

# Labour National Policy Forum: Public services that work from the start

## Sue Ryder Response

### March 2023

#### About Sue Ryder

Sue Ryder supports people through the most difficult times of their lives. For almost 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. Or providing specialist care, rehabilitation or support to someone with a neurological condition.

We want to provide more care for more people when it really matters. We see a future where our palliative and neurological 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. How can Labour ensure our public health services prevent worsening population health, ensure pandemic preparedness, address widening health inequalities, and offer early intervention programmes that reduce pressure on our communities and other services (in conjunction with wider social policy)?**

#### Prevention of worsening population health

In 2020/21, hospices supported an estimated 300,000 people in the UK, including people at the end of life, families, carers and bereaved relatives.<sup>1</sup> The hospice sector is instrumental in relieving pressure on the NHS, yet statutory funding is much lower than the total expenditure needed to deliver the care. Hospices receive around a third of the funding required to deliver vital palliative and end-of-life care (PEoLC) services from the Government and are reliant on fundraising activities and voluntary donations to cover the remaining costs.

This funding model is completely unsustainable and if it remains unaddressed, poses a serious risk to the future of palliative and end-of-life care being delivered to patients. Budgets are stretched tighter every year, with real term reductions in funding hindering the hospice sector's ability to improve and extend care and meet more people's needs. The impact of the COVID-19 pandemic and cost-of-living increases on fundraising also means that charitable income is less able to plug the widening funding gap.

Sue Ryder projects that demand for palliative care will rise by 55% between 2021/22 and 2030/31.<sup>2</sup> Without adequate funding, the hospice sector will not be equipped to meet this rising level of need, which will in turn negatively impact population health. A Labour Government must work with Integrated

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<sup>1</sup> Nuffield Trust and Hospice UK (2022), Support at the end of life: The role of hospice services across the UK. <https://www.nuffieldtrust.org.uk/files/2022-06/hospice-services-web-1-.pdf>

<sup>2</sup> 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](https://www.sueryder.org/sites/default/files/2021-03/Modelling_Demand_and_Costs_for_Palliative_Care_Services_in_England%20%281%29.pdf)

Care Systems (ICs) and the hospice sector to ensure funding is set at a more sustainable level for charitable health providers and that commissioned services keep pace with rising costs.

**Recommendation: A Labour Government could help safeguard the future of the hospice sector through the introduction of a sustainable funding model, supporting hospices to provide high quality palliative and end-of-life care and bereavement support both now and in the future.**

Ultimately, prevention of worsening population health can only be achieved if there is a good understanding of population health needs across the system.

The health and care system is not currently set up to properly understand PEOLC population health needs. This is because monitoring (including demographic monitoring) is not suitably carried out, leading to limited information on gaps in provision and inequalities in access to care.

Furthermore, a recent King's Fund report on end-of-life care found that commissioners were not making full use of available data or national resources for assessing local needs.<sup>3</sup> 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.

**Recommendation: A Labour Government could improve understanding of population health needs by overseeing the development of a national core dataset which specifies the PEOLC data that ICs, services and providers must collect and report.**

This would enable better planning and commissioning of appropriate services, facilitate greater integration and support both providers and central bodies to compare data and better understand the national picture. A core data set would also make it easier to identify where ICs are not meeting their population health needs, facilitating greater accountability.

Diversity data should be central to the development of a national core data set, in order to provide a full picture of PEOLC population health needs. Collation of diversity data is currently inconsistent across different healthcare providers and it is not always done well. This must be addressed in order to tackle inequality and commission appropriate services.

In 2022 Sue Ryder collaborated with partners in the sector to explore the key opportunities and challenges for end-of-life care in the context of the national transition to ICs. The full paper, '[Enablers for end-of-life care](#)', includes further detail about population health needs and data, as well as wider recommendations on funding and commissioning, workforce, collaboration and health inequalities.

### **Addressing widening health inequalities**

Health inequalities within PEOLC are widely recognised and well-evidenced. A 2022 review published in the British Medical Journal found there are '*persistent inequalities in hospice care provision: patients without cancer, the oldest old, ethnic minorities and those living in rural or deprived areas are under-represented in hospice populations*'.<sup>4</sup> Additionally, a 2021 Hospice UK report stated that '*Inequalities of*

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<sup>3</sup> 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>

<sup>4</sup> Tobin J, Rogers A, Winterburn I, *et al* (2022). Hospice care access inequalities: a systematic review and narrative synthesis. *BMJ Supportive & Palliative Care*. <https://spcare.bmj.com/content/12/2/142>

*access and standards of care are particularly felt by those who have already encountered unfairness and discrimination throughout their lives’.*

Sue Ryder, alongside many others in the sector, have undertaken research and outreach to understand the access barriers and lower standards of care that some population groups experience for palliative and end-of-life-care and bereavement support. Many providers of services have also begun to take action to address inequalities. However, the 2023 King’s Fund report into end-of-life care found that whilst commissioners recognised the importance of addressing inequality in end-of-life care, none had started taking action to reduce it.<sup>5</sup> Overcoming health inequalities within PEOLC and bereavement support requires a better understanding of population health needs by community and Place and real action from ICSs.

In addition, a sustainable funding model for hospice services must enable innovation to meet more diverse needs, helping the sector tackle inequality both now and in the future.

**Recommendation: A Labour Government could help to tackle inequalities in PEOLC and bereavement support by:**

- **Mandating the ‘minimum’ assessment of population health needs that an ICS must undertake – with addressing inequality being a central purpose of this standard.**
- **Creating a mechanism for holding ICSs to account if they don’t act upon their population health insights and commission services that will help to reduce inequality.**
- **Introducing a sustainable funding model for the PEOLC and bereavement sector that encourages innovation to meet more diverse population needs.**

## **Workforce**

In order to support the longevity of the hospice sector and meet increasing demand for PEOLC, the workforce shortage must also be addressed.

A sustainable funding model will go some way towards achieving this. The current lack of statutory funding means that hospices struggle to keep pace with NHS pay, exacerbating recruitment and retention challenges. However, there are wider factors contributing to workforce shortages that must also be addressed. Without adequate staffing, the amount of care that hospices can provide will be limited, resulting in higher levels of unmet need as demand for PEOLC grows.

PEoLC providers are a vital part of the health and social care system. Decisions that are made about the NHS impact us. Charitable providers of health services must be considered as part of a whole system approach to health and social care workforce planning.

**Recommendation: A Labour Government could help to solve workforce shortages by planning for the workforce as a whole system across health and social care, including for charitable providers of essential services. Workforce plans must consider all parts of the system as equal players to prevent unintended consequences for vital services that sit outside the core NHS structure.**

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<sup>5</sup> 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>

## Awareness of and access to PEOLC and bereavement support

Research has found that public understanding of and awareness around palliative care is low.

An evidence review published in the British Medical Journal in 2021 found that more than half of patients did not have any information about palliative care or hospice care.<sup>6</sup> Patients had limited information about pastoral care, social care and bereavement care and patients' awareness about individuals or centres providing palliative care or hospice care was also limited.

A 2021 study on public knowledge, attitudes and perceptions towards palliative care found that there are a range of knowledge gaps and misconceptions.<sup>7</sup> It also found that a reluctance to have taboo conversations around death and dying may deter people from accessing integrated palliative care services earlier on.

Greater public awareness around what PEOLC is and when it can be accessed would support more people to get the right support at the right time. This would relieve pressure on the NHS, both in hospitals and in the community, where care can be delivered by specialist palliative teams.

Left unsupported, bereavement is associated with increased risks to health and wellbeing, including mortality, physical health problems, physical disability, medication usage and hospitalisation.<sup>8</sup> Widow(er)s<sup>9</sup> and children bereaved of a parent<sup>10</sup> are more likely to visit their GP. Pre-pandemic, these increased health costs and reduced tax revenues were estimated to cost the UK economy £23bn and HM Treasury nearly £8bn annually.<sup>11</sup>

Sue Ryder's research into bereavement support across the UK has revealed high levels of unmet need. Our report, 'A better route through grief', found that 70% of respondents who had experienced a close bereavement reported that they could not access the support they would have liked.<sup>12</sup> This was driven by low availability and awareness of services, with some areas lacking variety and provision of services. It was also caused by high barriers to access for some types of support, with certain demographics finding it harder to access support than others.

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<sup>6</sup> Masoud B, Imane B, Naire S (2021). Patient awareness of palliative care: systematic review. *BMJ Supportive & Palliative Care*. <https://spcare.bmj.com/content/early/2021/10/10/bmjspcare-2021-003072>

<sup>7</sup> McIlfratrick, S., Slater, P., Beck, E. et al (2021). Examining public knowledge, attitudes and perceptions towards palliative care: a mixed method sequential study. *BMC Palliat Care*. <https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-021-00730-5>

<sup>8</sup> Stroebe, M.S., Schut, H., and Stroebe, W (2007) Health outcomes of bereavement. *Lancet*, 370, 1960-73. <http://www.comsegovia.com/paliativos/pdf/Health%20outcomes%20of%20bereavement.pdf>

<sup>9</sup> Stroebe et al (2007) *ibid*

<sup>10</sup> Lloyd-Williams, M and Wilkinson, C and Lloyd-Williams, F (1998) Do bereaved children consult the primary health care team more frequently? *European Journal of Cancer Care* 7, 120-124

<sup>11</sup> Sue Ryder (2020), Sue Ryder literature review. [https://www.sueryder.org/news/sue-ryder-calls-for-statutory-paid-bereavement-leave#:~:text=Grief%20experienced%20by%20employees%20who,research%20commissioned%20by%20Sue%20Ryder\\*](https://www.sueryder.org/news/sue-ryder-calls-for-statutory-paid-bereavement-leave#:~:text=Grief%20experienced%20by%20employees%20who,research%20commissioned%20by%20Sue%20Ryder*)

<sup>12</sup> 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>

**Recommendation: A Labour Government could help people to get the right support at the right time by:**

- **Improving public awareness and education around palliative and end-of-life care.**
- **Committing to the introduction of a bereavement pathway which accounts for individual need, facilitates equitable access to support and ensures people who are grieving access the intervention they need at the right stage.**

**2. What are the specific implications of policy proposals in this area for (a) women, (b) Black, Asian and minority ethnic people (c) LGBT+ people, (d) disabled people and (e) all those with other protected characteristics under the Equality Act 2010?**

Everybody should be able to access the PEoLC and bereavement support they need. However, as we have already highlighted within this response, some population groups face greater access barriers and experience lower standards of care and support.

Sue Ryder has been undertaking work to address inequalities in PEoLC and bereavement support at both a local and a national level. Locally, we have invested in a project in one of our service areas to understand the PEoLC needs of different communities, which is due to report soon. Nationally, we are working with sector partners and the Department of Health and Social Care (DHSC) to tackle inequality and support the commissioning of appropriate services for the groups outlined above.

However, progress in this area will be limited unless fundamental changes are introduced within the health and care system to better understand population health needs and ICSs are equipped to take action to address inequalities. To achieve this, sufficient funding must be made available to allow PEoLC and bereavement support services to respond to the needs of diverse communities and ICSs must be held to account for reducing inequalities.

This submission gives a high-level overview of our views. We would welcome the opportunity to discuss any of the contents in our response in more detail, including: our outlined positions, our underpinning evidence, and additional evidence in the pipeline. We can also arrange briefings where helpful. We look forward to supporting the Labour Party's policy development in the areas raised in this submission.

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