

## The Palliative Care Crisis: Inadequate Access, Care and Outcomes in the Face of Rising Demand

Palliative care is specialised multidisciplinary care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and those important to them.<sup>1</sup>

### Critical Gaps in Access and Provision

Access to palliative care remains highly patchy across the UK, with marked disparities based on geography, socio-economic status, health condition and the times that services are available. Rural communities and economically deprived areas are especially affected by this inequity, and individuals with non-cancer diagnoses are sometimes excluded from palliative care services despite facing similar or even more severe symptoms than those with cancer.<sup>1</sup> For example:

- In England and Wales, almost 600,000 people die each year.<sup>2</sup> Many of these individuals experience complex symptoms and healthcare needs towards the end of life.<sup>3</sup>
- Palliative care, which can improve quality of life, would be beneficial for approximately 90% of those with life-limiting conditions. However, despite its proven benefits, many people who could benefit from palliative care do not receive it in a timely manner.<sup>4</sup>
- The number of people who do receive palliative care is not recorded in any government figures.
- A national study on the final three months of people's lives in 2023<sup>4</sup> found that:
  - fewer than half of those who died had any contact with specialist palliative care – from a hospital or community palliative care team, or hospice
  - any contact with palliative care was disproportionately low for people without cancer, such as those with heart disease (24%) or dementia (25%)
  - almost one in five (19%) people who died had no contact with a GP in their final three months of life (either in person or over the telephone)
  - only 29% reported contact with palliative care doctors, nurses, or 'hospice at home' teams to help support them at home
  - only 19% reported receiving support from a palliative care team when in hospital, only 10% reported support in a care home
  - almost half (49%) reported they were unhappy with one or more aspect(s) of care
  - In the last week of life 35% of those who died were reported to be severely or overwhelmingly affected by pain and 40% were severely or overwhelmingly affected by breathlessness
- Only around 28,900 people die as an inpatient in hospices each year in England and Wales, around 5% of all deaths.<sup>2</sup>
- While around 60-80% of people express a preference to die at home,<sup>5,6</sup> in many regions most are unable to do so due to a lack of accessible palliative care support.<sup>6</sup>
- In 2023, 164,854 people (28%) died in their own homes, while 43% (252,037) died in NHS hospitals.<sup>2</sup>
- A national study in 2022 found that only around 30% of UK areas offer out-of-hours palliative care telephone support, even though this has been a NICE recommendation since 2011. 27% of areas offer no designated support at night and at weekends, and around 40% of areas offer partial coverage out of hours.<sup>7</sup>

- There are many missed opportunities to improve frail older people's recovery during hospital admission, and for proactive care in the community, which would improve quality of life and reduce emergency hospital attendance.<sup>8</sup>
- Despite their proven benefits, in the UK most hospices offering inpatient and community support are run by local charities, with only around a third of their funding coming from the NHS, with the remainder (over £1bn a year) raised by hospices themselves.<sup>9</sup>
- An over-reliance on charitable income means that hospice services are almost always better resourced in wealthier parts of the UK. Access to hospices services varies markedly across the UK.
- People from ethnic minority groups can miss out on palliative care and may be adversely impacted by policy changes, for example, as was evident during the COVID-19 pandemic.<sup>10</sup>

These gaps not only undermine patient choice and quality of life but also place additional strain on families and informal carers, who often assume caregiving responsibilities willingly, but with too little support or guidance. The fragmented access to palliative care also means that patients frequently face emergency admissions to manage symptoms that could have been addressed earlier through community-based palliative care.

### **Evidenced Benefits of Palliative Care**

Research supported by Cicely Saunders International and others provides substantial evidence of the benefits of early integrated palliative care, which goes beyond symptom management to address the broader concepts of 'total pain and suffering'.<sup>11,12</sup> Palliative care acknowledges and treats physical, psychological, social, and spiritual suffering, leading to improvements in the quality of life for both patients and their families.<sup>13</sup>

Studies show that timely palliative care helps patients better manage severe symptoms like pain, breathlessness, and anxiety, often without the need for repeated hospital visits. For instance, a study initiated by Cicely Saunders International found that an integrated palliative care breathlessness support service significantly improved patients' control over their symptoms, allowing them to stay at home, reducing reliance on acute care services, and reducing NHS costs.<sup>14,15</sup>

Palliative care also provides an invaluable layer of emotional and psychological support, enabling patients to feel more in control of their circumstances, and able to better express their priorities for care. Families, too, benefit from the structured support and guidance that palliative care teams offer, reducing the risk of burnout among caregivers and ensuring families are prepared for future challenges. Studies suggest that early palliative intervention even improves bereavement outcomes, helping to mitigate complex grief and supporting families through difficult times.<sup>16</sup>

Expanding palliative care in the community, hospices and hospitals would be beneficial in<sup>1</sup>:

- Supporting care at home and in the community
- Crisis prevention to avoid hospital admissions and aid smoother, less stressful, and often earlier discharge from hospital
- Cost-effectiveness and resource optimisation for the NHS, as well as holistic care to help people live well for the time they have left

These would be aided by digital innovation for improved access and coordination.

## **The Growing Need for Palliative Care in the UK**

Despite the current lack of provision of palliative care, research supported by Cicely Saunders International and others underscores the rapidly growing need for palliative care across the UK, with demand expected to rise by 42% by 2040, increasing by 161,842 more people/year, to total 537,240.<sup>3</sup>

This surge is largely driven by an ageing population and an increase in complex, life-limiting conditions, including multimorbidity, organ failure and complex illness at all ages. The need for palliative care goes beyond addressing end-of-life support, although this remains very important.

Palliative care involves managing symptoms and other complex concerns, supporting families and providing a compassionate framework that recognises the holistic nature of suffering. When introduced early it can prevent suffering and often includes rehabilitation to improve function and maintain independence.

## **Recommendations for Addressing Gaps in Palliative Care**

The Cicely Saunders International [\*Action Plan for Palliative Care\*](#)<sup>1</sup> outlines essential steps to address these critical gaps, calling for greater investment in palliative care research, training, and service expansion. Cicely Saunders International recommends a systematic approach that includes:

- Expanding palliative care expertise across all care settings, including hospitals, care homes, hospices, and home environments. This will require investment, but palliative care is cost-effective.
- Ensuring equitable access to high-quality palliative care services across the UK, with particular attention to underserved rural, economically disadvantaged, and minority populations.
- Investing in the development of community care services and out-of-hours palliative support to reduce hospital dependency and facilitate symptom management at home.
- Training health and care professionals, including primary care providers and social care workers, in the principles of palliative care to ensure more timely referrals and that patients' needs are met more comprehensively and compassionately.
- Integrating digital health tools to enhance care coordination, enable real-time outcomes data sharing, and ensure that patients and families receive more timely and seamless support.

Cicely Saunders International's and other's evidence demonstrates that these measures would significantly improve the quality of life for patients and families, helping them to live as well as possible, while also relieving the strain on the healthcare system.

## **A Call to Action**

We encourage our friends and supporters to join us in raising awareness of the critical shortage and fragmented availability of palliative care across the UK, as well as the need for appropriately funded, universally accessible services to support people with serious illness and those important to them.

For more information on these priorities, please refer to Cicely Saunders International's [\*Action Plan for Palliative Care\*](#).

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