England’s palliative care funding challenge

What is palliative care?

Palliative care is the care and support given to people with life-limiting conditions like cancer, heart failure and lung disease. It aims to give people the best quality of life possible. It focuses on managing pain and other symptoms over the weeks, months or years someone is living with a life-limiting condition. Palliative care includes the practical and emotional support people and those close to them need in order to spend the time they have left in the way they choose.

It can be provided in a variety of different settings, including at home, in a hospice or hospital depending on a patient’s needs and preference and, in addition to clinical care, can include giving practical and emotional support to patients and those close to them. Sue Ryder is one of the country’s leading providers of specialist palliative care, employing skilled professionals who are experienced in providing care and support for end-of-life patients with complex needs as a result of their terminal illness.

245,000 patients are expected to receive palliative care support in 2021/22 and based on recent trends, demand is projected to increase to 379,000 by 2030/31. This is due to a number of factors such as increased mortality rates caused by demographic changes, as well as a growing desire by patients to die at home rather than in hospital. Such a significant increase in demand for these services is leading to a crisis in the charitable care sector and it does not even address the number of people who are thought to need palliative care but don’t receive it: according to recent data, slightly less than 50% of all people dying in England receive palliative care and support, yet up to 90% of all people dying in England may have palliative care needs.

The Government’s view of the hospice sector

In the NHS Long Term Plan, the Government has recognised the essential role of the hospice sector in the delivery of personalised care. It highlights the crucial role of specialist hospices and the value of people being able to die in a place they have chosen. In Parliament, ministers have recognised that palliative care services are subject to an ‘overall increase in demand’; that they want to ‘support and strengthen palliative care’; and that the collapse in charitable donations poses a ‘most difficult and challenging problem’ for the sector. Indeed, the Health Secretary himself has repeatedly stressed the Government’s commitment to investing in ‘high quality palliative care’. However despite all this, so far no major new long-term investment has been forthcoming. The announcements in April and November 2020 of up to £325m of funding for hospices as part of the COVID-19 response was welcome, but did not fundamentally address the serious long-term funding issues facing the hospice sector.

If funding continues to remain at current levels, many providers will simply be unable to meet the demand required over the next decade. Sue Ryder is calling on the Government to urgently review the funding settlement for palliative care and commit to a significant real-terms increase in statutory funding for clinical palliative care services across England.
How palliative care is funded

The majority of palliative care services in England are provided by the charitable sector. The costs of service provision for specialist palliative care services provided by the sector are usually funded through a combination of fundraising activities, such as donations and income from charity shops, as well as statutory funding via the NHS’s local Clinical Commissioning Groups (CCGs).

On the ground, local health provision is evolving from CCGs towards an Integrated Care Systems (ICS) model – a reorganisation that is fundamental to the NHS Long Term Plan and its ambition to provide more personalised care. This approach to the provision of care means that more and more people are likely to want to die in a place of their choosing – and we know this is more likely to be at home or in a hospice rather than in a hospital. On that basis demand for specialist palliative care services by hospices from their local communities is going to increase further as a result of these changes.

While the Government recognises the vital role of the hospice sector in this changing healthcare landscape, it currently states that commissioning and funding of such services should be determined at a local level. This ‘disconnect’ between policy intent and funding is putting the hospice sector at risk and most importantly it risks the future of specialist palliative care services and all those who will one day need them.

On average, statutory funding now covers just over a third (37%) of total charity expenditure on palliative care services – or approximately £350m per year. While Government funding has slowly increased over the past seven years, as a proportion of total expenditure it has largely remained static.\(^1\)

Not only is this unsustainable for hospices in the medium term, the crisis has been made worse in the short term by the COVID-19 pandemic which has resulted in income from shops and fundraising activities plummeting. This has exacerbated the gap between resources and increasing demand for palliative care and support. Whilst COVID-19 has made things worse, the problem is not new and the charitable sector has seen its Return On Investment (ROI) income through fundraising and trading decline for each of the last seven years.\(^2\) Even before COVID-19, about a fifth of hospices were thought to be at risk of imminent closure due to extreme financial difficulties.\(^3\) Against this background, there are growing and significant concerns from palliative care service providers over their ability to raise the required funds to meet the future demand.

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\(^1\) Hospice UK Accounts Report 2020 - [https://www.hospiceuk.org/what-we-offer/hospice-finance/benchmarking](https://www.hospiceuk.org/what-we-offer/hospice-finance/benchmarking)
\(^2\) As above
The costs of service provision over the next decade

Sue Ryder has recently commissioned independent research to examine the costs required to meet the demand for palliative care services over the next ten years. It found that over the next ten years the total cost of hospice provision of palliative care services will be on average £947m per year.

Baseline scenario

If the current funding arrangements remain unchanged, and the Government continues to cover 37% of hospice sector costs, the Government would contribute around £350m per year. The charitable sector would continue to raise funds for the remainder, if it survives.

Scenario 1

If the Government increased its share of statutory funding to cover all the charitable sector’s clinical costs for palliative care services4 plus a contribution towards support services5, this would amount to 70% of total palliative care costs. This would result in an average additional Government expenditure of £313m per year over the next decade. This would increase average statutory funding to £663m per year - funding that would ensure that palliative care provision is protected from the prolonged effect of COVID-19 or other future shocks affecting the capacity of the independent hospice sector to raise funds.

Scenario 2

If the charitable sector could no longer raise any of the necessary funding and the Government was required to pay 100% of the costs of palliative care services provided by hospices, then the resulting additional costs to the Government would amount to £597m per year on average; equivalent to £947m in total per year.

Scenario 3

If, as many fear, the independent hospice sector collapses due to the continued lack of funding and palliative care services were instead provided directly by the NHS, then the cost of this would amount to approximately £834m per year, or an additional £484m per year compared to what the Government pays currently. However, this is not comparable to the scenarios above, as patients in the NHS receiving palliative care would be less likely to receive the holistic support that hospices provide to patients and their families, with the NHS instead focusing on pain and symptom management only. It is also highly unlikely that the NHS would have the capacity to accommodate the growing demand for these services so this would be a highly undesirable outcome for both Government and the people who would need these services in the years to come.

This research has highlighted the stark reality of the dangers currently facing the independent hospice sector. If high quality patient outcomes are to be preserved and the hospice sector is to continue to be able to provide these essential services, it is clear that the Government needs to commit to funding at least 70% of the sector’s total palliative care costs to ensure its future sustainability.

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4 Doctors, nurses, clinical administration staff
5 Catering, domestic, therapies and others
The need for a Government commitment on palliative care funding

Given the future increase in demand and the cost of £947m per year to meet that demand over the next decade, if funding continues in line with its current model, hospices will be required to raise £597m each year through fundraising. This is simply unrealistic, and the hospice sector cannot be balanced on this fragile basis.

Without a Government commitment to significantly increase levels of statutory funding to cover clinical costs for palliative care services, there is a genuine and serious risk of services being withdrawn and patients no longer being able to benefit from these essential services that provide so much vital support to themselves and their families.

The consequences of hospice closures would be nothing short of disastrous both for patients and those close to them. Without an independent hospice sector, the NHS would be forced to take on the extra demand and patients would no longer be able to benefit from the holistic and person-centred support that the hospice sector provides, as well as reducing patient choice. The COVID-19 pandemic has created a massive backlog in hospital activity, through cancellations, late diagnoses and a general increase in demand across the board. To further increase reliance on NHS services at this stage, by failing to invest properly in the hospice sector now, would be the wrong decision and would inevitably lead to poorer patient outcomes for those seeking comfort and dignity as they approach the end of their lives.

A commitment to fund 70% of total palliative care costs is the minimum required to ensure the sustainability of the independent sector and these vital services in the medium term. The total expenditure at this level would amount to around 0.5% of the current total NHS budget. While Sue Ryder recognises the difficulties facing the public finances, it is essential now that the Government takes this important step and sets the independent hospice sector on a positive and sustainable path for the future, allowing it to support more and more people.

How you can support

Sue Ryder is urging MPs of all parties to support its call for a new Government funding settlement to ensure statutory funding for all of the charitable sector’s clinical costs for palliative care services — this is essential if continuity of service provision is to be maintained in the coming years.

You can support our call by:

- Seeking a parliamentary debate to raise awareness of the funding crisis facing palliative care
- Tabling written questions or raising at departmental question time in Parliament
- Writing to the minister to raise your concerns about the future of palliative care funding
- Tweet your support using the hashtag #FundHospiceCare
- Initiate a Private Member’s Bill seeking to increase statutory funding for palliative care for the next financial year
- Raise the issue with your parliamentary colleagues and support Sue Ryder’s efforts to build parliamentary support.

Draft PQs and letters can be found here: https://shorturl.at/ktPWX

Contact

For further information, or for draft letters, PQs or other resources to support with the above, please contact:

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