# Submission to the House of Commons Health and Social Care Committee inquiry into "assisted dying/assisted suicide" on behalf of Care Not Killing (CNK Alliance Ltd) and Our Duty of Care

January 2023

<u>Care Not Killing (CNK)</u> is a UK-based alliance working to:

- promote more and better palliative care;
- ensure that existing laws against euthanasia and assisted suicide are not weakened or repealed;
- influence the balance of public opinion against any further weakening of the law.

Formed in 2005 to oppose Lord Joffe's Assisted Dying for the Terminally Ill Bill, CNK has since campaigned on the MacDonald and Harvie Bills at Holyrood, and the Falconer, Marris and Meacher Bills at Westminster, as well as intervening in major court cases including those of Tony Nicklinson, Noel Conway and 'Y'.

<u>Our Duty Of Care (ODOC)</u> is a group of UK healthcare workers who oppose the intentional killing of patients by assisted suicide or euthanasia, supported financially and administratively by CNK. Working with a wide range of healthcare professionals across the UK, ODOC has campaigned during the membership polls run by the Royal College of Physicians, Royal College of General Practitioners and British Medical Association to maintain medical opposition to assisted suicide.

# Summary

We hold that legal change to permit assisted suicide and/or euthanasia would be uncontrollable, unethical and unnecessary.

- 1. Uncontrollable, as we shall see, because the current law rests on a natural frontier with all forms of legalisation susceptible to escalating numbers of deaths, expansion and abuse including under-reporting.
- 2. Unethical owing to the effect on patients, especially vulnerable people who are made to feel a burden, and on doctors with conscientious objections.
- 3. Unnecessary because the principle challenge to end of life care is the failure to provide high quality palliative care of which we are capable, to many tens of thousands of patients every year.

(Answers word-count: 3,438)

CNK-ODOC Submission to the Commons Health Committee Inquiry on "Assisted Dying/Assisted Suicide"

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

Assisted suicide advocates paint euthanasia and assisted suicide (henceforth, "E&AS") as forms of healthcare, but they are not. A 2019 joint statement issued by the Canadian Hospice Palliative Care Association and Canadian Society of Palliative Care Physicians stated that:

"MAiD [Medical Assistance in Dying – E&AS] is not part of hospice palliative care; it is not an "extension" of palliative care nor is it one of the tools "in the palliative care basket"... Hospice palliative care and MAiD substantially differ in multiple areas including in philosophy, intention and approach."<sup>1</sup>

The UK is recognised as the world-leader in palliative care innovation and provision<sup>2</sup>, but there are still great disparities in what is available to individuals. A wish to die can, once properly explored, be an expression of a variety of forms of distress and is rarely a genuine desire to use lethal drugs to end life.

Professor The Baroness Finlay of Llandaff told peers in 2019:

"Currently, around 470,000 people of all ages die each year in England; about threequarters of them will not have a sudden death... Sadly, an estimated 92,000 people each year in England would benefit from palliative care but do not receive any at all, either from specialist palliative care professionals or generalists. The family suffers too: 83% of carers—around 400,000 people per year—suffer significant psychological morbidity."<sup>3</sup>

Put another way, Marie Curie tell us that "as many as 90% of people who die may have palliative care needs, [but] only around 50% of people who die receive any palliative care."<sup>4</sup> Various inquiries<sup>5</sup> have noted problems including poor communication and planning, inadequate out-of-hours services, and delays in diagnosis and referrals for treatment: needless barriers to providing high-quality palliative care of which we are capable.

Parliamentarians cannot safely consider "assisted dying" legislation before they can guarantee access to not just palliative care but also social support (including affordable housing) for people with chronic illnesses and disabilities. Canada has seen many examples of medically eligible people applying for E&AS not because of their condition but because of a lack of support. Recent examples include:

- 54-year-old Amir Farsoud who hit the headlines in November 2022 when he applied for MAiD because he was in danger of losing his housing and feared being made homeless<sup>6</sup>
- Roger Foley, who recorded a hospital employee offering him a MAiD death, citing the financial cost of his care and being unwilling to provide the care package best suited to Mr Foley<sup>7</sup>

<sup>4</sup> mariecurie.org.uk/globalassets/media/documents/policy/campaigns/health-and-care-bill-clause-16-briefing-website-version.pdf

<sup>&</sup>lt;sup>1</sup> cspcp.ca/wp-content/uploads/2019/11/CHPCA-and-CSPCP-Statement-on-HPC-and-MAiD-Final.pdf

 $<sup>\</sup>label{eq:construction} ^{2} \underline{impact.economist.com/perspectives/sites/default/files/2015\%20EIU\%20Quality\%20of\%20Death\%20Index\%20Oct\%2029\%20FINAL.pdf}{\label{eq:construction} }$ 

<sup>&</sup>lt;sup>3</sup> hansard.parliament.uk/lords/2019-06-14/debates/42F5A25C-76C0-4542-B8CA-E3625E2C096A/AccessToPalliativeCareBill

<sup>&</sup>lt;sup>5</sup> impact.economist.com/perspectives/sites/default/files/2015%20EIU%20Quality%20of%20Death%20Index%20Oct%2029%20FINAL.pdf

<sup>&</sup>lt;sup>6</sup> toronto.citynews.ca/2022/10/13/medical-assistance-death-maid-canada/

<sup>&</sup>lt;sup>7</sup> dyingwell.co.uk/stories/roger-foley/

• Paralympian Christine Gauthier, who applied for financial support as a veteran and was told, "if you're so desperate, madam, we can offer you MAID, medical assistance in dying"<sup>8</sup>

Thousands of people across the UK live with chronic and terminal illnesses while also contending with poverty, housing insecurity or discrimination. In December 2022, it was reported<sup>9</sup> that:

"the Department for Work and Pensions (DWP) has secretly abandoned work on a £106 million plan that was supposed to prevent suicides and other deaths of benefit claimants, learn from its mistakes, and deliver reform 'for the most vulnerable in society."

The UK cannot claim to be better placed to avoid repeating disturbing Canadian precedents, were E&AS legalised. There is a great danger in considering "assisted dying" legislation whilst there are such deficiencies in access to palliative care (and social support.) Many people would not be able to make a meaningful choice.

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

Where E&AS are legalised, the numbers of deaths tend to rise annually. E&AS accounted for at least 4.5% of Dutch deaths in 2021 (up from 4.1% in 2020<sup>10</sup>), and at least 3.3% of Canadian deaths in 2021 (up from 2.5% in 2020 and 2.0% in 2019<sup>11</sup>). Such laws are necessarily founded on arbitrary limits, which are breached with relative impunity, reinterpreted or expanded.

In 2013 in Belgium, 1.7% of all deaths were of physician-administered euthanasia without the explicit consent of the patient, representing over 1,000 deaths that year.<sup>12</sup> Similarly in 2010 in one survey in Belgium, 50% of nurses involved in administering euthanasia admitted to cases where no consent was obtained.<sup>13</sup>

In Oregon, doctor-shopping has become commonplace. Oregon Health Authority reports on assisted suicide show patients often being approved by doctors they have only known for a few days.<sup>14</sup> This impairs the ability to understand the patient and their illness, and detect coercion.

There is a growing body of research on complications in E&AS. Research published in the journal *Anaesthesia* suggested that a relatively high incidence of vomiting, prolongation of death and reawakening from coma could render such deaths "inhumane,"<sup>15</sup> while Dr Joel Zivot, writing in the *Spectator*, has observed that often, "paralytic drugs are used [in euthanasia]. These drugs, given in high enough doses, mean that a patient cannot move a muscle, cannot express any outward or visible sign of pain. But that doesn't mean that he or she is free from suffering."<sup>16</sup>

Regulation of E&AS relies on consistent and independent reporting in order to be meaningful. The European Court of Human Rights' ruling<sup>17</sup> in the case of Tom Mortier illustrates the difficulties of developing a robust system of post-mortem review. Tom's mother was Godelieva de Troyer, a

<sup>&</sup>lt;sup>8</sup> independent.co.uk/news/world/americas/christine-gauthier-paralympian-euthanasia-canada-b2238319.html

<sup>&</sup>lt;sup>9</sup> disabilitynewsservice.com/dwp-secretly-abandons-work-on-100m-plan-to-prevent-suicides-and-learn-from-errors/.

<sup>&</sup>lt;sup>10</sup> euthanasiecommissie.nl/de-toetsingscommissies/uitspraken/jaarverslagen/2021/maart/31/jaarverslag-2021

<sup>&</sup>lt;sup>11</sup> canada.ca/en/health-canada/services/medical-assistance-dying/annual-report-2021.html#a3.2

<sup>&</sup>lt;sup>12</sup> lozierinstitute.org/study-more-than-1000-deaths-hastened-without-patients-explicit-request-in-belgium/

<sup>&</sup>lt;sup>13</sup> dailymail.co.uk/news/article-1285423/Half-Belgiums-euthanasia-nurses-admit-killing-consent.html

<sup>&</sup>lt;sup>14</sup> <u>carenotkilling.org.uk/articles/oregon-2021-anorexia-hernias-feeling-a-burden/</u>

<sup>&</sup>lt;sup>15</sup> <u>carenotkilling.org.uk/articles/assisted-dying-inhumane/</u>

<sup>&</sup>lt;sup>16</sup> <u>spectator.co.uk/article/last-rights-assisted-suicide-is-neither-painless-nor-dignified/</u>

<sup>&</sup>lt;sup>17</sup> adfinternational.org/tom-mortier-ruling/

Belgian woman with long-term depression who was euthanised without the support of her psychiatrist by the co-chair of the euthanasia review body, to whose pro-euthanasia organisation she had donated money, with her son only finding out the day after she had died.<sup>18</sup>

Reporting deficiencies are widespread. The Disability Rights Education & Defense Fund tells us that:

"Oregon's annual reports on their assisted suicide statistics, highly praised by proponents as informative, actually tell us very little. Available data is quite minimal and there is no real oversight, investigation of abuse, enforcement, penalties for non-compliance, nor monitoring."<sup>19</sup>

Worthington, Regnard, Sleeman and Finlay published "the first study to compare the reporting on assisted suicide and euthanasia across all jurisdictions where it is legal" in *BMJ Supportive & Palliative Care* in December 2022. They found that:

"All of the information included within the reports is self-reported retrospectively by the prescribing clinician. Analyses from Belgium and the Netherlands, where review processes are established, have shown that 48% of assisted deaths in Belgium and one in five of such deaths in the Netherlands are not reported, and in some cases legal requirements are not followed."<sup>20</sup>

The *official* figures – E&AS as a proportion of all deaths – cited at the beginning of this answer should be read with this under-reporting in mind.

3. What are the professional and ethical considerations involved in allowing physicians to assist someone to end their life?

The World Medical Association is clear that doctors should not be required to participate in E&AS deaths and "nor should any physician be obliged to make referral decisions to this end".<sup>21</sup> All proposals brought forward pay lip service to rights of conscience, but demands are invariably placed upon healthcare professionals (including doctors, nurses and pharmacists.)

Belgium passed a new law in 2020, prohibiting bans on euthanasia in institutional care settings and forcing doctors with conscientious objections to make "effective referrals" (to doctors willing to process E&AS requests).<sup>22</sup> Canada also requires effective referrals from objecting physicians, with judges endorsing the arguments of Dying with Dignity Canada that:

"If a doctor is unwilling to take the less onerous step of structuring their practice in a manner that ensures that their personal views do not stand in the way of [facilitating E&AS] ... then the more onerous requirement of a transfer into a new specialty is a reasonable burden for that doctor to bear."<sup>23</sup>

<sup>&</sup>lt;sup>18</sup> adfinternational.org/tom-mortier/

<sup>&</sup>lt;sup>19</sup> dredf.org/public-policy/assisted-suicide/oregon-so-called-safeguards-and-minimal-data/

<sup>&</sup>lt;sup>20</sup> Worthington A, Regnard C, Sleeman KE, et alComparison of official reporting on assisted suicide and euthanasia across jurisdictionsBMJ Supportive & Palliative Care Published Online First: 30 December 2022. doi: 10.1136/spcare-2022-003944

<sup>&</sup>lt;sup>21</sup> wma.net/policy-tags/euthanasia/#:~:text=The%20WMA%20reiterates%20its%20strong,euthanasia%20and%20physician%2Dassisted%20suicide.

<sup>&</sup>lt;sup>22</sup> <u>ieb-eib.org/en/news/end-of-life/euthanasia-and-assisted-suicide/breaking-news-the-belgian-constitutional-court-rejects-the-appeal-relating-to-the-2020-law-on-euthanasia-2086.html?backto=search</u>

<sup>&</sup>lt;sup>23</sup> canlii.org/en/on/onca/doc/2019/2019onca393/2019onca393.html

What importance does the Committee place on conscience rights? What of the rights of patients in units not permitted to exclude E&AS? Do MPs agree that it is better for doctors to leave their specialties, or medicine itself, than impede an assisted suicide – especially given current NHS staffing difficulties? It is worth remembering that BMA<sup>24</sup>, RCP<sup>25</sup> and APM<sup>26</sup> surveys have all shown that doctors working in specialties closest to dying people – palliative medicine, geriatric medicine, respiratory medicine and general practice – are most opposed.

Would state funding be in question for homes and hospices which refused permission?<sup>27</sup> At least one hospice in Canada has lost funding owing to its unwillingness to provide euthanasia deaths on its premises, and a New Zealand judge has ruled that health authorities would be within their rights to consider willingness to permit E&AS when reviewing funding for hospices.<sup>28</sup>

How would financial considerations factor into the reality of legalised assisted suicide? We are all aware of the ongoing funding and staffing pressures within health and social care.

Prior to the expansion of Canada's MAiD law beyond terminal illnesses, the Parliamentary Budget Office there produced a report which estimated that under the then-law, 6,465 people would die by MAiD in 2021 – 2.2% of all deaths – with net healthcare savings of \$86.9m. The PBO expected amending the law to add 1,164 deaths to that figure in the first year alone, leading to increased healthcare savings in 2021 of \$149m – almost £87m.

Earlier that same year (2020), the journal *Clinical Ethics* published a controversial paper in which ethicist David Shaw and health economist Alec Morton argued, per *The Times*, "that granting terminally-ill patients help to die would save money and potentially release organs for transplant."<sup>29</sup>

However, focussing on improving palliative care provision instead would not only improve patient outcomes but would often also have financial benefits – without hastening patients' deaths. For example:

"Reducing unplanned and potentially avoidable hospital admissions [by guaranteeing out-ofhours palliative care access] would not only be less distressing for patients and their families, but would also reduce pressure on NHS hospitals – with around 5.5 million bed days among people in the last year of life in England, we estimate that the total cost of these admissions is more than £1.2bn" (Marie Curie<sup>30</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?

Disability rights campaigner Baroness Campbell of Surbiton has said of "assisted dying" proposals in Westminster:

"The [present] law combines deterrence with discretion... [and] rests on a natural frontier. It rests on the principle that we do not involve ourselves in deliberately bringing about the

<sup>&</sup>lt;sup>24</sup> <u>carenotkilling.org.uk/articles/bma-assisted-dying-poll-takeaways/</u>

<sup>&</sup>lt;sup>25</sup> carenotkilling.org.uk/articles/rcp-consultation-key-takeaways/

<sup>&</sup>lt;sup>26</sup> apmonline.org/wp-content/uploads/2015/05/APM-survey-on-Assisted-Suicide-website.pdf

<sup>&</sup>lt;sup>27</sup> scoop.co.nz/stories/AK2006/S00673/euthanasia-referendum-threat-to-hospice-movement.htm <sup>28</sup> toronto aitmanus as (2020/02/05/b a barries loss funding after sufficient states with a set in the s

<sup>&</sup>lt;sup>28</sup> toronto.citynews.ca/2020/02/25/b-c-hospice-loses-funding-after-refusing-to-provide-assistance-in-dying/

<sup>&</sup>lt;sup>29</sup> carenotkilling.org.uk/articles/widening-canadas-euthanasia-law-set-to-save-149m/

<sup>&</sup>lt;sup>30</sup> mariecurie.org.uk/globalassets/media/documents/policy/campaigns/health-and-care-bill-clause-16-briefing-website-version.pdf

deaths of other people. What the proponents of "assisted dying" want is to replace that clear and bright line with an arbitrary and permeable one... If terminal illness, why not chronic and progressive conditions? And, if chronic and progressive conditions, why not seriously disabled people? I am already on the list."<sup>31</sup>

Westminster bills – Falconer, Marris, Meacher – have typically followed the Oregon model: terminally ill, adult residents who doctors expect to die within six months.

Leaving aside the amendment to Oregon's law allowing the waiving a 15-day waiting period<sup>32</sup>, that state has seen a more startling expansion. Without any amendment to the statute, health officials now interpret the law as including chronically ill people who forego "administration of life-sustaining treatment".<sup>33</sup> Recent annual reports have listed underlying illnesses including anorexia, arthritis, arteritis and complications from a fall.<sup>34</sup> Those same reports frequently show patients far exceeding<sup>35</sup> six months between approval and ingestion of the lethal drugs, and of course this doesn't reflect how long they might have lived without doing so. Predicting life expectancy, especially many months from death, is imprecise: a 2017 UCL study found that over half (54%) of those predicted to die within a specified time period lived longer than expected.<sup>36</sup>

It is important to note examples of compromises in the framing of assisted suicide legislation being accepted in the short term, and later pushed back against. One year after New Zealand's E&AS law came into effect, the politician who championed its passage, David Seymour, called for one of its defining "safeguards" – a six-month prognosis being required – to be excised<sup>37</sup>. Just last year, the same campaign group which co-wrote Oregon's assisted suicide law forced the state, through the courts, to abandon its residency requirement<sup>38</sup>, and is now engaged in similar action against Vermont<sup>39</sup>.

Canada's law is not yet seven years old, and specialists and parliamentarians there are considering expansion to "mature minors" – having already extended from terminal illnesses to chronic illnesses, and with a further extension to mental illnesses in 2023 only "temporarily" paused in December. Belgium extended its law to children in 2014 by primary legislation, but politicians in the Netherlands – where the current laws already apply to children as young as 12 – are considering a similar move by regulation. The Groningen Protocol in the Netherlands, applying to disabled infants, has never been written into law by the Dutch Parliament. Once euthanasia has become accepted medical practice, incremental extension to those who cannot give informed consent can occur without Parliamentary scrutiny.

References to "unbearable suffering" are entirely subjective: how can doctors be expected to judge whether the suffering is at a degree to qualify for an E&AS death? The Netherlands' law uses similar language, requiring that "there was no reasonable alternative solution for the situation in which he [the applicant] found himself."<sup>40</sup> This broad criterion has not only seen the numbers of deaths rise year on year, but has also seen the rate of increase accelerate (as

<sup>31</sup> telegraph.co.uk/comment/10717795/It-sends-a-shiver-down-my-spine.html

<sup>33</sup> carenotkilling.org.uk/articles/six-months-redefined/

<sup>&</sup>lt;sup>32</sup> oregonlive.com/politics/2019/07/new-law-shortens-death-with-dignity-waiting-period-for-some-patients.html

<sup>&</sup>lt;sup>34</sup> Oregon Death with Dignity Act Data Summary 2021, Footnote 3, Page 14.

oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year24.pdf

<sup>&</sup>lt;sup>35</sup> <u>carenotkilling.org.uk/articles/longer-than-expected/</u>

<sup>&</sup>lt;sup>36</sup> carenotkilling.org.uk/articles/longer-than-expected/

<sup>&</sup>lt;sup>37</sup> nzherald.co.nz/nz/euthanasia-laws-too-strict-and-should-be-relaxed-act-leader-david-seymour-says/AEC6XMXQRJG35CAAZ42KDU7Y5M/

<sup>&</sup>lt;sup>38</sup> npr.org/2022/03/30/1089647368/oregon-physician-assisted-death-state-residents

<sup>&</sup>lt;sup>39</sup> cbsnews.com/news/woman-sues-over-residency-requirement-for-assisted-suicide-vermont/

<sup>40</sup> wetten.overheid.nl/BWBR0012410/2021-10-01/0

indicated at Q2.) Belgian law also uses the concept of 'unbearable' suffering. The number of deaths by euthanasia has risen over time in Belgium from just 24 in 2004 to 2,699 in 2021. The Belgian Federal Control Committee itself has stated: "the unbearable nature of the suffering is largely subjective and depends on the patient's personality, ideas and values."<sup>41</sup>

Baroness Campbell is right: the only clear, defensible, non-arbitrary line is to maintain the current law.

5. What protections could be put in place to protect people from coercion and how effective would these be?

We make no recommendations as we believe none would be sufficient.

A survey in England and Wales conducted by the charity SafeLives found that on average, victims at high risk of serious harm or murder live with domestic abuse for 2-3 years before getting help. 85% of victims sought help five times on average from professionals in the year before they got effective help to stop the abuse.<sup>42</sup> How would subtle coercion be effectively detected, particularly in a shorter timeframe when the participating healthcare professionals may not know the patient well?

At the heart of the debate on assisted suicide is a balancing of rights and responsibilities. The compatibility of the blanket ban on assisted suicide with human rights legislation has been repeatedly tested in the highest courts. Lord Justice Sales, Mrs Justice Whipple and Mr Justice Garnham concluded in 2017 that:

'It is legitimate in this area for the legislature to seek to lay down clear and defensible standards in order to provide guidance for society, to avoid distressing and difficult disputes at the end of life and to avoid creating a slippery slope leading to incremental expansion over time of the categories of people to whom similar assistance for suicide might have to [be] provided... we find that section 2 [of the Suicide Act] is compatible with the Article 8 rights [private and family life].'43

6. What information, advice and guidance would people need in order to be able to make an informed decision about whether to access assisted dying/assisted suicide services?

While we will not make recommendations, we do note that there is significant public misunderstanding concerning "assisted dying".

Former Supreme Court justice Lord Sumption has observed that although law change advocates claim "the public is overwhelmingly in favour, a lot of polling evidence suggests that that rather depends on the degree of detail which goes into the asking of the question."<sup>44</sup> 2014 ComRes polling<sup>45</sup> found that respondents moved from 73%-12% in favour to 43%-43% once just a few arguments against legalisation had been heard. A July 2021 survey in the UK found that more

<sup>&</sup>lt;sup>41</sup> Federal Control Committee, First Report, 2004, p.16

<sup>&</sup>lt;sup>42</sup> SafeLives (2015), Insights Idva National Dataset 2013-14. Bristol: SafeLives. Available at: safelives.org.uk/policy-evidence/about-domestic-abuse#top%2010 <sup>43</sup> carenotkilling.org.uk/articles/appeal-judges-dismiss-conway-bid/

judiciary.uk/wp-content/uploads/2017/10/r-conway-v-ssj-art-8-right-to-die-20171006.pdf

<sup>44</sup> downloads.bbc.co.uk/radio4/reith2019/Reith 2019 Sumption lecture 1.pdf

<sup>&</sup>lt;sup>45</sup> <u>carenotkilling.org.uk/public-opinion/assisted-dying-public-opinion/</u>

than half of respondents thought the term "assisted dying" meant "providing hospice-type care to people who are dying" or "giving people who are dying the right to stop life-prolonging treatment."<sup>46</sup> Only 42% realised that it refers to giving lethal drugs to a patient to end their life intentionally.

The Association for Palliative Medicine published feedback<sup>47</sup> from a membership survey in 2022, which found that more than half of respondents (67%) said patients and families think they are definitely or probably practicing covert euthanasia.

"Palliative care is already equivalent to euthanasia in the public's mind here – they associate syringe pumps with euthanasia and this is a myth we have to dispel on a daily basis when interacting with patients and their families in the hospital."

Most respondents (87%) felt there has not been enough press coverage of good deaths: does the vociferous persistence of "assisted dying" advocates in fact eclipse public awareness of lifechanging palliative care, to the detriment of both patients and professionals?

Doctors are expected to inform patients of all available options, even if they have a conscientious objection to taking part, as per the GMC's guidance<sup>48</sup>. A patient who expresses a wish to die needs a compassionate response and space to explore what that really means, since often it is not a genuine wish to die but an expression of another form of distress. However, a doctor who raises the issue of E&AS, may be perceived to be suggesting or recommending that as a course of action. Combined with the inevitable pressures of the cost of treatment and lack of resources, this may well lead to people seeking death by E&AS owing to external pressures.

Canada's law states that no healthcare professional commits an offence "if they provide information to a person on the lawful provision of medical assistance in dying," paving the way for a 2019 document issued by the Canadian Association of MAID Assessors and Providers which asserts that "physicians and nurse practitioners... involved in care planning and consent processes have a professional obligation to initiate a discussion about MAiD if a patient might be eligible for MAiD."<sup>49</sup>

If E&AS became legal and a mandatory part of healthcare discussions, no person with an eligible illness would be able to avoid considering the "choice" on offer and may well feel a public duty to die in order to avoid being a burden on family, friends and care services. This is increasingly the case in Oregon with over 50% of those having an assisted suicide now regularly citing this reason for seeking death.<sup>50</sup>

# 7. What capabilities would a person need to be able to consent to assisted dying /assisted suicide?

We make no recommendations, but highlight the complexities of capacity assessment. The Association for Palliative Medicine in its briefing on Baroness Meacher's Bill noted that:

<sup>&</sup>lt;sup>46</sup> <u>dvingwell.co.uk/wp-content/uploads/2021/09/Survation-Assisted-Dying-Survey-July-2021-Summary-3.pdf</u>

<sup>&</sup>lt;sup>47</sup> apmonline.org/wp-content/uploads/2022/01/APM-Member-Survey-2021-final.pdf

<sup>&</sup>lt;sup>48</sup> gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/good-medical-practice/domain-3---communication-partnership-and-teamwork#paragraph-31

<sup>&</sup>lt;sup>49</sup> nationalpost.com/news/canada/canada-maid-medical-aid-in-dying-consent-doctors

<sup>&</sup>lt;sup>50</sup> More than 54% in 2021 <u>oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Pages/ar-index.aspx</u>

"Assessing capacity to decide to die is momentous and cannot be established safely on a single assessment. The MCA [Mental Capacity Act] 2005 explicitly excludes its influence on decisions concerning assisted suicide."<sup>51</sup>

There would inevitably be decisions to make about advance directives with regards to E&AS. The Netherlands permits euthanasia for patients on the basis of mental illness and dementia (115 and 215 deaths respectively in 2021<sup>52</sup>). A Dutch woman with dementia was restrained by her family to allow a doctor to euthanise her in line with an advance directive.<sup>53</sup> When the doctor and the family sought to conduct the euthanasia procedure, the patient resisted and said no three times. The doctor put a sedative in the patient's coffee and she was held down by her son-in-law whilst the doctor administered the lethal drugs to end her life. At a subsequent trial, the doctor was acquitted and later the Supreme Court of the Netherlands confirmed that doctors acting in this way is compatible with the Dutch euthanasia law. The courts ruled that the doctor "did not have to verify the current desire to die."<sup>54</sup>

### 8. What should the Government's role be in relation to the debate?"

It has been the practice of the major parties, even where there exists a policy supportive of legal change, to allow MPs and peers free votes, and this must continue: no Government or prospective Government should bring forward a bill, or whip parliamentarians when votes occur. The Government (and parties wishing to form Governments) should also refrain from promoting a campaign they claim to be neutral on by giving it Government time.

We object to the options proposed under question five in the shorter survey. Further research into palliative care would surely be beneficial (although there is an argument to be made that what is needed is for the existing body of analysis to be given effect), but – reflecting the message of Canadian practitioners we cited in our answer to Q1 – such research must be kept entirely separate from the question of E&AS. A Citizen's assembly would usurp the proper role of elected representatives, while a referendum, as has been seen, would produce more heat than light with a yet greater focus on hard cases rather than detailed analysis of the evidence. No-one can pretend that Parliament has not considered these questions at length and in detail in recent years – through bills, committees, questions and other debates – and this should remain a question for Parliamentarians. The September 2015 Commons debate showcased Parliamentary deliberation well, and we close with the words of then-Bath MP Ben Howlett, who said in that debate:

"I admit that I came into the House thinking that I would support the Bill, but listening to the speeches made by other Members... has completely changed my mind."<sup>55</sup>

- <sup>54</sup> apnews.com/article/europe-health-courts-dementia-euthanasia-1ed45f0819e788708da51d161b48e9f8
- apnews.com/article/a041563e55204279bfb8e335a19c2802

<sup>&</sup>lt;sup>51</sup> apmonline.org/wp-content/uploads/2021/10/APM-Meacher-Bill-Briefing-to-Peers-2021.pdf

<sup>&</sup>lt;sup>52</sup> euthanasiecommissie.nl/de-toetsingscommissies/uitspraken/jaarverslagen/2021/maart/31/jaarverslag-2021

<sup>53</sup> bbc.co.uk/news/world-europe-52367644

<sup>&</sup>lt;sup>55</sup> publications.parliament.uk/pa/cm201516/cmhansrd/cm150911/debtext/150911-0002.htm#15091126001804