

**Written evidence submitted by Dr Lesley Williamson and Professor Katherine Sleeman, on behalf of the Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation, King's College London (ADY0402)**

The [Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation](#), King's College London, is a world-leading palliative care institute, integrating research, education, and clinical care. It is one of a handful of centres across the world dedicated to delivering high quality palliative and end of life care research and has informed palliative care policy and practice in the UK and globally.

With clinical and academic expertise in palliative care, we would like to offer evidence that may facilitate the Committee's inquiry. The evidence included in this submission responds primarily to question one regarding palliative care. We provide evidence to the other questions where it is relevant to palliative care. We have drawn on evidence from the Cicely Saunders Institute, as well as from other researchers in the UK and elsewhere.

### **1.1 To what extent do people in England and Wales have access to good palliative care?**

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Palliative care can improve symptom burden and quality of life for people affected by serious illness.<sup>1, 2</sup> It can enhance their experiences of security,<sup>3</sup> increase the likelihood of dying at home,<sup>4</sup> and reduce hospitalisation towards the end of life.<sup>5-7</sup> Importantly, palliative care can be provided at the same or lower overall cost.<sup>8, 9</sup> In England and Wales, around three quarters of people who die would benefit from palliative care.<sup>10</sup> Population ageing means that 160,000 more people are expected to need palliative care by 2040, up to a 43% increase compared to 2020.<sup>11</sup>

- 1.1.1 Out of hours services to support people in their own homes are variable and fragmented across the UK.<sup>12</sup> Only 1 in 4 UK areas provides access to designated palliative care phone lines, even though this has been a NICE recommendation since 2011.<sup>12</sup>
- 1.1.2 The further away a patient lives from a hospice, the less likely they are to die in a hospice. This effect is greater in rural than urban areas.<sup>13</sup> The dose-response association is also observed in different regions of England.<sup>14</sup>
- 1.1.3 Provision of end-of-life care can be challenging in care homes due to uncertain illness trajectories,<sup>15, 16</sup> variable access to external support,<sup>15, 16</sup> and unaddressed educational and emotional needs.<sup>17</sup> During the Covid-19 pandemic, care home staff reported making high stakes decisions in isolation, with variable support from health professionals or coherent guidance.<sup>18</sup> The NIHR funded CovPall Care Homes study generated ten policy recommendations for palliative and end of life care in care homes.<sup>19</sup>
- 1.1.4 There are known inequalities in access to palliative care services across a range of patient characteristics,<sup>20, 21</sup> including:
  - Age: Older people are referred to hospice care later than younger people,<sup>22</sup> and less likely to receive palliative care,<sup>20</sup> including those with multimorbidity despite having similar symptoms as other patient cohorts.<sup>23</sup>
  - Ethnicity: People from minoritised ethnic groups are less likely to receive early palliative care within hospital,<sup>24</sup> care in hospices,<sup>21, 25</sup> or home care,<sup>25</sup> and encounter barriers to

accessing bereavement care.<sup>26</sup> Policies introduced during the Covid-19 pandemic may have had a disproportionate negative impact on patients from minoritised ethnic groups, resulting in inequitable care at the end of life.<sup>25</sup>

- Socioeconomic position: Low socioeconomic position (for example living in a deprived area, having low education) is a risk factor for hospital death and other indicators of poor quality end-of-life care, with evidence of a dose-response relationship indicating inequality persists across the social stratum.<sup>27</sup> During the Covid-19 pandemic, socioeconomic inequalities in palliative and end of life care grew.<sup>28</sup>
- LGBTQ+: People from LGBTQ+ communities experience active and anticipated discrimination in healthcare, disproportionately worse health outcomes, and a higher incidence of serious illness compared to cisgender heterosexual persons.<sup>29</sup> Many experiences are characterised by concern associated with a pervasive culture of discrimination and stigma, the heteronormative and cisnormative assumptions of health workers, social isolation, and concerns about confronting an undignified death.<sup>30</sup>
- Diagnosis: People with serious illness other than cancer are particularly likely to encounter barriers to accessing palliative care,<sup>21</sup> and experience emergency hospital use towards the end of life.<sup>6</sup> Patients with conditions other than cancer have reduced access to palliative care facilities compared to those with cancer,<sup>31</sup> even though symptom burden can be similar.<sup>32</sup> More than 90% of people who die in hospices have cancer<sup>33</sup> (even though cancer accounts for only 25% of all deaths<sup>34</sup>).

## **1.2 How can palliative care be improved?**

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The Cicely Saunders International Palliative Care Action Plan identifies the major challenges facing the palliative care system, and outlines evidence-based solutions.<sup>35</sup> It identifies seven areas for improvement and outlines 24 achievable actions to improve the care, increase the efficiency, and future-proof the palliative care system against accelerated demand.<sup>35</sup> Additional evidence is presented here, complementing the seven areas of improvement.

### **1.2.1 Provide palliative care expertise in places where people are cared for: hospitals, care homes, hospices and at home**

- To correspond with current trends, palliative and end-of-life care provision in care homes and the community needs to double by 2040, when care homes are likely to become the most common place of death.<sup>36</sup> The Better End of Life Report 2021 highlighted the importance of community services including palliative care teams and primary care teams in delivery of high quality palliative and end of life care during the Covid-19 pandemic.<sup>37</sup> Policy priorities identified include support and recognition of care homes, family members and carers, and primary care services as providers of palliative and end-of-life care.<sup>37</sup>
- Adequate funding is a priority to ensure accessibility of palliative care. A review of funding models across the world, including England, found that funding is seldom linked to population need, perpetuating existing inequities. Furthermore, palliative care

funding often comprises a mix of charitable, public, and private payers, which, in practice, can cause uncertainty around responsibility and sustainability.<sup>38</sup> Therefore, to enable an economically viable and equitable allocation of resources, palliative care must be based on patient need rather than diagnosis or prognosis.

#### 1.2.2 Make joined up care a reality

- Integrated care (including primary care, community nurses, palliative care) is an essential part of ensuring high quality palliative care in care homes;<sup>39</sup> collaboration across disciplinary boundaries is important for older people with advanced disease.<sup>40</sup> Investment and greater integration of hospice and palliative care services within the wider system will facilitate organisational resilience and continue to drive cost-effective innovations.<sup>41</sup>
- To make integrated care a reality, palliative care requires greater prioritisation in national and local policy. A documentary analysis of national UK health and care policy documents shows that palliative care is rarely prioritised, even though it can achieve stated policy goals of integrated care for people with advanced illness.<sup>42</sup> Documentary analysis of Integrated Care System strategies, found only a quarter framed palliative and end-of-life care as a priority; few mentioned the need for equal access to care and outcomes at the end of life, or how strategies would lead to better patient outcomes.<sup>43</sup>

#### 1.2.3 Empower patients and carers to have greater choice and control over the things that are important to them

- Advance care planning can increase use of hospice and palliative care and prevent hospitalisation, and may increase compliance with patients' end-of-life wishes and satisfaction with care.<sup>44</sup> End-of-life conversations have also been associated with reduced healthcare costs, with better quality of death.<sup>45</sup> However, advance care planning is complex, must be individualised and cannot be a tick-box exercise.<sup>46</sup>
- It is essential to note that the preferences of older adults with illness are frequently influenced by their desire to remain independent and 'get back to normal' or to seek a new normal.<sup>47</sup> Clinicians must have the resource and capacity to identify and work towards an achievable 'normal' with patients and families and improve quality of life.

#### 1.2.4 Invest in community care services

- Costs of end-of-life care increase with proximity to death, with hospital inpatient care accounting for over 60% of total costs.<sup>48</sup> While palliative care input during hospital admissions can help reduce costs,<sup>49</sup> community palliative care input has also been associated with reduced acute care costs over the last year of life.<sup>50</sup>
- New models of community palliative care are clinically effective and cost effective in supporting people who may otherwise face barriers in accessing palliative care, for example:
  - The Optimising PalliaTive care for Older People (OPTcare Elderly) trial comprised short-term integrated palliative care for frail older people living. Symptom distress

reduced, with decreased costs from the intervention compared with usual care. Psychosocial support to reduce anxiety and maintain independence were valued.<sup>51</sup>

- A randomised trial of a breathlessness support service for adults with refractory breathlessness and advanced disease, which involved a short-term, single point of access service of early integrated palliative care. Findings showed improved breathlessness mastery with early integrated palliative care compared to usual care, and improved six-month survival for patients with severe illness other than cancer.<sup>52</sup>
- Community palliative care out-of-hours is currently inadequate and fragmented; consequently, people may have no option but to attend the emergency department. In a Delphi study, the most important components of out-of-hours care as rated by people with advanced illness and their carers are: 1) hands-on visits from district and community nurses, 2) prescription, delivery, and administration of medicines, and 3) shared electronic patient records and advance care plans.<sup>53</sup>

#### 1.2.5 Provide healthcare professionals and carers with high-quality palliative care training

- Primary care professionals and care home workers are key providers of palliative and end-of-life care. Therefore, high-quality palliative care training among healthcare professionals is required to ensure patients' needs are met, and appropriate referrals to specialist palliative care are made. GPs report that their exposure to training is inadequate and inconsistent, that end of life care is complex, and their confidence in end-of-life care is low.<sup>54</sup>
- Specialist palliative care teams provide indirect care to large numbers of patients through training non-specialist staff. For example, King's College Hospital NHS Trust palliative care team developed clinical guidelines for the care of people with Covid-19 and delivered 'bite-sized' teaching to over 500 nurses and junior doctors over a 6-week period during March-April 2020. This was valuable for staff who had been redeployed with little training or experience in care of dying patients. Providing all health care professionals with clear, accessible clinical guidance supported by face-to-face teaching is essential.<sup>55</sup>
- A national survey on the assessment and management of common end-of-life symptoms found variation in prescribing practice, training gaps and poor access to psychological and psychiatric services in the UK. This study highlights the need for improved training and evidence-based national guidance to support clinical decision-making and service development.<sup>56</sup>

#### 1.2.6 Use outcome measures to embed a system of continuous learning and improvement

- Use of patient-centred outcome measures (PCOMs) improves awareness of unmet need and allows professionals to act to address patients' needs. It consequently benefits patients' physical, emotional and psychological quality of life.<sup>57</sup>
- The Palliative care Outcome Scale (POS), Integrated Palliative care Outcome Scale (IPOS) and disease-specific versions are used worldwide and have been shown to help screen

for and manage common symptoms in advanced illness,<sup>58, 59</sup> assess quality of life,<sup>60</sup> audit practice,<sup>61</sup> and facilitate training and research.<sup>62</sup> Despite these benefits, outcome measures are used inconsistently in routine palliative care. This is due to service and systemic barriers, including limited knowledge, lack of suitable technology and inconsistent national drivers to encourage use of outcome measures.<sup>63-65</sup>

#### 1.2.7 Fund world-leading research into palliative care

- The focus on disease-directed care in the last weeks of life are often futile and can compromise the patient's quality of life. Therefore, substantial investment in research into palliative and end-of-life care must be prioritised, redirecting efforts from disease-directed care to palliative care to ensure symptom relief and to meet patient choice at the end of life.<sup>66</sup> This must include investment in routine data collection on receipt of palliative care to understand how many people receive palliative care or the level of need in different patient groups.

### **1.3 Would improvements in palliative care negate some of the arguments for assisted dying/assisted suicide?**

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Given the complexity of serious illness, approaches to alleviate suffering must not be reduced to a binary choice between palliative care and assisted dying / assisted suicide (AD/AS). Improving equitable access to high-quality palliative care is urgently needed, irrespective of any move towards legalisation of AD/AS. This cannot be considered in isolation of broader health and social contributors to suffering among people with advanced illness.

- 1.3.1 The needs of people affected by serious illness are diverse and complex. In conceptualising this complexity, research suggests a need to consider pre-existing and cumulative complexity, the dynamic aspects of complexity, invisible complexity, service-/ system-level factors and societal influences to consider and meet patients' needs effectively.<sup>67</sup> In addition, family have important influences over shaping the care preferences of older people with illness.<sup>68</sup>
- 1.3.2 The experience of serious illnesses and approaching the end-of-life can be complicated by external factors, which cannot be managed by palliative care alone. Evidence from Canada indicates that assessors for Medical Assistance in Dying (MAiD) infrequently encountered patients choosing MAiD due to unmet need, but many encountered situations in which their patients' suffering had been made worse due to social determinants of health.<sup>69</sup>
- 1.3.3 Secondary analysis of interviews with patients with a range of serious illness shows that uncertainty is a central feature of the illness experience and affects patients' information needs, preferences, and future priorities for care. Complexity and unpredictability of illness were a major part of the uncertainty experience.<sup>70</sup> Better understanding and communication around uncertainty in the clinical setting is needed to better meet and address needs, help to engage and empower patients, and facilitate patient-centred care.<sup>70, 71</sup>

- 1.3.4 Issues of complexity and uncertainty extend to advance care planning. End-of-life care preferences can change over time.<sup>72</sup> In a study with older adults with terminal cancer, findings showed that the will to live fluctuated towards the end of life, influenced by distressing symptoms.<sup>73</sup> A study carried out in South London found that most patients expressing a desire for hastened death experience a reduction in this following palliative care.<sup>74</sup>

## **2 What can be learnt from the evidence in countries where assisted dying / assisted suicide is legal?**

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In this section we wish to highlight two pieces of evidence relating to palliative care.

- 2.1 In Canada, it has been found that palliative care resources were disproportionately consumed by MAiD requests, while non-MAiD patients had reduced access to palliative care. Research must prioritise how AD/AS legislation might indirectly affect care for people nearing end-of-life, with strategies to mitigate adverse impacts.<sup>75</sup>
- 2.2 Data collected and routinely reported in jurisdictions where AD/AS is legal is varied and information on potential harms or complications of assisted dying is incomplete. These data mostly come from simple retrospective reports completed by the doctor who supplied the lethal prescription, without independent verification or prospective data collection. Only around half of official reports document whether patients were enrolled in hospice or palliative care services. Where this information is reported, there is no indication of duration or scope of involvement.<sup>76</sup>

## **4 What, if any, are the physical and mental health criteria which would make an individual eligible to access assisted dying / assisted suicide services?**

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In this section we would like to highlight some of the evidence around prognostication.

- 4.1 In the Oregon model of AD/AS, which is followed in several states of America and elsewhere, eligibility includes a prognosis of six months or less.<sup>77</sup> However, prognostication is not exact.<sup>78</sup> Therefore, eligibility for AD/AS based on proximity to death may be impractical. It also carries risk of discrimination against people who have terminal illness that are more chronically progressive, such as neurological illness.<sup>79</sup> We note that in jurisdictions that have legalised AD/AS, arguments have been made that safeguards are discriminatory.<sup>80</sup>
- 4.2 Prognosis is often difficult to estimate, particularly for conditions with more unpredictable trajectories, such as chronic respiratory disease, organ failure, neurodegenerative disease, or frailty. Poor prognostication can impede timely end-of-life care discussions and referral to palliative care,<sup>81</sup> and hospice use.<sup>21</sup> The 'surprise question', a prognostic tool to help identify people with palliative care needs, is found to be of variable accuracy.<sup>82</sup>



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