

## 8) Is palliative care enough for every single case?

### 8.1 Definitions of palliative care and end of life

A general definition of palliative care is care and support received at any stage, from beginning to end of life, during a chronic or serious illness. It includes - but by definition is not limited to - end-of-life care. It can start from the point of diagnosis, and is specialised medical care that focuses on providing relief from pain and other symptoms. The World Health Organisation definition from 2002 is:

“an approach that improves quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention of suffering by early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.”<sup>1</sup>

Section 257 of the Westminster Impact Assessment for AD<sup>2</sup> defines palliative care as:

The care needed is often divided into two categories:

257.1. ‘specialist care’ delivered by professionals specifically trained in palliative and end-of-life care to support someone with complex symptom management in any setting.

257.2. ‘non-specialist or universal care’, delivered by health and social care professionals in any setting by, for example, district nurses or social carers, in primary care settings by GPs, and in secondary care settings by hospital staff.

The Leadership Alliance for the Care of Dying, a coalition of 21 national medical, palliative care and charitable organisations define ‘end of life’ as:

“Patients are ‘approaching the end of life’ when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with:

- (a) advanced, progressive, incurable conditions
- (b) general frailty and co-existing conditions that mean they are expected to die within 12 months

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<sup>1</sup> Ashby, Michael (2016) *How We Die: A View from Palliative Care*. QUT Law Review Vol 16, Issue 1: p6. <https://lr.law.qut.edu.au/article/view/619/581>

<sup>2</sup> Impact Assessment: Terminally Ill Adults (End of Life) Bill (as amended in the House of Commons Public Bill Committee) **IA No:** DHSCIA9682 <https://publications.parliament.uk/pa/bills/cbill/59-01/0212/TIABImpactAssessment.pdf>

- (c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- (d) life-threatening acute conditions caused by sudden catastrophic events.”<sup>3</sup>

## **8.2 Positions held on AD within palliative care representative organisations**

Representative bodies for palliative care focus on respecting the views and wishes of the suffering individual, but AD remains contentious within a number of palliative care representative organisations. In general, palliative care organisations maintain a ‘no decision about me without me’ approach, one key exception being where a suffering patient requests an assisted death. They maintain that respect for individual autonomy cannot be an absolute value. A request for an assisted death can be viewed as a ‘despairing cry’ that can be argued to invalidate the legitimacy of the request and implying that counselling and drugs, when provided will suffice.

A common position remains that current palliative provision is sufficient. However it can be observed that the current anti-assisted dying orthodoxy is becoming increasingly vigorously debated and challenged within the palliative care community. The most positive supporters of assisted dying are unsurprisingly national palliative systems that have adopted assisted dying as a choice for their patients, and who arguably have been best able to test and allay the perennial concerns often expressed by opponents.

## **8.3 Current positions on AD of palliative care representative organisations**

*External to the UK*

### **8.3.1 The International Association for Hospice and Palliative Care**

A 2022 IAHPC Assisted Dying Practices and Euthanasia Survey<sup>4</sup> of members found:

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<sup>3</sup> [https://assets.publishing.service.gov.uk/media/5a7e301ced915d74e33f09ee/One\\_chance\\_to\\_get\\_it\\_right.pdf](https://assets.publishing.service.gov.uk/media/5a7e301ced915d74e33f09ee/One_chance_to_get_it_right.pdf)

<sup>4</sup> IAHPC Assisted Dying Practices and Euthanasia Survey. 2022. <https://iahpc.org/resources/publications/special-issues/assisted-dying-practices/methodology-and-key-findings/>

- 49% support the availability of physician-assisted suicide. Of these, 56% think that it should be available only for specific situations (exceptional cases), with narrowly defined safety criteria.
- 47.5% support the availability of euthanasia. Of these, 55% think that it should be available only for specific situations (exceptional cases), with narrowly defined safety criteria.
- 45% stated that assisted dying or euthanasia should not be available at all.
- 5.7% and 7.6% were not sure about legalizing assisted dying or euthanasia, respectively.

**8.3.2 The European Association for Palliative Care (EAPC)** in their paper Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force<sup>5</sup>, in 2003 argued that

“None of the following should be seen as euthanasia within the definitions used here: withholding futile treatment; withdrawing futile treatment; ‘terminal sedation’ (the use of sedative medication to relieve intolerable suffering in the last days of life).”

The most recent white paper<sup>6</sup> in 2016 recognises that there is a case to be made, and certainly a debate to be had, about assisted dying, whilst continuing for now with the status quo. They acknowledge that

“complete consensus seems to be unachievable”.

They acknowledge that a number of member states have introduced assisted dying support.

Finally the EAPC details the process of ‘*palliative sedation*’, which the EAPC sees as

“acceptable, ethical practice”<sup>7</sup>,

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<sup>5</sup> Palliative Medicine 2003; 17: 97 /101 Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force Lars Johan Materstvedt, David Clark, John Ellershaw, Reidun Førde, Anne-Marie Boeck Gravgaard, H Christof Muller-Busch, Josep Porta i Sales and Charles-Henri Rapin <https://eapcnet.eu/eapc-publications/>

<sup>6</sup> EAPC (2016) Euthanasia and physician-assisted suicide - *A white paper from the European Association for Palliative Care*. [https://hospicecare.com/uploads/2019/3/Euthanasia\\_and\\_physician-assisted\\_suicide- A white paper from the European Association for Palliative Care.pdf](https://hospicecare.com/uploads/2019/3/Euthanasia_and_physician-assisted_suicide- A white paper from the European Association for Palliative Care.pdf) or <https://view.pagetiger.com/ceniuje/1>

<sup>7</sup> ibid

although the white paper notes that this had been the focus of much debate and also did not achieve consensus.

The white paper makes limited acknowledgement of the synergistic effect found in Belgium between existing palliative care and the introduction of assisted dying procedures as an additional choice for patients. It describes “integrative palliative care”<sup>8</sup> and the “growing involvement of palliative care professionals and teams in what they call ‘the accompaniment of euthanasia”<sup>9</sup>. The white paper notes that

“it is recognized that within Europe several approaches to euthanasia and physician assisted suicide (PAS) are emerging, and open and respectful debate surrounding this is to be encouraged.....The EAPC encourages its members to engage in direct and open dialogue with those who promote the legalization of euthanasia and PAS.”<sup>10</sup>

#### *Internal to the UK*

<https://www.palliativecarescotland.org.uk/news/news/sppc-submissions-to-parliament-on-the-assisted-dying-bill/>

<https://www.mariecurie.org.uk/document/assisted-dying-scotland-stage-one-responses-for-publication-2024>

<https://www.palliativecarescotland.org.uk/content/publications/SPPC-Response-to-Proposals-for-an-Assisted-Dying-Bill.pdf>

**8.3.3 The Association of Palliative Care Social Workers** in their November 2024 Statement on Assisted Dying<sup>11</sup> take no position on AD, but summarise key arguments for and against and detail a range of recommendations should the legislation pass.

**8.3.4 The Association for Palliative Medicine (of Great Britain and Ireland (APM))**: a 2022 APM Scotland survey noted that “75% of Scottish APM members responding would not be willing to participate in any part of

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<sup>8</sup> ibid

<sup>9</sup> ibid

<sup>10</sup> ibid

<sup>11</sup> Association of Palliative Care Social Workers. Statement on Assisted Dying, November 2024. <https://apcsw.org.uk/wp-content/uploads/sp-client-document-manager/7/apcsw-full-statement-on-assisted-dying-november-20241.pdf>

the assisted dying process and 98% stated that assisted dying should not be part of mainstream healthcare.”<sup>12</sup>

### **8.3.5 Hospice UK** strike a neutral tone of “no collective view”, stating:

“We believe that the assisted dying discussions must include how we can make good palliative care available and accessible to everyone, whoever they are and wherever they live.”<sup>13</sup>

### **8.3.6 The Scottish Partnership for Palliative Care**

In the Scottish Partnership for Palliative Care (SPPC) Response<sup>14</sup> to Proposals for an Assisted Dying for Terminally Ill Adults (Scotland) Bill, the organisation stated:

“Assisted dying raises issues of a moral, personal and ethical nature upon which many of SPPC’s member organisations (for example our member NHS Boards and some charities) are institutionally unable to hold a position. SPPC therefore does not adopt a position in principle either in support or in opposition to a change in the law.

Instead, SPPC’s approach is:-

- To take a factual and evidential approach rather than a moral or religious one
- To educate and inform about palliative and end of life care
- To challenge misinformation about palliative and end of life care
- To acknowledge and give an account of complexities which tend to get lost in polarised debates
- To be honest about the limits of palliative care to relieve all suffering
- To be honest about the current deficiencies in care towards the end of life experienced by some people”

The Partnership also noted that:

“Most symptoms towards the end of life can be effectively managed most of the time.”

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<sup>12</sup> <https://apmonline.org/wp-content/uploads/APM-Position-Statement-on-Assisted-Dying-October-2024-v2.pdf> 22/04/25

<sup>13</sup> <https://www.hospiceuk.org/assisted-dying> 22/04/25

<sup>14</sup> <https://www.palliativecarescotland.org.uk/content/publications/SPPC-Response-to-Proposals-for-an-Assisted-Dying-Bill.pdf>

They argue for better resources and resource management in Scotland. In relation to the practicalities of AD they express concerns over evaluation of capacity, slippery slope, coercion, level of knowledge of medical staff evaluating each request and to intervene if problems arise with ingestion of the lethal dosage, and staff welfare.

## 8.4 Responses to other palliative concerns

In addition to the common concerns (slippery slope, coercion of the vulnerable etc) expressed by opponents of AD, further concerns have been raised by representatives within the palliative care community and in relation to palliative care. For example, Mortier et al<sup>15</sup>, while describing the introduction of AD as “a dangerous experiment” claim that their analysis of assisted death’s in Belgium indicated that a significant percentage of patients receiving euthanasia did not see a palliative care specialist or a palliative care team or a psychiatrist. Their research does not detail in how many of these cases such support was available but refused, and in how many cases further treatment had been recognised as futile. In Scotland palliative care is available when needed and the Holyrood proposals include a review by a medical experts.

Hudson et al<sup>16</sup> raise a number of additional palliative concerns that can be briefly examined:

8.4.1 Where AD is legal, patients may fear the use of opioids is part of an unwanted and unmentioned AD process.

It is common practice in Scotland for skilled medical staff, and especially those involved in palliation, wherever possible to address any concerns and provide full and clear explanations and reassurances about any proposed treatment.

8.4.2 An over-medicalised death may remove the personal element, denying the patient a “broader spiritual, psychological, and social focus”.

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<sup>15</sup> [https://www.academia.edu/79518034/Between\\_Palliative\\_Care\\_and\\_Euthanasia?  
email work card=view-paper](https://www.academia.edu/79518034/Between_Palliative_Care_and_Euthanasia_email_work_card=view-paper)

<sup>16</sup> Hudson et al. Legalizing physician-assisted suicide and/or euthanasia: Pragmatic implications [https://www.academia.edu/108813987/\\_Legalizing\\_physician\\_assisted\\_suicide\\_and\\_or\\_euthanasia\\_Pragmatic\\_implications?  
email work card=view-paper](https://www.academia.edu/108813987/_Legalizing_physician_assisted_suicide_and_or_euthanasia_Pragmatic_implications_email_work_card=view-paper)

The Scottish proposals in no way preclude “broader spiritual, psychological, and social support”.

8.4.3 Without proper advisory support, the patient themselves may ‘misdiagnose’ their challenges, choosing AD over other options.

Again, skilled palliative staff should be able to address any such confusion and explain the alternative options available. AD is positioned as a final option, with all others palliative options explained and offered.

8.4.4 Assessing mental capacity can be problematic for doctors.

Specialists can be consulted, and training provided. Ensuring capacity is a key element of the Scottish proposals.

8.4.5 “Estimations of life expectancy are typically erroneous.” There may be outliers.

Predictions may not be accurate to the minute in many cases, but the judgement of experienced staff and clinical evidence available on the pace of progression generally tends to be fairly reliable.

8.4.6 Requiring opinions from other specialists ties up valuable time and resources. AD needs a multidisciplinary team response on the palliative team side rather than a single consultation which could be seen as tantamount to tokenism.

Current Scottish AD proposals provide for multi-disciplinary support. Multi-disciplinary support is already an integral part of the palliative care system.

8.4.7 Doctors may not have the additional counselling or “exquisite skills, judicious timing, and the capacity to engage in shared decision making” to participate in AD. A broad review and adaptation of current medical curricula would be required.

Specialists can be involved and consulted, as detailed in the Scottish proposals. Additional training, where required, can be provided.

8.4.8 The challenge of integrating AD into palliative provision may be overburdensome.

The process of integration appears to have taken place effectively elsewhere after AD has been introduced.

8.4.9 There may be risks that decisions for AD may be rushed, and either without understanding or trying palliative support at all, or of patients not having had equal access (due to differing regional provision or differences in insurance coverage), or the patient's understanding of the “failure” of palliative care may be based on experience of some available options, but not all possible other means of palliative support.

Insurance coverage is not a significant issue in Scotland. Palliative care in Scotland is recognised to be of a high quality. Skilled palliative staff already provide necessary explanations of available palliative options, and availability to all is significantly more universal than in systems elsewhere based around private insurance. All other palliative options will be available and explained to patients. AD would exist as a final option.

8.4.10 Some doctors and palliative care staff hold personal beliefs in opposition to AD, and conscientious objection should not be penalised.

No medical staff-member will be compelled to participate unwillingly. This is guaranteed within the Scottish Bill.

8.4.11 Why should doctors and palliative care staff be involved at all in administration, when the Swiss system allows volunteers and counsellors to administer, and in Oregon AD “need not be physician-assisted”?

Current Scottish proposals envision better regulation and support within a medical environment. In the Scottish proposals, a doctor may prescribe a fatal dose, but cannot legally administer it, although they will remain present. Worthington et al<sup>17</sup> raise the possibility of adverse effects of drugs used in AD, and as rare as this may be, if this occurs, medical support being immediately available would make sense. Cohen-Almagor<sup>18</sup> echoes the views of many that Physician Assisted Dying is more controlled, safer, better supervised and less open to abuse or mishap than simply leaving a patient to their own devices and a lethal pill:

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<sup>17</sup> Ana Worthington, Ilora Finlay, Claud Regnard. Efficacy and safety of drugs used for ‘assisted dying’. *Br Med Bull*. 2022 May 4;142(1):15–22. doi: [10.1093/bmb/ldac009](https://doi.org/10.1093/bmb/ldac009) <https://pmc.ncbi.nlm.nih.gov/articles/PMC9270985/>

<sup>18</sup> Cohen-Almagor, R. An argument for physician-assisted suicide and against euthanasia. <https://www.academia.edu/20327902/>  
[An Argument for Physician Assisted Suicide and Against Euthanasia?email\\_work\\_card=view-paper](https://www.academia.edu/20327902/)

“Physicians are best equipped in terms of knowledge and expertise to provide aid-in-dying.”

As Deliens<sup>19</sup> notes:

“Many of the professional skills and knowledge for quality palliative care are very similar to these that are needed for proper exploration and assessment of a euthanasia request. In Belgium after 20 years, there is no significant political or ideological or medical or palliative care opposition against euthanasia anymore; it has been embraced by society, by clinicians, and also by palliative care associations. Furthermore, a great many palliative care professionals are involved in the practice of euthanasia.”

## 8.5 Responses to the argument that current palliative care is sufficient

Tragically there will still always be cases where current palliative care cannot improve the life of patients or sufficiently alleviate unbearable suffering. In studies such as ‘Trends in Medical Aid in Dying in Oregon and Washington’ where the reasons for choosing an assisted death are cited as lost autonomy, independence, and control<sup>20</sup>, a closer look at the data confirms that:

“Most patients who acquired lethal prescriptions had cancer or terminal illnesses that are difficult to palliate and lead to loss of autonomy, dignity, and quality of life.”

In the Westminster Parliament Kim Leadbeater gave the example where Tom’s family begged doctors to intervene, while

“Tom vomited faecal matter for five hours before he ultimately inhaled the faeces and died. He was vomiting so violently that he could not be sedated, and was conscious throughout”.<sup>21</sup>

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<sup>19</sup> Deliens, Luc. IAHPC. Vol 24, No4, April 2023. Belgium’s 20-year history of assisted dying is well accepted by the public and health care practitioners; ideally, it should be integrated into palliative care. <https://iahpc.org/resources/publications/special-issues/assisted-dying-practices/luc-deliens/>

<sup>20</sup> Rabadi et al (2019) *Trends in Medical Aid in Dying in Oregon and Washington*. JAMA Netw Open. 2019;2(8):e198648. doi:10.1001/jamanetworkopen.2019.8648 [https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2747692?utm\\_source=For\\_The\\_Media&utm\\_medium=referral&utm\\_campaign=ftm\\_links&utm\\_term=080919](https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2747692?utm_source=For_The_Media&utm_medium=referral&utm_campaign=ftm_links&utm_term=080919)

<sup>21</sup> <https://www.theguardian.com/commentisfree/2024/nov/29/assisted-dying-bill-life-death-mps>

The report “The Inescapable Truth About Dying in Scotland”<sup>22</sup> provides compelling case-studies and evidence that palliative support as it currently legally operates is insufficient in a range of cases. In the report, “

“the Office of Health Economics concludes that, even if every dying person in Scotland who needed it had access to the excellent level of care currently provided in hospices, 591 people a year would still have no effective relief of their pain in the final three months of their life. Evidence suggests that if people suffering from other unrelieved symptoms during the dying process were included this number would be much higher.”<sup>23</sup>

It can also be noted that where assisted dying has been available, in the end many who apply do not in the end take up that option - they are simply reassured that it would be available if and when other forms of palliative care are no longer enough. Feeling that they have taken back a degree of control of what remains of their life, and during a period where they can feel they have lost agency and dignity to intractable illness, is of no small benefit to patients.

Assisted dying as an additional final choice within palliative care is argued by supporters of AD as logical and compassionate. As Fantails et al<sup>24</sup> note:

“Relief of suffering through an assisted death can be argued as a distinct entity to palliative care, with the former – if safely and carefully considered – potentially an important way of fulfilling a clinician’s duty to preserve autonomy and do good for a patient – for example, in cases where alternatives are treatments which provide no benefit or do not prolong or improve the quality of life of a terminally ill patient.”

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<sup>22</sup> <https://features.dignityindying.org.uk/inescapable-truth-scotland/>

<sup>23</sup> ibid

<sup>24</sup> Fantails et al (2018) *Euthanasia and assisted dying: what is the current position and what are the key arguments informing the debate?* Journal of the Royal Society of Medicine, Volume 111, Issue 11: Pages 407-413 <https://journals.sagepub.com/doi/full/10.1177/0141076818803452>

## 8.6 Current numbers

On average, 17 people a day in the UK experience painful deaths that cannot be relieved by the best palliative care<sup>25</sup>.

According to the Office of Health Economics<sup>26</sup>, in the UK there are

“50,709 palliative care patients dying in some level of pain each year. Of these patients, 5,298 would still experience no pain relief at all in the last three months of life.”

They reiterated the above to the Westminster Parliament:

“there is recognition that the application of current best practice protocols for palliative care, such as the WHO's cancer pain ladder for adults or the NICE guidelines, cannot alleviate pain for all end-of-life patients.....Our estimate of 5,298 patients who would die without any pain relief at all represents an aspirational, best-case scenario where every patient receives the very highest standard of care as provided in hospices.”<sup>27</sup>

Chris Whitty recently argued that

“Modern medicine is amazing at keeping people alive and extending life ... “but I think the question should be what do people want themselves”.<sup>28</sup>

There is a point where the wonders of modern medicine turn from real relief to real trauma, keeping people alive while their incurable, intractable and excessive suffering continues. Supporters of AD argue that there are cases where palliative care currently available, however good, is not prolonging life, but instead prolonging a poor death.

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<sup>25</sup> Dignity In Dying: The Inescapable Truth About Dying in Scotland (2019): study commissioned by the campaign group Dignity in Dying and conducted by the Office of Health Economics, a research company. <https://features.dignityindying.org.uk/inescapable-truth/>

<sup>26</sup> Cookson et al (2019) *Unrelieved Pain in Palliative Care in England*. National Institute for Health Research. <https://www.ohe.org/publications/unrelieved-pain-palliative-care-england>

<sup>27</sup> <https://committees.parliament.uk/writtenevidence/116982/pdf/>

<sup>28</sup> Devlin, Hannah (2023) *Prioritise quality of life over prolonging it for elderly, Chris Whitty tells medics*. Guardian. <https://www.theguardian.com/society/2023/nov/10/prioritise-quality-of-life-over-prolonging-it-for-elderly-chris-whitty-tells-medics>

## 9 Is Assisted Dying incompatible with palliative care?

### 9.1 How palliative carers already participate in the death of patients in Scotland

We do not live in a state of “decreed compulsory living”<sup>29</sup>. There exists a range of methods and current ethical rules that enable the ending of a life within a medical context to be legally justified. Clarke & Egan<sup>30</sup> reiterate a common criticism of what many see as artificial distinctions between current practice and proposed AD practice:

“Passive euthanasia is accepted and in reality is widely practised. It is often called withdrawal of therapy. If further care is unlikely to be of any therapeutic benefit, a physician is not obliged to continue therapy. The current approach is for a physician to declare that future therapy is futile and then to withdraw therapy on the basis of futility.”

There are a good number of bioethicists, including Beauchamp and Childress themselves, who see little distinction between “killing” and “allowing to die”<sup>31</sup>  
<sup>32 33</sup>.

The attempt by opponents of AD within palliative care to differentiate medical involvement and assistance in current accepted practices in Scotland - such as of withholding treatment, withdrawing futile treatment, overdose by terminal sedation, or supporting a patient medically in dehydrating and starving themselves to death - from assisted dying is seen by critics of that position as splitting very fine hairs and at best a conceptual convenience. Indeed, Loewy<sup>34</sup> refers to the current common practice of Voluntary Stopping of Eating and Drinking as “physician stimulated starvation” and that

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<sup>29</sup> Dankwort, Juergen. (2024). Voluntary Assisted Dying: The Impasse and a Way Forward. Canadian Journal of Bioethics / Revue canadienne de bioéthique, 7(4), 64–70. <https://doi.org/10.7202/1114959ar>

<sup>30</sup> D L Clarke, A Egan. Euthanasia – is there a case?  
[https://www.academia.edu/117086765/Euthanasia\\_is\\_there\\_a\\_case?email\\_work\\_card=view-paper](https://www.academia.edu/117086765/Euthanasia_is_there_a_case?email_work_card=view-paper)

<sup>31</sup> White, Lucie. EUTHANASIA, ASSISTED SUICIDE AND THE PROFESSIONAL OBLIGATIONS OF PHYSICIANS. <https://philpapers.org/archive/WHIEAS-2.pdf>

<sup>32</sup> Beauchamp, T & Childress, J 1983, Principles of Biomedical Ethics (2nd ed.), Oxford University Press, Oxford.

<sup>33</sup> Brock, D 1992, Voluntary and active euthanasia, Hastings Center Report, vol. 22, no. 2, pp.10-22.

<sup>34</sup> <https://www.academia.edu/113873484/>  
Euthanasia Physician Assisted Suicide and Other Methods of Helping Along Death?  
email\_work\_card=view-paper

“it should most certainly not be suggested to the patient as an alternative because the physician out of cowardice is unwilling to prescribe medication to accomplish the same end.”

The argument in the end is whether there is significant difference ethically and under the law between a more direct causality approach i.e. supplying a pill, as compared to administering a drug to a patient over days until they weaken enough to die from an overdose or from dehydration and starvation or a mixture of both.

Palliative care already is already strongly regulated, and current proposals for assisted dying would introduce further strong and specific regulation. Downar et al note that there are:

“parallels between media reports about the misuse of AD and reports of wrongful deaths due to the misuse of palliative care (PC) in jurisdictions where AD was not legal. Ultimately, we cannot justify having a different response to these reports when they apply to AD instead of PC, and nobody has argued that PC should be criminalized in response to such reports....We must remember that PC (palliative care) is no stranger to accusations of harm and wrongful death (especially among the vulnerable) in jurisdictions wherein AD is not legal. If we trust the oversight mechanisms that are used for accusations of malpractice or wrongful death in any jurisdiction, we should trust them in jurisdictions where AD is legal.”<sup>35</sup>

## 9.2 VSED - the currently legal and acceptable way for a person to actively end their life with medical support

Jox et al<sup>36</sup> define VSED as the intention and act of causing the shortening and ending a life:

“VSED is a form of suicide by omission – the person’s omission of eating and drinking directly causes death.”

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<sup>35</sup> Downar, MacDonald and Buchman (2023) *Medical Assistance in Dying, Palliative Care, Safety and Structural Vulnerability*. J Palliat Med. 2023 Sep; 26(9):1175-1179. doi: 10.1089/jpm.2023.0210. Epub 2023 Jul 3. PMID: 37404196 <https://pubmed.ncbi.nlm.nih.gov/37404196/>

<sup>36</sup> Jox, Ralf J, Black, Isra orcid.org/0000-0001-5324-7988, Borasio, Gian Domenico et al. (1 more author) (2017) Voluntary stopping of eating and drinking: is medical support ethically justified? BMC Medicine. 186. ISSN 1741-7015 <https://doi.org/10.1186/s12916-017-0950-1>

According to Wechkin et al<sup>37</sup>:

“VSED is a deliberate, self-initiated action by a patient with decision-making capacity (DMC) to hasten death in the setting of suffering refractory to optimal palliative interventions, prolonged dying that the person finds intolerable, or expected deterioration or suffering due to an irreversible illness, that the person regards as unacceptable. This action is typically undertaken by a patient with a serious illness associated with a life expectancy of months or years. VSED is characterized by the exercise of a specific choice at a specific time and is dependent on the patient having sufficient decisional capacity at the time that VSED is initiated.”

### **9.2.1 Deep and continuous palliative sedation without artificial nutrition and hydration.**

Most commonly, VSED in Scotland is supported by medical staff, and is carried out in conjunction with deep sedation. The patient is placed into an induced coma which continues until death. It is commonly argued that although the level of sedation is potentially lethal as the body weakens from starvation and dehydration, death is foreseeable but not intended (the doctrine of double-effect) by the provision and maintenance of the dosage. However as death is intended from the process as a whole, and in view of the lack of available research, the contribution of the dosage to overall cause of death remains open to debate.

### **9.2.2 Is VSED significantly different from AD?**

A common argument is that medical involvement in Voluntary Stopping Eating and Drinking remains at ‘arms-length’, thereby removing any accusation of direct complicity and causality. Jox et al<sup>38</sup> note that:

“Most Western jurisdictions seem to permit medical support for VSED, even in jurisdictions where assisted dying is prohibited by law.... the widely held position by palliative care societies, professional bodies of

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<sup>37</sup> [https://www.jpsmjournal.com/article/S0885-3924\(23\)00565-1/fulltext](https://www.jpsmjournal.com/article/S0885-3924(23)00565-1/fulltext)

<sup>38</sup> Jox, Ralf J, Black, Isra orcid.org/0000-0001-5324-7988, Borasio, Gian Domenico et al. (1 more author) (2017) Voluntary stopping of eating and drinking: is medical support ethically justified? *BMC Medicine*. 186. ISSN 1741-7015 <https://doi.org/10.1186/s12916-017-0950-1>

physicians, legal scholars, and ethicists to disapprove of assisted suicide but approve of and even promote medically supported VSED appears inconsistent”.

Liu et al<sup>39</sup> contend that there are three types of ‘Deep and Continuous Palliative Sedation without Artificial Nutrition and Hydration’. Type 1 is palliative sedation that will not hasten the patient’s death. Type 2 might, but is not certain to, hasten death, as in the doctrine of double-effect. Type 3 is certain to hasten death. They note that all three types are practiced in Australia, Colombia, the Netherlands, Switzerland, the United States of America. The first two exist within palliative care provision in Scotland as, arguably, does the third.

Liu et al<sup>40</sup> note that Type 3 is perceived as a form of euthanasia in Australia, Colombia, the Netherlands, and Switzerland, and would be regarded as a form of AD in Ireland. Liu et al<sup>41</sup> acknowledge the risk that “there could be a situation where Type 3 Deep and Continuous Palliative Sedation without Artificial Nutrition and Hydration is allowed in the absence of the safeguards usually associated with euthanasia.” Jox et al<sup>42</sup> are more forthright in arguing that:

“VSED falls within the concept of suicide, albeit with certain unique features (non-invasiveness, initial reversibility, resemblance to the natural dying process). Second, we demonstrate, on the basis of

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<sup>39 39</sup> Liu, Richard, Pope, Thaddeus Mason and and Xu, April, Deep and Continuous Palliative Sedation without Artificial Nutrition and Hydration: An International Review (September 14, 2024). 35 Indiana International & Comparative Law Review XXX (forthcoming 2025)., 35(1) Indiana International & Comparative Law Review 67-151 (2025), Available at SSRN: <https://ssrn.com/abstract=4956660> or <http://dx.doi.org/10.2139/ssrn.4956660> <https://open.mitchellhamline.edu/cgi/viewcontent.cgi?article=1622&context=facsch> 27/04/25

<sup>40</sup> Liu, Richard, Pope, Thaddeus Mason and and Xu, April, Deep and Continuous Palliative Sedation without Artificial Nutrition and Hydration: An International Review (September 14, 2024). 35 Indiana International & Comparative Law Review XXX (forthcoming 2025)., 35(1) Indiana International & Comparative Law Review 67-151 (2025), Available at SSRN: <https://ssrn.com/abstract=4956660> or <http://dx.doi.org/10.2139/ssrn.4956660> <https://open.mitchellhamline.edu/cgi/viewcontent.cgi?article=1622&context=facsch> 27/04/25

<sup>41</sup> Liu, Richard, Pope, Thaddeus Mason and and Xu, April, Deep and Continuous Palliative Sedation without Artificial Nutrition and Hydration: An International Review (September 14, 2024). 35 Indiana International & Comparative Law Review XXX (forthcoming 2025)., 35(1) Indiana International & Comparative Law Review 67-151 (2025), Available at SSRN: <https://ssrn.com/abstract=4956660> or <http://dx.doi.org/10.2139/ssrn.4956660> <https://open.mitchellhamline.edu/cgi/viewcontent.cgi?article=1622&context=facsch> 27/04/25

<sup>42</sup> Jox, Ralf J, Black, Isra orcid.org/0000-0001-5324-7988, Borasio, Gian Domenico et al. (1 more author) (2017) Voluntary stopping of eating and drinking: is medical support ethically justified? BMC Medicine. 186. ISSN 1741-7015 <https://doi.org/10.1186/s12916-017-0950-1>

paradigmatic clinical cases, that medically supported VSED is, at least in some instances, tantamount to assisted suicide. This is especially the case if a patient's choice of VSED depends on the physician's assurance to provide medical support.”

While the primary purpose of medical support in VSED may be symptom relief, as in AD the outcome is expected to be death. They go on to argue that:

“Two elements of assistance in suicide are critical for our argumentation. First, the assistance is instrumental for death to occur, meaning that, without the assistance, the suicide would not (or could not) occur. Second, the assisting person knows and at least partially shares the patient's intention to induce death.”<sup>43</sup>

VSED is practiced within Scottish palliative care as a best available option where a patient seeks to end their life. It is most commonly performed in conjunction with medical staff supporting the patient by inducing a coma and continuing to administer sedation, monitor the patient and provide care.

This is clearly the case, especially where VSED operates in conjunction with an induced coma.

### **9.2.3 Is VSED problematic?**

In terms of public awareness, although euthanasia has a page on the NHS Scotland public website, there was still no mention anywhere relating to VSED or VRFF, in acronym or full-form on April 30 2025.

There is also an absence of published research specifically in relation to the support of VSED in palliative care in Scotland.

Some within palliative care suggest the practice of VSED remains relatively uncommon in the UK, while elsewhere research suggests a much more

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<sup>43</sup> Jox, Ralf J, Black, Isra orcid.org/0000-0001-5324-7988, Borasio, Gian Domenico et al. (1 more author) (2017) Voluntary stopping of eating and drinking: is medical support ethically justified? *BMC Medicine*. 186. ISSN 1741-7015 <https://doi.org/10.1186/s12916-017-0950-1>

common occurrence - Bolt et al<sup>44</sup> found in that in their survey of over 700 physicians between October 2011 and June 2012 in the Netherlands,

"46% had cared for a patient who hastened death by VSED".

In their literature review, Mensger et al<sup>45</sup> found that

"surveys from different countries have shown that 32%–62% of participating healthcare professionals had already accompanied a person during VSED".

The Scottish Partnership for Palliative Care note that:

"there are no systematic mechanisms in place to measure and understand the experiences and outcomes of people dying in Scotland".<sup>46</sup>

While VSED has always been legal in Scotland, there is a definite lacuna in general in research into VSED. Lowers et al<sup>47</sup> found that:

"Few studies have looked specifically at the incidence of VSED."

Pope et al<sup>48</sup> confirm that:

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<sup>44</sup> Bolt EE, Hagens M, Willems D, Onwuteaka-Philipsen BD. Primary care patients hastening death by voluntarily stopping eating and drinking. *Ann Fam Med*. 2015 Sep;13(5):421-8. doi: 10.1370/afm.1814. PMID: 26371262; PMCID: PMC4569449.

Christina Mensger, Yang Jiao, Maximiliane Jansky, Christian Banse, Friedemann Nauck, Monika Nothacker, Henrike Stanze. Voluntarily stopping eating and drinking (VSED): A systematic mixed-methods review focusing on the carers' experiences. *Health Policy* **Volume 150**, December 2024, 105174. <https://www.sciencedirect.com/science/article/pii/S0168851024001842> 27/04/25

<sup>46</sup> <https://www.palliativecarescotland.org.uk/content/publications/SPPC-Response-to-Proposals-for-an-Assisted-Dying-Bill.pdf>

<sup>47</sup> Jane Lowers, Sean Hughes, Nancy J. Preston. Overview of voluntarily stopping eating and drinking to hasten death. *Annals of Palliative Medicine*, **Vol 10, No 3 (March 31, 2021)** <https://apm.amegroups.org/article/view/44492/html> 27/04/25

<sup>48</sup> Liu, Richard, Pope, Thaddeus Mason and and Xu, April, Deep and Continuous Palliative Sedation without Artificial Nutrition and Hydration: An International Review (September 14, 2024). 35 Indiana International & Comparative Law Review XXX (forthcoming 2025)., 35(1) Indiana International & Comparative Law Review 67-151 (2025), Available at SSRN: <https://ssrn.com/abstract=4956660> or <http://dx.doi.org/10.2139/ssrn.4956660> <https://open.mitchellhamline.edu/cgi/viewcontent.cgi?article=1622&context=facsch> 27/04/25

“Deep and continuous palliative sedation combined with withholding or withdrawal of artificial nutrition and hydration....has gone largely unexamined”.

General articles discussing VSED go back before 2000 - in 1993, Bernat et al<sup>49</sup> called for systematic research on VSED, but Mensger et al<sup>50</sup> in 2024 found available research dealt less with practice, and

“mostly dealing with the ethical and legal issues”,

and in their literature review Ivanović et al<sup>51</sup> note that

“articles provide marginal insight into VSED for hastening death. Research is needed .... intensive examination of the literature shows that the subject under study has been marginally researched and that there is no scientific basis on which VSED could be explained in all of its dimensions”.

The authors go on to describe existing research as a

“continuous interweaving of published articles. In this respect, we conclude that the evidence was artificially reproduced over time through repeated citations of narrative reviews without new insights based on original studies.”<sup>52</sup>

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<sup>49</sup> Bernat JL, Gert B, Mogielnicki RP. Patient refusal of hydration and nutrition. An alternative to physician-assisted suicide or voluntary active euthanasia. *Arch Intern Med.* 1993;153(24):2723–2728.

<sup>50</sup> Christina Mensger, Yang Jiao, Maximiliane Jansky, Christian Banse, Friedemann Nauck, Monika Nothacker, Henrike Stanze. Voluntarily stopping eating and drinking (VSED): A systematic mixed-methods review focusing on the carers' experiences. *Health Policy Volume 150*, December 2024, 105174. <https://www.sciencedirect.com/science/article/pii/S0168851024001842> 27/04/25

<sup>51</sup> Ivanović, Nata & Bueche, Daniel & Fringer, André. (2014). Voluntary stopping of eating and drinking at the end of life - A 'systematic search and review' giving insight into an option of hastening death in capacitated adults at the end of life. *BMC palliative care.* 13. 1. 10.1186/1472-684X-13-1. <http://www.biomedcentral.com/1472-684X/13/1> 27/04/25

<sup>52</sup> Ivanović, Nata & Bueche, Daniel & Fringer, André. (2014). Voluntary stopping of eating and drinking at the end of life - A 'systematic search and review' giving insight into an option of hastening death in capacitated adults at the end of life. *BMC palliative care.* 13. 1. 10.1186/1472-684X-13-1. <http://www.biomedcentral.com/1472-684X/13/1> 27/04/25

## 9.2.4 Current providers of VSED cannot guarantee equality of provision

There are references to VSED in advisory documents by disparate medical organisations such as the GMC in 2015<sup>53</sup>, the BMA in 2019<sup>54</sup> and the Royal College of Physicians in 2021<sup>55</sup>. Compassion in Dying, in their 2022 report Voluntarily stopping eating and drinking (VSED): A call for guidance<sup>56</sup> note:

“The lack of guidance on VSED leads to significant inconsistencies in how it is managed by clinicians.”

Liu et al<sup>57</sup> note:

“[Deep and Continuous Palliative Sedation Without Artificial Nutrition and Hydration] is often not governed by a clear legal framework.”

Dignity in Dying<sup>58</sup> argue that

“Unlike other end-of-life practices, there are also no standardised guidelines in the UK for how healthcare professionals should support people who decide to hasten their death via VSED.”

They note that inadequate pain relief can result from a lack of clear guidance.

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<sup>53</sup> General Medical Council, Patients seeking advice or information about assistance to die, June 2015, [https://www.gmc-uk.org/-/media/documents/gmc-guidance—when-a-patient-seeks-advice-or-information-about-assistance-to-die\\_pdf-61449907.pdf](https://www.gmc-uk.org/-/media/documents/gmc-guidance—when-a-patient-seeks-advice-or-information-about-assistance-to-die_pdf-61449907.pdf)

<sup>54</sup> British Medical Association, Responding to patient requests for assisted dying: guidance for doctors, June 2019, <https://www.bma.org.uk/media/1424/bma-guidance-on-responding-to-patient-requests-for-assisted-dying-for-doctors.pdf>

<sup>55</sup> Royal College of Physicians, Supporting people who have eating and drinking difficulties, March 2021, <https://www.rcplondon.ac.uk/projects/outputs/supporting-people-who-have-eating-and-drinking-difficulties>

<sup>56</sup> Compassion in Dying. Voluntarily stopping eating and drinking (VSED): A call for guidance. Nov 2022. <https://cdn.compassionindying.org.uk/wp-content/uploads/vsed-call-for-guidance-november-2022.pdf>

<sup>57</sup> Liu, Richard, Pope, Thaddeus Mason and and Xu, April, Deep and Continuous Palliative Sedation without Artificial Nutrition and Hydration: An International Review (September 14, 2024). 35 Indiana International & Comparative Law Review XXX (forthcoming 2025)., 35(1) Indiana International & Comparative Law Review 67-151 (2025), Available at SSRN: <https://ssrn.com/abstract=4956660> or <http://dx.doi.org/10.2139/ssrn.4956660> <https://open.mitchellhamline.edu/cgi/viewcontent.cgi?article=1622&context=facsch> 27/04/25

<sup>58</sup> Dignity In Dying: The Inescapable Truth About Dying in Scotland (2019): study commissioned by the campaign group Dignity in Dying and conducted by the Office of Health Economics, a research company. <https://features.dignityindying.org.uk/inescapable-truth/>

A Yougov survey in July 2022 commissioned by Compassion In Dying<sup>59</sup> of over 500 UK professionals found that

“50% of the respondents did not have correct information about the legal status of VSED” and “94% of the respondents said it would be helpful for health and care professionals to have guidance on the legal and clinical aspects of VSED”.

### 9.2.5 Known issues with VSED

Fringer and Staengle<sup>60</sup> describe VSED as

“a critical but poorly understood issue”.

Compassion in Dying<sup>61</sup> cite recent examples of patients experiencing difficulty in accessing information, being stonewalled, being referred to psychiatric services and in one case a patient requesting VSED being sectioned seven days before his death. They note:

“People have also reported that their healthcare team refused to provide pain relief and symptom management when stopping eating and drinking.”<sup>62</sup>

Without sufficient research it remains impossible to confirm that VSED deaths are as peaceful as some would claim, and there is anecdotal evidence to the contrary. Bolt et al<sup>63</sup> note that

“the literature mostly comprises commentaries and case reports rather than original research.....They mention possible serious complications,

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<sup>59</sup> <https://compassionindying.org.uk/resource/voluntarily-stopping-eating-and-drinking-vsed/#backlink-12> 27/04/25

<sup>60</sup> Fringer, André and Stängle, Sabrina. Scientia, Nov 11, 2020 Editor's Pick, Medical & Health Sciences <https://digitalcollection.zhaw.ch/server/api/core/bitstreams/0c46ed58-fe59-4e8c-a073-f5736cb68321/content> 28/04/25

<sup>61</sup> <https://compassionindying.org.uk/resource/voluntarily-stopping-eating-and-drinking-vsed/#what-people-tell-us-about-vsed> 27/04/25

<sup>62</sup> Compassion in Dying. Voluntarily stopping eating and drinking (VSED): A call for guidance. Nov 2022. <https://cdn.compassionindying.org.uk/wp-content/uploads/vsed-call-for-guidance-november-2022.pdf>

<sup>63</sup> Bolt EE, Hagens M, Willems D, Onwuteaka-Philipsen BD. Primary care patients hastening death by voluntarily stopping eating and drinking. Ann Fam Med. 2015 Sep;13(5):421-8. doi: 10.1370/afm.1814. PMID: 26371262; PMCID: PMC4569449.

such as a prolonged dying phase, thirst or hunger, agitation, delirium, and overburdened family members”.

Wax et<sup>64</sup> al state that

“VSED is an intense process fraught with new sources of somatic and emotional suffering for individuals and their caregivers”.

Jean Davis<sup>65</sup>, while undergoing VSED without an induced coma, described the experience as:

“It is hell. I can’t tell you how hard it is. You wouldn’t decide this unless you thought your life was going to be so bad. It is intolerable.”

The Patients Rights Council<sup>66</sup> describes the process as follows:

“As a person dies from dehydration, his or her mouth dries out and becomes caked or coated with thick material; lips become parched and cracked; the tongue swells and could crack; eyes recede back into their orbits; cheeks become hollow; lining of the nose might crack and cause the nose to bleed; skin begins to hang loose on the body and becomes dry and scaly; urine would become highly concentrated, leading to burning of the bladder; lining of the stomach dries out, likely causing the person to experience dry heaves and vomiting; body temperature can become very high; brain cells dry out, causing convulsions; respiratory tract also dries out causing thick secretions that could plug the lungs and cause death. At some point the person’s major organs, including the lungs, heart, and brain give out and death occurs.”

Proper palliative care can reduce the suffering of the patient as they starve and dehydrate. Wechkin<sup>67</sup> et al note that for those who remain awake experiencing VSED,

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<sup>64</sup> Wax JW, An AW, Kosier N, Quill TE. Voluntary Stopping Eating and Drinking. J Am Geriatr Soc. 2018 Mar;66(3):441-445. doi: 10.1111/jgs.15200. PMID: 29532465.

<sup>65</sup> Guardian. Sun 19 Oct 2014 14.19 BST <https://www.theguardian.com/society/2014/oct/19/right-to-die-campaigner-starved-herself-jean-davies> 28/04/25

<sup>66</sup> The Patients Rights Council. Voluntarily Stopping Eating & Drinking: Important Questions & Answers [https://www.patientsrightscouncil.org/site/wp-content/uploads/2013/03/VSED\\_Questions.pdf](https://www.patientsrightscouncil.org/site/wp-content/uploads/2013/03/VSED_Questions.pdf) 28/04/25

<sup>67</sup> Hope Wechkin, Robert Macauley, Paul T. Menzel, Peter L. Reagan, Nancy Simmers, Timothy E. Quill. Clinical Guidelines for Voluntarily Stopping Eating and Drinking (VSED). Journal of Pain and Symptom Management. Volume 66, Issue 5 E625-E631 November 2023 [https://www.jpsmjournal.com/article/S0885-3924\(23\)00565-1/fulltext](https://www.jpsmjournal.com/article/S0885-3924(23)00565-1/fulltext) 27/04/25

“end-of-life dreams and visions....may be eased with antipsychotic medications”,

However the Patients Rights Council cite a case where despite a patient being

“administered small doses of morphine to combat cramps and a sedative to relieve ‘emotional anxiety’

but

“after more than two weeks, she was “howling with anguish.””

It is also reasonable to note the same option to offer medication in response to visible suffering is not available to those in an induced coma whose peaceful stillness may belie a far from peaceful experience. While some may feel reassured by the apparent peace of their loved one in a comatose state, others can find it a more negative experience. The patient, although apparently comatose and inactive, may experience traumatic delirium, and possibly discomfort. At the same time, a traumatic deathwatch where days can extend into weeks is forced upon loved ones. There is also a sense of abandoning their loved one experienced by those who cannot stay 24 hours a day, due to the many other commitments they have. They may well be robbed of the catharsis from being with their loved one until and at the end.

A great deal has been taken on faith in the absence of research, in relation to VSED, simply because it has allowed the medical community to maintain a veneer of a passive role in the process.

Opponents of AD continue to argue that the implementation of AD within palliative care crosses a line in terms of direct involvement and causality in a willing patient’s end. However, there is now an ongoing and vigorous debate within palliative care organisations, and the previous opposition by other British medical representative organisations has been replaced by the adoption of a neutral stance to AD (see section 10).

In view of the successful adoption of AD within palliative care in various countries, it is reasonable to assume that at least a section of Scottish medical staff will be comfortable with the putative more active role required by AD.

In view of the lack of research supporting VSED despite its common implementation, an argument can be made that in avoiding a death-watch for loved ones and waking suffering or silent discomfort, and possible traumatic delirium, the brevity of the AD process may be both preferable and more compassionate.

Implementation of the McArthur Bill may also avoid a great deal of the ambiguity and poor understanding amongst not only the public but medical staff as to legal liability and acceptable practice in VSED.

### 9.3 Where AD has been integrated into palliative care

Where assisted dying has already been introduced (see map<sup>68</sup>), it has been possible to successfully integrate within palliative practice, as an additional and final choice available to patients.

In response to the EAPC White Paper, Chambaere et al<sup>69</sup> argue that

“the White Paper ignores the extensive experience and substantial body of relevant empirical evidence in jurisdictions that have legalised euthanasia and/or physician-assisted suicide. Palliative care organisations within these jurisdictions have already had to react to legal assisted dying and thus provide prime ‘case studies’. In these jurisdictions, professional palliative care is in fact involved in the vast majority of cases where requests have been made.”

Bernheim et al<sup>70</sup> examined “the effect of the process of legalisation of euthanasia on palliative care by reviewing published historical, regulatory, and epidemiological evidence in Belgium” and concluded:

“we found few professional stances contending that palliative care and legalisation of euthanasia are antagonistic, no slippery slope effects, and no evidence for the concern of the European Association for Palliative Care that the drive to legalise euthanasia would interfere with the development of palliative care. Rather, there were many indications of reciprocity and synergistic evolution”.

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<sup>68</sup> <https://wfrtds.org/worldmap/>

<sup>69</sup> Chambaere et al (2016) *The European Association for Palliative Care White Paper on euthanasia and physician-assisted suicide: Dodging responsibility*. Palliative Medicine Volume 30, Issue 9. <https://doi.org/10.1177/0269216316664470>

<sup>70</sup> Bernheim et al (2008) Development of palliative care and legalisation of euthanasia: Antagonism or synergy? BMJ. Apr 19;336(7649):864–867. <https://pmc.ncbi.nlm.nih.gov/articles/PMC2323065/>

## 10) Will introducing assisted dying reduce funding for palliative care and other areas of medicine?

An attempt to stifle debate within palliative care representative organisations on the issue of AD was observed by a number of contributors to the Second Report of Session 2023–24 of the House of Commons Committee report<sup>71</sup>, but more recently voices supporting AD within the palliative care community have opened up the debate.

A common and key theme of opposition to AD within palliative care organisations is the fear of defunding of palliative care, and a possible loss of prestige, if assisted dying is introduced. This has not proven to be the case in states where assisted dying is now established. A key argument that opponents within palliative care put forward is that insufficient resources for palliative care is the key reason why problems exist in caring for those for whom currently available palliative support is simply insufficient. It is an argument that implies that medical science, if funded sufficiently will be a panacea for all conditions. Again, this is a choice to ignore the existence of conditions and levels of suffering and indignity for which there is simply no modern medical solution. It is understandable that palliative carers are protective of their budgets and very reluctant to see anything introduced that could potentially drain resources. However in states where assisted dying has been introduced, and this question has been researched, funding and resources have either remained consistent or actually increased.

A debate does indeed exist in general on the level of availability of quality care and sufficient places in care homes/palliative care facilities. There is an argument for seeking further improvements in the provision of palliative care, but this is not a justification for the denial of the additional choice of assisted dying being available to those who need it. Two things can be true - that it is in the interests of patients to see improvements in palliative care resourcing, and also in the interest of patients to have the additional choice of AD available, if they wish, as part of palliative care. As Downie and Schuklenk<sup>72</sup> note

“As Justice Smith observed in Carter: “the argument that legalization should not be contemplated until palliative care is fully supported rests, as Dr. van Delden observed, on a form of hostage-taking.”

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<sup>71</sup> <https://publications.parliament.uk/pa/cm5804/cmselect/cmhealth/321/report.html#footnote-393-backlink>

<sup>72</sup> Downie and Schuklenk (2021) *Social determinants of health and slippery slopes in assisted dying debates: lessons from Canada*. BMJ Journal of Medical Ethics 2021;47:662–669 <https://jme.bmj.com/content/medethics/47/10/662.full.pdf>

As Champaere et al note, assisted dying does not replace palliative care, but becomes a vital and valid element within palliative care:

“We found an increased demand for euthanasia in Belgium between 2007 and 2013, as well as growing willingness among physicians to meet those requests, mostly after the involvement of palliative care services. This finding indicates that, after 11 years of experience, euthanasia is increasingly considered as a valid option at the end of life in Belgium.”<sup>73</sup>

In their study “Does legal physician-assisted dying impede development of palliative care? The Belgian and Benelux experience.”, Champaere and Bernheim examined the seven European countries with the highest rate of increase in palliative care (PC) provisions. The rate of increase was

“the highest in the Netherlands and Luxembourg, while Belgium stayed on a par with the UK, the benchmark country. Belgian government expenditure for PC doubled between 2002 and 2011.”<sup>74</sup>

Professor Jan Bernheim and Professor Rutger Jan van der Gaag noted that legislative change in Belgium and the Netherlands had been intrinsically linked with palliative care and they now boast some of the best palliative care provisions in Europe. Champaere and Bernheim<sup>75</sup> note

“The hypothesis that legal regulation of physician-assisted dying slows development of PC is not supported by the Benelux experience. On the contrary, regulation appears to have promoted the expansion of PC.”

The recent Westminster assisted dying inquiry found that the introduction of assisted dying:

‘has been linked with an improvement in palliative care in several

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<sup>73</sup> Champaere et al (2015) *Correspondence: Recent Trends in Euthanasia and Other End-of-Life Practices in Belgium*. The New England Journal of Medicine. <https://www.nejm.org/doi/full/10.1056/NEJMc1414527>

<sup>74</sup> Champaere K & Bernheim, J (2015) *Does legal physician-assisted dying impede development of palliative care? The Belgian and Benelux experience*. Journal of Medical Ethics;41:657-660. <https://jme.bmjjournals.com/content/41/8/657.long>

<sup>75</sup> ibid

‘jurisdictions.<sup>76</sup>

In the House of Commons’ assisted dying inquiry final oral evidence session in July 2023, Professor James Downar, Head of the Division of Palliative Care at the University of Ottawa, explained that since the introduction of an assisted dying law in 2016, Canada had seen

“the strongest growth of palliative care in its history.”<sup>77</sup>

Downar reiterated this in his written statement:

“funding/support for clinical palliative care has increased dramatically in much of the country since MAiD became legal”.<sup>78</sup>

Palliative Care Australia, which had originally opposed AD, informed the House of Commons’ assisted dying inquiry that it had come to the clear conclusion that the introduction of AD had augmented, not detracted from, palliative care.<sup>79</sup>

The recent Health and Social Care Committee’s assisted dying inquiry final report (29th February 2024)<sup>80</sup> concluded:

“In the evidence we received, we did not see any indications of palliative and end-of-life care deteriorating in quality or provision following the introduction [of assisted dying]; indeed the introduction of [assisted dying] has been linked with an improvement in palliative care in several jurisdictions.”

Assisted dying can be one of the choices within compassionate palliative care, and can lead to an improvement in resourcing for palliative care. Peer-

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<sup>76</sup> House of Commons Health and Social Care Committee Assisted Dying/Assisted Suicide Second Report of Session 2023–24 (2024) [committees.parliament.uk/publications/43582/documents/216484/default/](https://committees.parliament.uk/publications/43582/documents/216484/default/)

<sup>77</sup> Stillwell, Nathan (2023) *The assisted dying inquiry: Everything important that was said*. Humanists UK. <https://humanists.uk/2023/07/11/the-assisted-dying-inquiry-everything-important-that-was-said/#:~:text=In>

<sup>78</sup> Downar, Prof James (2024) *Written evidence submitted by James Downar, MDCM, MHSc (Bioethics), FRCPC (ADY0161)* <https://committees.parliament.uk/writtenevidence/115997/pdf/>

<sup>79</sup> <https://humanists.uk/2023/07/11/the-assisted-dying-inquiry-everything-important-that-was-said/>

<sup>80</sup> Health and Social Care Committee’s assisted dying inquiry final report (29th February 2024). <https://publications.parliament.uk/pa/cm5804/cmselect/cmhealth/321/report.html>

reviewed research confirms that the introduction of the option of assisted dying either makes no difference, or in fact leads to a positive debate about, and improvement in, the quality of care.

It was noted in Westminster Parliamentary evidence that:

“In jurisdictions adopting legislation, there were indirect system improvements and increased funding for palliative care that occurred alongside the introduction of assisted dying. It reflected debate around the importance placed upon assisted dying as a complement to palliative care and not as an alternative to palliative care.”<sup>81</sup>

The Assisted Dying for Terminally Ill Adults (Scotland) Bill<sup>82</sup> 2021 consultation cited some examples relevant to this particular question:

“In 2015, the Palliative Care and Quality of Life Interdisciplinary Advisory Council (PCAC) was established in Oregon by Senate Bill 608. The legislation seeks to improve the lives of people who would benefit from palliative care and to facilitate better coordination of care. When the Australian State of Victoria passed assisted dying legislation, the government reviewed palliative care services in the area. As a result, an extra \$72 million has been provided in Victoria to increase palliative care beds and access to home-based palliative care. In Western Australia, where assisted dying legislation was passed in 2019, the government announced a further AU\$17.8 million for palliative care projects based on the recommendations of the Joint Select Committee Report on End of Life Choices. A report commissioned by Palliative Care Australia which examined assisted dying around the world found ‘no evidence to suggest that palliative care sectors were adversely impacted by the introduction of legislation. If anything, in jurisdictions where assisted dying is available, the palliative care sector has further advanced.’ Two years after assisted dying was legalised in Canada, the Minister of Health tabled a ‘Framework on Palliative Care in Canada’. This framework provides a vision for palliative care in Canada and an implementation plan. The government committed funding of \$6 billion over 10 years to improving palliative care with an

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<sup>81</sup> Duckworth, Prof Stephen (2022) *Written evidence submitted by Professor Stephen Duckworth OBE, DSc, PhD, FKC, MSc LRCP MRCS (ADY0002)* <https://committees.parliament.uk/writenevidence/114065/pdf/>

<sup>82</sup> McArthur, Liam (2021) *Assisted Dying for Terminally Ill Adults (Scotland) Bill: A proposal for a Bill to enable competent adults who are terminally ill to be provided at their request with assistance to end their life.* <https://www.parliament.scot/-/media/files/legislation/proposed-members-bills/assisted-dying-for-terminally-ill-adults-scotland-consultation-2021-final.pdf>

additional \$184.6 million to improve home and palliative care for indigenous communities.”