

Written evidence submitted by Cicely Saunders International (ADY0357)

Cicely Saunders International was established by Dr Dame Cicely Saunders in 2002. We fund palliative care research, education, training and information support for patients, families and healthcare professionals. We want to ensure that everyone has access to good palliative care - in hospitals, in hospices, in care homes and at home in the community.

In collaboration with academic partners at King's College London and NHS Trusts, we established the UK's first purpose-built institute of palliative care and rehabilitation (Cicely Saunders Institute, King's College London). We fund research to develop capacity in palliative care, treat difficult symptoms such as breathlessness, empower patients and families, and promote palliative care for older people, who are often marginalised and disadvantaged in being able to access the benefits of palliative care, and we identify and promote best practice in palliative care. In 2021 we published [*You Matter Because You Are You a seven-point Palliative Care Action Plan*](#) that identifies the major challenges now facing the palliative care system, and outlines evidence-based solutions for each of them.

Please see below our responses to questions 1) and 8) from the APPG Call for Evidence.

1) To what extent do people in England and Wales have access to good palliative care? a) How can palliative care be improved, and b) would such improvements negate some of the arguments for assisted dying/assisted suicide?

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 the family. Palliative care is provided by a specially-trained team of doctors, nurses and other specialists who work together with a patient's other doctors to provide an extra layer of support. Palliative care is based on the needs of the patient, not on the patient's prognosis. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.

Putting the person before their disease, palliative care addresses what is known as 'total pain', a concept developed by Dame Cicely Saunders, which includes not only physical pain, but also other symptoms and conditions, which might be psychological, social or spiritual. It is evidence-based, and improves not only patients' experience of their care, but also the experiences of their families and loved ones.

In addition, palliative care contributes towards the cost-effective functioning of the health and social care system, enabling greater patient choice where it is available. As the COVID-19 pandemic has demonstrated clearly, such support is needed in all places where people are cared for - at home, in the community, in hospital, in hospices or in care homes.

Patient surveys indicate that most of us – around 80% – would prefer to die at home or our place of residence, but in some parts of England and Wales, fewer than 50% do so because the necessary services are not there to support them. Without expanding the resources and capacity to provide

palliative care in all settings – whether home, community, hospital, hospice or care home – we will remain unable to meet the choices of patients and their families.

a) How can palliative care be improved?

Restrictions on patient choice at the end of life revolve around adequate services to support people, control symptoms and ensure they do not feel a burden on family or society, and coordination and information sharing between health and social care providers. Being unable to share information and coordinate care quickly enough in what is frequently an urgent situation can restrict patients' choices and impact their care.

The following are therefore necessary to ensure proper provision of palliative care:

- 1) Provide palliative care expertise in places where people are cared for: hospitals, care homes, hospices and at home with 24/7 access to specialist palliative care healthcare professionals to control symptoms and support families
- 2) Make joined up care a reality by making coordination and information sharing a reality between health and social care providers
- 3) Empower patients and carers to have greater choice and control over the things that are important to them such as how and where they are cared for
- 4) Invest in community care services, including out of working hours
- 5) Provide healthcare professionals and carers with high-quality palliative care training
- 6) Use outcome measures to embed a system of continuous learning and improvement to measure and ensure the effectiveness and safety of patient care
- 7) Invest in research to discover better treatments, therapies and self-management of symptoms. For example, there is no medicinal product licensed in the UK for the symptomatic management of severe breathlessness in advanced disease (which affects 2 million people in the UK) and new therapies are urgently needed, but research to discover and test these is lacking.

Palliative care teams and hospices make up a very small part of the healthcare system. In the UK, there are only approximately 3,000 hospice or palliative care beds, yet around 70-80% of the more than 500,000 people who die every year do so after a period of decline and deterioration requiring palliative care, and this is due to increase by 40% by 2040. The Research has found that terminally ill people are struggling to access essential care at home during evenings and weekends.

There is a lack of investment in research in palliative care, and it is often not well understood. For example less than 0.5% of all research spending (from charities and government) in the UK is allocated to palliative and end of life care. Contrast this with the fact that 20% of health care costs are generated in the last year of life, and almost all doctors, nurses and allied health professionals are involved in care for people with serious and advanced illness.

There is also a major lack of workforce capacity. There are more professors of oncology working in the Royal Marsden Hospital than professors in palliative care working across the world. Further, the World Health Organization reports that the majority of health professionals worldwide have little or no knowledge of the principles and practices of palliative care. There are few opportunities for doctors and other clinicians to train in palliative care. It is a specialty within medicine, but there are few academic clinical opportunities, including for research, to develop much-needed capacity for the future, and take care forward.

Research funded by Cicely Saunders International indicates that being able to offer meaningful patient choice requires healthcare services that are designed to facilitate planning for an uncertain future, particularly in conditions with an unpredictable prognosis such as multiple sclerosis, dementia or organ failure. The researchers concluded there needs to be a whole system strategic approach. They highlight the need for health professionals to be skilled and trained in engaging with discussions with patients. They also highlight the need for information to be shared in real-time across services.

Research into older people's preferences for services and support concluded that older people living with a life-limiting illness want their care to focus on quality of life, easy access to services, and sufficient support for relatives.

Some key aspects of successful and cost-effective care were:

- **Patient engagement:** patients are well-informed and participate in decisions about their care
- **Goals of care:** healthcare professionals help patients develop their own goals, so that patients actively visualise these goals and participate in their own care
- **Workforce capacity:** skilled multidisciplinary teams available with sufficient resources (skills, training and team capacity) to meet patients' individual needs.

The researchers demonstrated that a focus on these areas prevents functional decline and improves quality of life for people with advanced disease, irrespective of prognosis. The findings also help service providers understand what quality of life oriented care looks like, and how important, and often low-cost, changes to care are effective.

[b\) would such improvements negate some of the arguments for assisted dying/assisted suicide?](#)

In 2022 an article appeared in the BMJ reporting on an analysis of data from the Office for National Statistics (ONS) about suicide and assisted suicide.

In the ONS analysis patients with newly diagnosed physical health conditions (predominantly heart disease and chronic obstructive pulmonary disease) were matched with control patients to examine the risk of suicide after diagnosis of physical illness. Matching accounted for various sociodemographic characteristics (age, gender, and so on) but notably did not account for mental illness or depression. There is a well-described association between physical and mental illness, so the higher risk of suicide after diagnosis of physical illness might represent a higher prevalence of mental illness in this group.

The article in the BMJ quoted assisted dying campaigners, who argue that the ONS analysis provides evidence to support legalisation of assisted dying. However the ONS analysis only shows that after diagnosis of some physical illnesses, the risk of suicide is higher. It provides evidence neither for nor against law change. The priority must be to understand why there is a higher risk of suicide after diagnosis of physical illness and how to reduce this.

The ONS analysis was covered extensively in the media as part of a Dignity in Dying campaign that described the cohort as “dying.” This is misleading. Overall, 72% of the cohort survived for more than two years (after which no data are provided).

It is concerning to see the ONS analysis used to support a campaign to legalise assisted suicide, rather than to call for better mental healthcare and support for people with physical illnesses particularly as research shows that providing palliative care to people improves both physical and mental health symptoms and leads to a reduction in suicidal ideation.

There is also a reliance on the notion of advance care planning. However research supported by Cicely Saunders International, conducted during the Covid pandemic, found that the pandemic exacerbated already-existing challenges to conducting high-quality, individualised advance care planning. This included the ability to maintain a personalised approach, and sharing information between services. Decision-making is complex, and it is more difficult to ensure it is done properly when there are workload pressures. There is an urgent need to ensure advance care planning is properly resourced to ensure it is individualised to incorporate the values, priorities, and ethnic/cultural/religious context of each person.

8) What should the Government’s role be in relation to the debate?

In summary access to good palliative care for people in England and Wales is highly variable and many groups are disadvantaged in trying to access palliative care. The [POST note on Palliative and End of Life Care](#) summarises key components of palliative and end of life care and recent changes in UK policy, including the recent Health and Care Act (2022). The POST note stated that an estimated 100,000 people in the UK that could benefit from palliative care die without receiving it each year. It highlighted that access to palliative and end of life care improves quality of life for patient and family, and reduces symptom burden. The Act places a duty on Integrated Care Boards (ICBs) to commission services or facilities for palliative care. The POST note presents evidence of inequalities in accessible provision on palliative and end of life care, and the impact of Covid-19. In conclusion providing access to palliative care across the health system in a joined up way to every patient that needs it, and supporting research to improve symptom treatments and care, should be the Government’s most urgent priorities, rather than devoting time and resources to debating a change in the law.

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