



All-Party Parliamentary Group on Hospice and End of Life Care: Hospice Funding Inquiry

Sue Ryder Submission

September 2023

About Sue Ryder

Sue Ryder supports people through the most difficult times of their lives. For 70 years our doctors, nurses and carers have given people the compassion and expert care they need to help them live the best life they possibly can.

We take the time to understand what's important to people and give them choice and control over their care. This might be providing care for someone at the end of their life, in our hospices or at home. Or helping someone manage their grief when they've lost a loved one.

We want to provide more care for more people when it really matters. We see a future where our palliative care reaches more communities; where we can help more people begin to cope with bereavement; and where everyone can access the quality of care they deserve.

- 1. What reflections do you have on the state of government and NHS funding for hospices prior to the introduction of the statutory requirement to commission palliative care?**
- 2. What changes have you seen in the funding of palliative and end of life care services, including hospices, since the introduction of the statutory requirement?**

Prior to the introduction of the statutory requirement to commission palliative care, hospice funding was patchy, insufficient and too short-term. It has also historically not risen in line with inflation, which has been brought starkly to light during the cost-of-living crisis.

This year, Sue Ryder has seen around a 10% increase in the costs to keep our palliative and end-of-life care (PEoLC) services running. This figure is around 20% over the past three years. These inflationary increases are not reflected in the Government/NHS funding we receive, which has increased by an average of only 1% over the last year and 3% over the last three years. Any extra funding that is provided to address shortfalls is often non-recurrent, which can help with short-term cash flow, but does not sustain services in the longer-term.

At the same time, hospice Service Directors are increasingly being told by Integrated Care Board (ICB) leadership and commissioners that there is no more funding to go around. In some cases, we have begun to receive letters informing us that cuts of up to 30% are being made to ICB funding and to 'expect changes'. One cost saving initiative that we are seeing is commissioning responsibilities for PEoLC being absorbed into wider portfolios. This is hugely concerning as it means existing services are facing increased financial risk and is particularly damaging for our ability to engage and plan.

Other external factors, such as increased NHS pay awards, are also driving up the cost of service delivery within the charitable hospice sector. Funding has been made available to support contracted

healthcare providers keep pace with NHS pay, however the existence of additional funding does not guarantee that it will reach the intended recipient. This was the case for Sue Ryder with the 1.7% uplift announced in July 2022. In relation to this funding, NHS England stated, “the allocation will also take account of cost increases on services provided by non-NHS providers... Funding must be flowed appropriately to all providers.”¹ However, none of our services received this uplift to support equivalent increases, which means that we are out of step with the market and are at risk of losing staff and diminishing quality.

Keeping pace with NHS pay increases is challenging, and often not possible for us, with the majority fundraised budgets we have. The charitable hospice sector needs the Government to commit to continually funding pay increases for hospice staff to ensure we are able to recruit and retain the workforce needed to deliver vital, specialist PEOC services. Without ensuring pay parity, there will be increasing unmet need across ICS footprints and inequalities in access will worsen.

Overall, we have seen no improvement to hospice funding since the introduction of the statutory requirement. The situation is now arguably worse as existing challenges have been exacerbated by external factors and ICS devolution means that the Government is reluctant to acknowledge its role in ensuring plans and funding are adequate.

The current funding model leaves charitable hospices increasingly reliant on fundraising activities and voluntary donations to cover the majority of running costs. Dependence on the generosity of members of the public to pay the salaries of doctors and nurses is not something that would be tolerated in other core areas of healthcare, such as maternity services, cancer care or A&E. Hospices are the only statutory service that rely on fundraising to keep going, despite end-of-life care being an essential service that so many of us will need.

Statutory funding provided to the charitable hospice sector delivers an incredibly high return on investment for the NHS. Research from 2021 found that the independent hospice sector provides £947 million worth of care each year and just £350 million of this comes from statutory funding, meaning **the hospice sector saves the NHS an estimated £597 million a year.**² These figures will now be even higher due to high inflation between 2021 and the present. Additionally, demand for palliative care is set to grow by 55% in the next 10 years so these costs will continue to rise.³ Without the charitable hospice sector, the NHS would have to absorb the entirety of this cost and would struggle to deliver the quality of care that is enabled by the hospice model. The Government and NHS are able to make these significant savings due to the goodwill of the general public who donate their money to fund vital healthcare. **The level of funding needed from donations to secure**

¹ <https://www.england.nhs.uk/wp-content/uploads/2022/07/B1863-2022-23-Pay-Award.pdf>

² Sue Ryder (2021), Modelling demand and costs for palliative care services in England. https://www.sueryder.org/sites/default/files/2021-03/Modelling_Demand_and_Costs_for_Palliative_Care_Services_in_England%20%281%29.pdf

³ Ibid.

continuity of service provision is unacceptable, the Government must create a more sustainable model.

This uncertain and unsustainable funding model leaves charitable organisations under constant financial pressure and creates ongoing challenges to make ends meet, plan for the future and secure financial stability, particularly in the context of increasing need. It also exacerbates inequalities as providers simply do not have enough funding to expand and develop their services to address unmet need and reach underserved communities.

The national rhetoric around the importance of PEOLC appears to have slightly improved by the introduction of the statutory duty. However, this has not converted to improvements in ICS planning or in the funding that is made available to deliver PEOLC. This seems to largely be down to two factors; the firefighting of immediate pressures facing ICBs such as waiting lists, bed blocking and winter planning; and a lack of ICB budget to explore and change to more effective operating models that recognise the value of PEOLC, particularly in alleviating pressure on acute services. This is compounded by the absence of detailed guidance on what is 'appropriate' and little accountability for deprioritising the duty.

3. How do you feel government and NHS hospice funding is affecting or could affect service delivery?

As evidenced throughout this response, hospices are being forced to cover the increasing shortfall in statutory funding and are reliant on charitable donations to cover these costs. On top of this, the cost-of-living crisis has made it increasingly difficult to fundraise, placing already stretched services under further financial strain.

Without a sustainable funding solution, there is a genuine and serious risk of services being withdrawn or even closed, with patients and their families losing out on the specialist, holistic support that hospice services offer. In some areas this is already a reality - a recent ITV news report outlined how a number of hospices have had to close beds in order to stay afloat.⁵ With 96% of hospices expecting a budget deficit in the upcoming year⁶, it is highly likely that more will be forced to follow suit. This is particularly concerning amidst the growing demand for PEOLC.

Government and NHS hospice funding is negatively affecting service delivery in a number of ways. It impacts our ability to plan properly; it worsens workforce shortages, which in turn affects the level of care we can provide; and it inhibits our ability to innovate.

Recent examples of how funding has impacted our ability to plan properly include:

- One of our services was promised an uplift of 1.8% for the 2023/24 financial year, which would not have come close to covering the increase in our costs. We were then informed that this was in fact going to be just a 0.8% uplift due to cost-cutting measures.
- We have seen non-recurrent funding being given by the ICB at the end of the financial year in recognition of the shortfall in funding for hospice services. A substantial amount of this

⁵ <https://www.itv.com/news/2023-08-25/lives-are-worth-something-hospices-tell-itv-news-of-funding-crisis>

⁶ Ibid.

money was then converted in Q1 to a down payment for some of what was to be given as statutory funding this year.

- Two of our services that received no increase in statutory funding this year are now operating at a structural deficit and are having to use reserves to cover the shortfall. This is unsustainable.

In the face of current funding pressures, we have to make changes to our services to ensure people can receive the care they need. For example, in response to workforce shortages at one of our services (of which systemic underfunding of PEOC workforce planning is a significant contributing factor), we have changed the model of care to ensure we continue to look after as many people as we can (nurse led beds), but no additional funding has come with that. This is in contrast to another service where we have received non-recurrent funding for a similar initiative. This highlights inconsistency across the system and can create a postcode lottery of service provision where hospices are unable to deliver additional, innovative services without funding attached. The NHS highlights the importance of innovation, particularly technological innovation which ICBs have large budgets to be able to support, however even when we have innovated at our cost and demonstrated value for money, often we have not seen any additional funding to help to maintain these initiatives.

The broader hospice funding model also inhibits innovation. The flexibility to think differently, innovate and trial new approaches is vital to understanding whether current ways of working are the right ones, and identifying changes that can deliver benefits (addressing inequality, improving outcomes and making cost savings). For example, when looking to address growing unmet need in local populations, there are population groups who cannot or will not access services without them being delivered in new ways. However, this can only happen with commitment to supporting new approaches and an appropriate base level of guaranteed funding to match this.

The current practice of short-term contracts, that often do not cover even half of the clinical costs of providing care, is also detrimental to innovation in hospice care as providers must frequently focus their efforts on the next round of commissioning. Short-term contracts increase systemic inequality as providers can't guarantee a substantive enough income for a long enough period to develop new services outside existing footprints, which will be better able to reach underserved communities. Increasing the length and value of contracts would enable providers to spend more of their limited time and resources investing in developing solutions and evolving services to improve care and address unmet need.

4. In your view/experience, is government funding for hospices being provided in line with the guidance produced by NHSE?

No. Whilst the statutory requirement was welcome, it was made without consideration of cost or how it would be funded.

Additionally, NHS England (NHSE) guidance requires further development if it is to be fit for purpose in supporting ICBs with their statutory duty. The current version of the guidance is too ambiguous about what constitutes 'appropriate' provision of palliative care, as per the Health and Care Act 2022, and the actions ICBs must take to commission palliative care services in line with this.

In particular, NHSE guidance lacks specificity around approaches to population health needs assessment and addressing of health inequalities, as well as expectations regarding minimum standards of service provision. For example, it states that commissioners should, “pay particular attention to access to specialist palliative care services” and, “ensure access to out of hours services”.⁷ This leaves the guidance open to interpretation, risks potential for substandard provision and creates a situation where ICBs can deprioritise PEOLC in favour of other areas, without repercussions.

NHSE guidance stipulates that ICBs must commission bereavement services, recognising their value and importance within palliative and end-of-life care.⁸ Yet we know that bereavement support is not funded consistently. Sue Ryder’s research, *A better route through grief*, found that there are disparities in the availability of bereavement services across the country, creating a patchwork of support.⁵ Whilst this research was conducted before publication of NHSE guidance, we have seen little movement on funding of bereavement support since.

Sue Ryder does not receive any funding for our bereavement support services, which are widely accessed and demonstrate positive outcomes. In 2021/22 over 150,000 people visited Sue Ryder’s online bereavement community and we delivered over 4,700 free online bereavement counselling sessions.⁶ 96% of people agreed that counselling sessions helped to improve their emotional wellbeing and 82% felt better equipped to cope with their grief and bereavement following their sessions.⁷

Bereavement support services must be sustainably funded in order for Integrated Care Boards to meet population health needs and comply with the Health and Care Act 2022.

Gaps in the provision of PEOLC are well-evidenced. Just one example of this is Marie Curie research from 2022, which found that 27% of areas in the UK have no designated line for out of hours palliative and end-of-life care and 52% of areas had only partial or no access to equipment out of hours.⁹ It should also be recognised that, even where specialist palliative care services are commissioned, statutory funding does not even cover clinical costs. As we have outlined throughout this submission, hospices are largely propped up by charitable donations, receiving around a third of the funding required to deliver vital PEOLC from the Government.

Furthermore, we know that many ICBs are not yet able to adequately assess population health needs. A recent King’s Fund report found that most end-of-life care commissioners did not have a complete view of needs across their local area.¹⁰ Need was often understood based on levels of demand reported by providers for each service separately, making it difficult to build a complete picture or identify unmet need.

⁷ NHS England (2021), *Palliative and end of life care: Statutory guidance for integrated care boards (ICBs)*. <https://www.england.nhs.uk/wp-content/uploads/2022/07/Palliative-and-End-of-Life-Care-Statutory-Guidance-for-Integrated-Care-Boards-ICBs-September-2022.pdf>

⁸ Ibid.

⁹ Sue Ryder (2022), *A better route through grief: Support for people facing grief across the UK*. <https://www.sueryder.org/sites/default/files/2022-06/A%20better%20route%20through%20grief%20report.pdf>

¹⁰ The King’s Fund (2023), *Dying well at home: Commissioning quality end of life care*. <https://www.kingsfund.org.uk/sites/default/files/2023-02/dying-well-at-home-summary-2023.pdf>

In order for appropriate funding of hospice services to be realised, more explicit NHSE guidance is needed. Guidance should provide greater direction on population health needs assessment and set out a baseline level of provision for core PEOLC services, with enough flexibility to allow for local circumstances. This would not only better equip ICBs to meet their statutory duty, but it would also enable greater accountability. At present, failure to define 'appropriate' provision of palliative care services allows ICBs to set their own parameters, which in turn restricts the ability to hold them to account for not delivering on their statutory duty.

5. What evidence do you have of whether the current government funding system for hospices is working? If not, what needs to change to make this system function better?

The evidence we have provided throughout this response demonstrates that the current funding model is not working, we have services relying on their reserves. Hospices are at the whim of individual ICBs and how they choose to distribute funding, without sufficient guidance or funding in place from the Government and NHS England to aid them in doing so.

In England, demand for palliative care is projected to **rise by 55% in the next ten years**.¹¹ Against a backdrop of rising demand, urgent change is needed to ensure that everybody receives the best possible care and support at the end of their lives.

In order to secure the future of palliative care provision, **the Government must deliver a new funding solution for hospices which recognises end-of-life care as a core component of our health and care system. Any new funding solution should ensure that the Government is responsible for covering the clinical costs of delivering care.** We estimate that this equates to 70% of total palliative care costs and that this is the minimum required to ensure the sustainability of the hospice sector. The alternative is likely to be hospice closures, resulting in the overstretched NHS having to provide end-of-life care services at an additional cost of **£484 million each year for the Government**, before accounting for inflationary costs and pay increases since 2021.¹²

Whilst any system would need to account for hospices that do not require or wish to have more funding, the system could also ensure that adequate surplus amounts from fundraising are invested into service improvement and back into populations and tackling inequality.

6. What are your relationships with your commissioners like, how have these changed, if at all, since the introduction of ICBs and the statutory requirement and do these relationships have any bearing on funding?

Sue Ryder has seven hospice services providing care across five ICS footprints. Our relationships with commissioners vary by ICB and are influenced by a number of factors, including: whether PEOLC is considered an ICB priority, the size of a commissioner's brief and restructures within the ICB.

¹¹ Sue Ryder (2021), Modelling demand and costs for palliative care services in England.

https://www.sueryder.org/sites/default/files/2021-03/Modelling_Demand_and_Costs_for_Palliative_Care_Services_in_England%20%281%29.pdf

¹² Ibid.



In our experience, relationships with commissioners have little bearing on funding. More often than not, there is simply no additional money at their disposal and individual commissioners lack the authority to make the systemic changes needed to the funding model or to deliver more innovative, joined up, services. The reality is that given the current pressures on the ICB/ICS for cost savings, it is very challenging to have discussions about part of the system that is underfunded, fragile and yet essential. In these challenging times, we are increasingly finding ourselves in a position where we need to find funding for parts of the NHS that no longer have it which is absolutely unsustainable. Therefore, whilst there is undeniable value to positive relationships with engaged commissioners, the impact on overcoming funding challenges is limited.

7. Does the new ICS structure create any barriers or opportunities to engaging with commissioners

We have tried to capitalise on the opportunities that new ICS structures have facilitated for commissioner engagement, for example hosting visits to our services to raise awareness of the value of PEO LC. However, the engagement opportunities and challenges differ by ICS.

In some locations, structures are still changing following the formal establishment of ICSs. This has made it difficult to identify individuals with PEO LC in their remit, inhibiting early engagement with the relevant commissioners.

There is also no consistency as to who has responsibility for PEO LC within an ICB. Not only has this added to the challenge of identifying stakeholders, but it directly impacts the quality of engagement. For example, one ICB in which Sue Ryder is based has a specific PEO LC commissioner who has worked very closely with us on remodelling services and sharing of funding opportunities. Concerningly, this role has now been adopted into a wider remit. In our experience, this level of engagement is not replicated in ICBs where PEO LC sits within a much wider remit. This has been the case for an ICB we operate within where the Head of Community Contracts holds responsibility for PEO LC.

Everybody dies, and commissioning decisions should reflect the fact that high-quality PEO LC is integral in aiding people with life-threatening illnesses to have the best quality of life possible and supporting them to have a good death. With that in mind, all ICBs must impress the importance of PEO LC delivery on their Directors of Commissioning. As part of this, we recommend that every ICS has a PEO LC Lead to ensure greater accountability for meeting their statutory duty to deliver appropriate PEO LC for their population.

Contact:

Sophie Meagher
Policy and Public Affairs Officer
sophie.meagher@sueryder.org