessments.

The UK Commission on Bereavement also identified financial pressures on carers with 43% of adult consultation respondents experiencing financial difficulties, rising to 50% for those who experienced the death of their partner or spouse.[46] Extending statutory bereavement leave and pay entitlement of two weeks to all people with a close relationship to a person who has died would be one step towards alleviating this burden.

5 Innovative practice

Here we share some case studies of service models and approaches that are successfully addressing some of the challenges identified in the 'Time to care' survey report.

5.1 Integrated Mersey Palliative Care Team (IMPaCT)

The IMPaCT service was established in 2020 and includes Marie Curie, Woodlands Hospice, Liverpool University Hospitals Foundation Trust and MerseyCare NHS Trust.

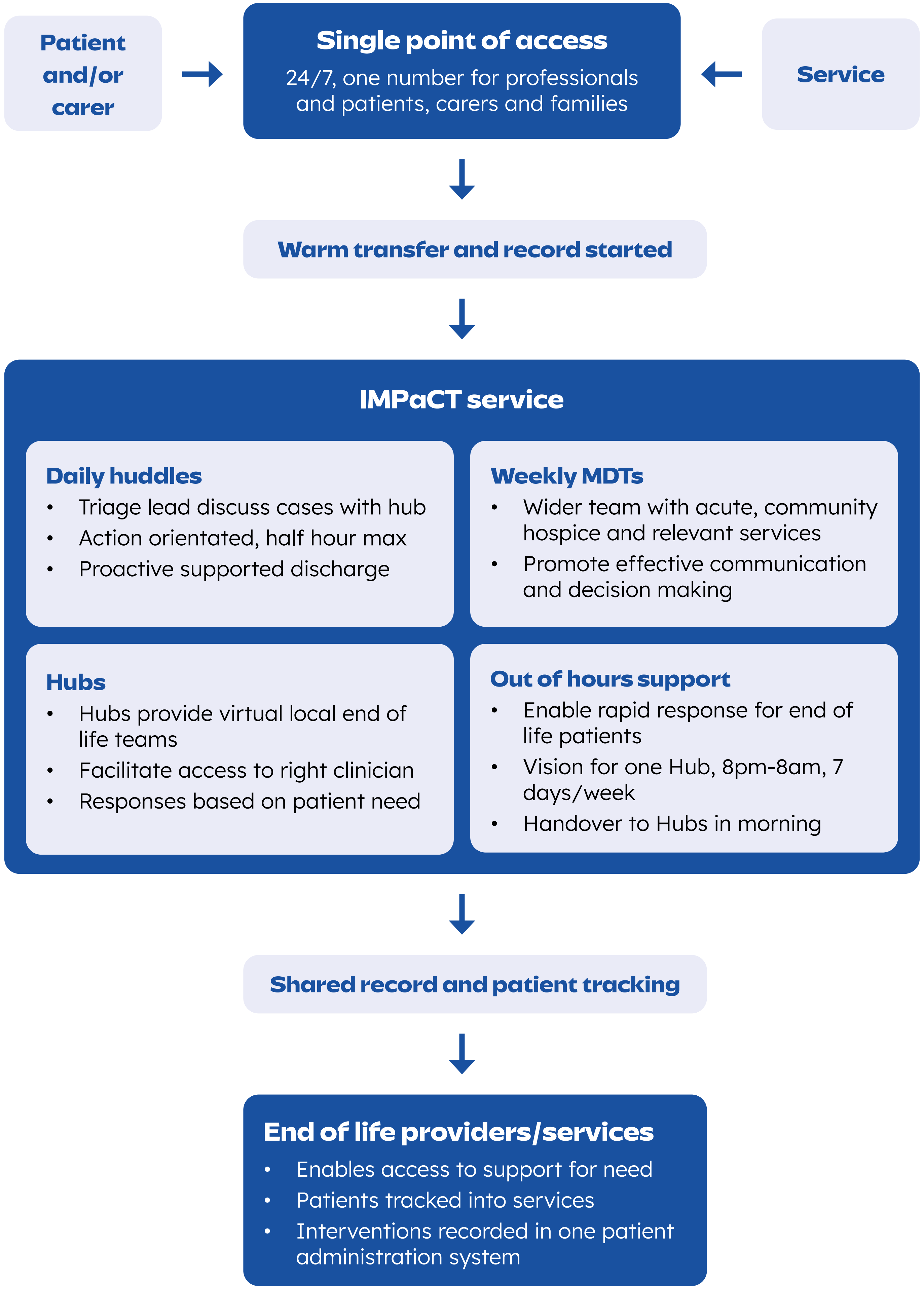
Before the IMPaCT service, palliative and end of life care was fragmented and difficult to navigate, resulting in more hospital admissions in the last days of life than the national average and fewer people dying at home. By addressing the gap in collaborative working across services, IMPaCT aims to increase the number of people with palliative care needs identified, reduce emergency hospital admissions, and improve coordination of timely care through an integrated, joined-up workforce.

The IMPaCT service operates out of two palliative and end of life care hubs, which patients, carers and health and care professionals can contact through a 24/7 single point of access palliative and end of life care telephone line. The hubs interface with providers across the health and care system to facilitate efficient patient flow.

Fundamental to the IMPaCT model are the daily hub-based huddles and weekly multidisciplinary team (MDT) meetings, involving acute, emergency, hospice, and community providers. These foster collaboration, reduce duplication and increase workforce efficiency (See Figure 3). Over 4,000 patients have been discussed at MDT meetings between April 2021 and March 2023. Strong relationships between the IMPaCT service and community-based services are critical to supporting the community-based workforce, including GPs and district nurses, who face increasing pressures.

In an external evaluation, people supported by the service reported an improvement in continuity of care, increased confidence in the plan for care and improved support with physical health, such as pain management. The IMPaCT service has been found to have contributed to a 9.3% increase in the proportion of people being included on supportive palliative care registers, a 13.0% decrease in emergency hospital admissions and a 13.6% decrease in deaths occurring in hospital.

Figure 3. IMPaCT service delivery model



Single point of access

24/7, one number for professionals and patients, carers and families

Warm transfer and record started

IMPaCT service

Daily huddles
- Triage lead discuss cases with hub
- Action orientated, half hour max
- Proactive supported discharge

Weekly MDTs
- Wider team with acute, community hospice and relevant services
- Promote effective communication and decision making

Hubs
- Hubs provide virtual local end of life teams
- Facilitate access to right clinician
- Responses based on patient need

Out of hours support
- Enable rapid response for end of life patients
- Vision for one Hub, 8pm-8am, 7 days/week
- Handover to Hubs in morning

Shared record and patient tracking

End of life providers/services
- Enables access to support for need
- Patients tracked into services
- Interventions recorded in one patient administration system

5.2 Durham Urgent Hospice Care at Home service

County Durham's Urgent Hospice Care at Home service (previously known as Rapid Response) began in 2012 to meet the urgent palliative and end of life care needs of patients and their carers in the community. The service is primarily funded by the Integrated Care Board, with around a quarter of funding from Marie Curie, and operates 24/7 for 365 days per year.

The service has two shifts (7am to 7.30pm and 7pm to 7.30am), each covered by two teams consisting of one Registered Nurse and one Healthcare Assistant. In addition to providing urgent, hands-on care, the team supports with collecting and arranging medications if not already in the home and with rapid hospital discharges. The service uses the same clinical record system as other community teams, such as GPs and District Nursing, enabling safe and effective communication and continuity of care.

In April 2023, the service integrated with the local Single Point of Access (SPA) for all referrals and reaffirmed their commitment to deliver urgent care within 2-hours of request, in line with the Integrated Care Systems' Urgent Community Response service requirement.

Following integration with the SPA, activity increased significantly, with 2,440 visits completed between April and October 2023 alone. The last formal evaluation of the service, in 2013, showed that hospital admission was avoided on at least one occasion for 74% of patients who received care through the service and, based on this, estimated a savings of around £1,330,000 in hospital costs across the county.

Other system benefits include supporting an overstretched district nursing service, reducing pressure on GPs, and identifying patients with palliative care needs for the supportive palliative care register. Benefits to patients include timely symptom management, as well as emotional support, advice and signposting. 97% of patients who received care through the service between April and October 2023 achieved their preferred place of death.

5.3 Reactive Emergency Assessment and Community Team (REACT) Service

Marie Curie's REACT is an innovative, integrated service model for improved palliative and end of life care in Bradford District and Craven. With social impact bond [47] funding, the service launched in June 2022 in response to local unwarranted clinical variation, health inequalities and system pressures.

REACT is a partnership between Marie Curie Hospice, Bradford Teaching Hospitals NHS Foundation Trust and Social Finance, with support from a place-based steering group.

REACT has two, interlinking arms:

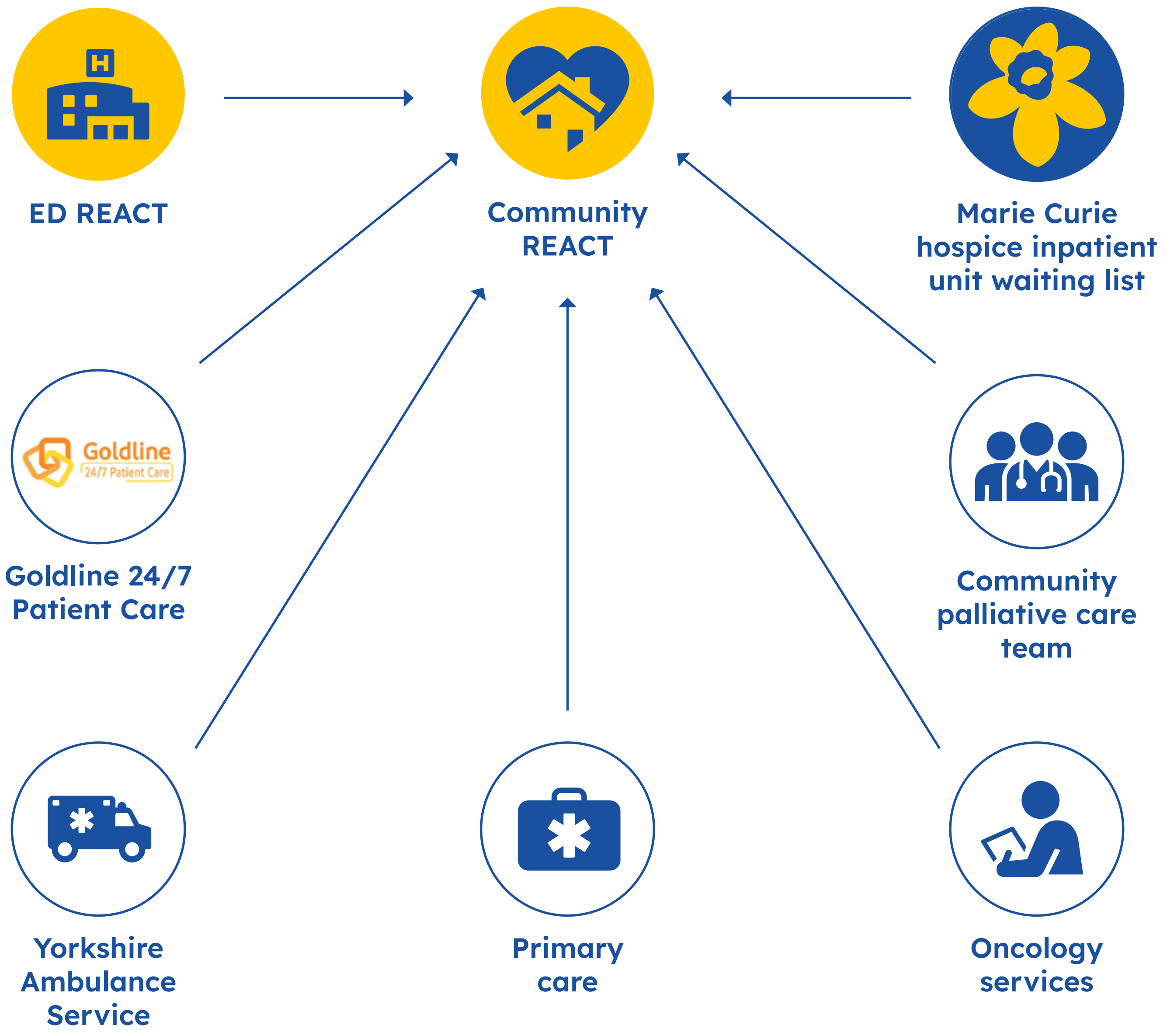
- **Emergency Department (ED) REACT**: a consultant-led in-reach model in which patients with palliative care needs presenting to the ED are proactively identified, assessed, treated, and offered an alternative to hospital admission through a supported transition into Community REACT.
- **Community REACT**: a multidisciplinary urgent community response service and virtual ward for patients in crises in their last year of life, delivering holistic care and support for up to 72 hours before facilitating transfer of care to appropriate community services.

Community REACT accepts referrals directly from community palliative care teams, the Bradford Marie Curie hospice's inpatient unit waiting list, and oncology services, thereby preventing unnecessary ambulance conveyances and ED visits. Direct referral options for primary care providers, the ambulance service and Goldline (the regional single point of contact) are planned.

Most Bradford providers use the same clinical record system, which has aided the integrated model's success. The team is exploring multidisciplinary team 'huddles' to ensure seamless transitions across care settings. The service currently operates seven days per week, 8am-8.30pm and collaborates with out-of-hours providers, such as Goldline, as needed.

Between June 2022 and May 2024, REACT received 984 referrals, of which 35% were not previously known to palliative services. 70% of people supported by REACT had non-cancer diagnoses and 38% were from the most deprived areas. For people in their last year of life referred to ED REACT, mean bed days reduced from 38 to 20 for those admitted to hospital, and to 15 for those admitted to Community REACT. Interim evaluation indicates the model's financial sustainability, with a 2:1 return on investment. Patient and staff experiences have been overwhelmingly positive.

Figure 4. REACT service delivery model



5.4 Carer Support Needs Assessment Tool Intervention (CSNAT-I)

The Carer Support Needs Assessment Tool Intervention (CSNAT-I) is a five stage, person-centred process of assessing and supporting the needs of informal family carers using a comprehensive tool (the CSNAT). The CSNAT is an evidence-based tool that enables carers to identify, express and prioritise areas where they need more support. [48] Carers are encouraged to consider their own needs, separate from the needs of the patient. The five stages of the CSNAT-I are shown in Figure 5.

The CSNAT-I achieves local authorities' statutory duty to assess carers' needs [49] and enables the delivery of tailored support to carers. It is also being used by charitable hospices, some NHS Trusts, specialist palliative care teams and is being piloted in primary care services. At least 85 UK-based organisations, and at least 83 organisations abroad, hold a CSNAT-I practice license, which can be obtained for free following completion of practitioner training.

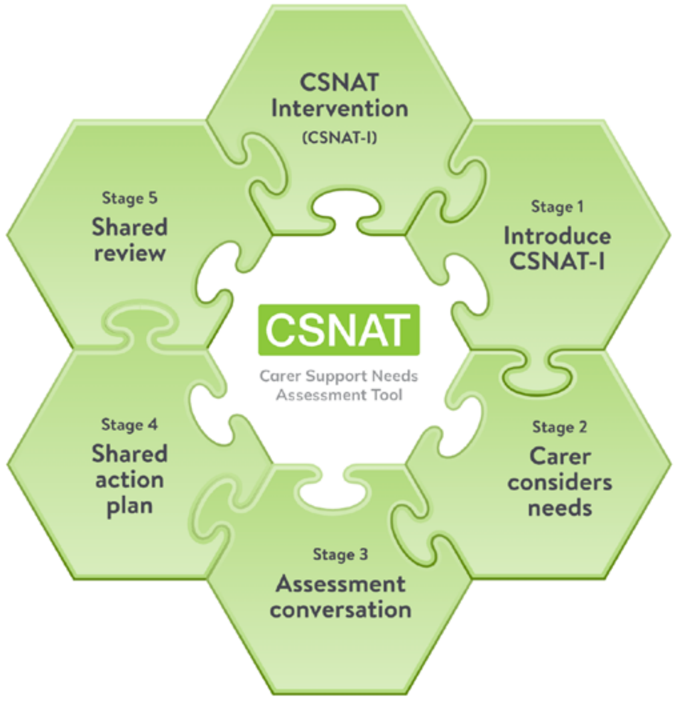
Application of the CSNAT-I in practice has demonstrated numerous benefits for carers, including:

- feelings of validation, reassurance and empowerment [50]
- improved preparedness to care [51]
- reduced strain and distress [52]
- reduced early grief and improved psychological and physical health post-bereavement [53]
- and improved interactions with healthcare professionals.

> **"It formalised what I probably knew I needed, but it's difficult to articulate when you're going through it…"**
>
> Carer

Using the CSNAT has also been shown to increase health and care professionals' confidence in conversations with carers by formalising the carer support process. [54, 55] Potential benefits to the health and care system include more efficient and targeted use of resources, by focussing on what truly matters to each individual carer, and reduced strain on acute care services, by proactively identifying and addressing carers' current and potential physical and mental health and wellbeing needs to limit the likelihood of crises.

Figure 5. The 5-stages of the CSNAT-I



Source: https://csnat.org/

6 Conclusion

In this briefing we have summarised the key findings of a major nationally representative post-bereavement survey, which revealed patchy, inconsistent and inequitable provision of palliative and end of life care, and explored some of the implications of this evidence for policy and practice.

The survey showed that many people are dying at home with high symptom burden including breathlessness, pain and mental health needs. People who are financially insecure are more affected by these symptoms. Groups such as people aged over 85 and those with conditions other than cancer are more likely to miss out on specialist palliative care.

While some people, especially those accessing specialist palliative care, report positive experiences of high quality care, many described the difficulties of accessing overstretched, poorly coordinated services that lacked the time to provide the care and support that was needed. The capacity of the health and care workforce is insufficient to meet the needs of people who are dying at home.

Many unpaid carers felt unprepared and unsupported. Providing and coordinating care took considerable time with significant financial and emotional consequences. Where care is insufficient or poor it can result in guilt and anxiety for carers, increase the use of acute care services and lead to debilitating symptoms of bereavement.

With the rise in numbers of people with palliative care needs and the increased use of home as a place of care, better integration of palliative care into community services, and integration of these with hospital and hospice-based services, is essential. The positive experiences of some survey respondents and the models of good practice in this briefing show that this can be done well.

Workforce pressures, particularly out-of-hours, lie behind many of the experiences of poor care. Developing the skills of community-based staff, such as more nurse prescribers and better advance care planning are key to meeting rising demand. This must be supported by good digital infrastructure including shared electronic records, and service models that optimise skills use and efficient coordination.

If more end of life care is to be provided in the community, funding and commissioning must respond to this pattern of demand. Failure to do so means greater reliance by default on already stretched ambulance and hospital services. This will fail to improve patient care and make it harder to address the inequalities in access that already exist.

The innovative models and approaches shared here demonstrate that good palliative care is possible. As dying, death and bereavement affect us all, it is in everyone's interest to get this right.

7 Policy recommendations

	Recommendation	For action by
Making a good end of life experience possible for all	Develop a national strategy for palliative and end of life care to support delivery of local plans.	• UK Government • NHS England
Better symptom management support	Improve access to medicines through more pharmacies stocking palliative medicines and more professionals trained to prescribe and administer them.	• NHS England • Integrated Care Boards
	Produce and consult on new guidelines for mental health support for all people approaching the end of their life.	• National Institute for Health and Care Excellence
Delivering 24/7 community care	Strengthen equitable access to palliative care through increased investment in primary care and community nursing services.	• UK Government
	Ensure 24/7 access to palliative and end of life care including through a single point of access offering advice, guidance and support.	• Integrated Care Boards

	Recommendation	For action by
Better integrated services and timely co-ordination of care	Commission services that offer everyone the opportunity to set out their wishes for the end of life and ensure these plans are shared and followed by health and care providers.	• Integrated Care Boards
	All health and care professionals should be funded to receive training in and have time to follow clear national guidance on advance care planning.	• UK Government
	Electronic care coordination 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.	• Integrated Care Boards
A workforce that is fit for purpose	Publish, at least every two years, independently verified projections of future demand for the palliative and end of life care workforce (including specialist palliative care) and ensure a properly resourced plan is in place for meeting this demand.	• UK Government
	Make palliative and end of life care training a compulsory part of training and continuing professional development for all health and care workers, not just those in regulated professions.	• UK Government
Improve support for unpaid carers	Increase support for carers of people at the end of life through better identification, needs assessment, financial and bereavement support.	• Local Authorities
	Extend statutory bereavement leave and pay entitlement of two weeks to all people with a close relationship to a person who has died.	• UK Government

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