JERSEY ASSISTED DYING CITIZENS' JURY

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Humanists UK

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1. Hello, my name is Andrew Copson and I am the Chief Executive of Humanists UK. Humanists UK is the national charity working on behalf of the non-religious. In Jersey we are represented by our section Channel Islands Humanists, which has hundreds of members and supporters across both Bailiwicks.

2. Today I am going to make three points. First, I will share the humanist perspective on assisted dying, and explain why Humanists UK supports the right to die. Second, I will discuss why we advocate for a law inclusive of both the terminally ill and incurably suffering. Finally, I will highlight international evidence proving the efficacy of assisted dying safeguards.

Humanist perspective on assisted dying

3. Humanists recognise that all life is valuable but believe someone's *quality of life* is also important when making decisions about life and death. We value human beings' *personal autonomy* and believe they should have the right to make their own decisions about how they live and die.

4. We support legal assisted dying for numerous reasons, but critically because:

   (a) We think autonomy is a fundamental human right, and Jersey's citizens deserve the same rights as currently enjoyed by more than 350 million people around the world.

   (b) Palliative care has unavoidable limits, and it cannot give everyone the good death they'd want. For example, in the UK, even if everyone got the

best possible palliative care it's estimated over 6,000 people would still die with no relief in the final stages of their life.[1]

(c) Assisted dying is an equality issue. Currently only those who can afford the £10,000 cost of going to Switzerland are able to die with dignity.[2] For most people, the only legal option is starving oneself to death. This is cruel and inhumane.

Eligibility for assisted dying

5. With regards to who should be able to access an assisted death, we think in many cases such people will be terminally ill. But we don't think there is a moral case to limit assisted dying solely to people with six months left to live. Instead we think incurably suffering people should also be eligible, provided they have made a clear, well-considered, and voluntary decision.

6. For the avoidance of any doubt, what that would mean is that someone suffering from a horrible and terminal condition, such as cancer, could ask for help, but equally so could someone like Tony Nicklinson – who was paralysed from the neck down and faced years of increasing misery before he starved himself to death.

7. There are three strong reasons underlying our position:

    a. As a matter of principle, we think a six-month rule would be discriminatory against the incurably suffering. This is significant because the suffering of people with incurable illnesses is no less severe than those with terminal conditions. If anything, it's worse since people with incurable illnesses face longer periods of pain without reprieve.

[1] According to the Office of Health Economics, even if every dying person who needed it had access to good quality palliative care, 6,394 people would still have no effective relief of pain in the final three months of their life. This would equate to 17 people dying in pain every day. See: Zamora *et* al, 'Unrelieved Pain in Palliative Care in England' Office of Health Economics (2019). Available at: https://www.ohe.org/publications/unrelieved-pain-palliative-care-england

[2] According to research from the UK Assisted Dying Coalition, at least one Brit per week travels to Switzerland for an assisted death. See: 'UK's first Assisted Dying Coalition formed to campaign for millions who want right to die', Humanists UK (2019). Available at: https://humanism.org.uk/2019/02/08/uks-first-assisted-dying-coalition-formed-to-campaign-for-millions-who-want-right-to-die/

b. Internationally the vast majority of countries favour an inclusive change in the law. Assisted dying is legal or will soon become legal for people with terminal and incurable medical conditions in Austria, Belgium, Canada, Italy, Germany, Luxembourg, the Netherlands, Switzerland, and Spain. It is also what is proposed in Ireland. This shows that in the eyes of all these countries, safeguards are possible even with the incurably suffering.

c. Imposing a six-month limitation is arbitrary and we fear it would prove unworkable in practice. According to the recent BMA consultation – the largest survey of medical opinion ever in the UK – if the law were to change, 59% of doctors would prefer for assisted dying to be inclusive of those with incurable illnesses.[3] That's because doctors freely admit they cannot accurately predict when someone only has six months left to live. But even if they could, there is no reason why someone becomes more deserving of a choice when they have six months to live, rather than seven, or eight etc.

Safeguards and protection of the vulnerable

8. Although we firmly support the legalisation of assisted dying, we believe a change in the law must be accompanied by strong and robust safeguards.

9. It is clear that where assisted dying has been made legal, there is no credible evidence it has ever posed any threat to vulnerable people. Whilst numerous independent studies prove this, I would encourage the panel to look at the three studies most pertinent to the countries it has been tasked with considering. They are attached to my remarks.[4]

[3] 'Doctors vote to end assisted dying opposition in landmark BMA survey' Humanists UK (2020). Available at: https://www.mydeath-mydecision.org.uk/acclaimed-doctors-call-upon-parliament-to-stop-ignoring-assisted-dying-reform/

[4] First, probably the most comprehensive study to squarely address if legal assisted dying places vulnerable groups at risk, is a 2007 investigation by Professor Battin *et al*. It focused on the impact of assisted dying in Oregon between 1998 and 2006 and the Netherlands between 1990 and 2005, and concluded that in both countries people were accessing assisted deaths free from coercion. The result was a reduction in suffering. For example it found: *'[the authors] found no evidence to justify the grave and important concern often expressed about the potential for abuse—namely, the fear that legalised physician-assisted dying will target the vulnerable or pose the greatest risk to people in vulnerable groups … [and] there is no current factual*

10. In summary, we invite this panel to recommend Jersey takes a leading stance on assisted dying, by supporting the legalisation of a right to die for adults of sound mind, who are either terminally ill or incurably suffering, subject to robust safeguards.

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support for so-called slippery-slope concerns about the risks of legalisation of assisted dying – concerns that death in this way would be practised more frequently on persons in vulnerable groups.'

See Battin *et al*, 'Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in ''vulnerable'' groups', J Med Ethics 2007;33:591–597. Available at: https://web.archive.org/web/20150906114244/https://livinganddyingwell.org.uk/sites/default/files/LDW%20-%20Research%20-%20Oregon%20-%20Battin.pdf

Equally, a separate independent study from Dr Deliens *et al* focused on Belgium in 2009 and similarly reported that:

> *'The repeatedly expressed concern that vulnerable people (older people, disabled people, those with psychiatric disorders) would more easily receive euthanasia is not supported by our data. On the contrary, we found that requests for euthanasia from patients 80 years and older are granted less often and withdrawn more often.'*

See Deliens *et al*, 'Physician-Assisted Dying and the Slippery Slope: the Challenge of Empirical Evidence', (2008) 45 Willamette L Rev 91). Available at: https://www.nejm.org/doi/full/10.1056/NEJM200002243420806

Finally, a rigorous study on Canada's assisted dying regime by Dr James Downar *et al*, the current head of palliative care at the University of Ottawa, found that:

> *'Another common concern about the legalization of MAiD is the potential for people who face social or economic vulnerabilities to be pressured into MAiD. However, our data indicate that people from traditionally vulnerable demographic groups (from an economic, linguistic, geographic or residential perspective) were far less likely to receive MAiD, consistent with findings from the US and Europe.'*
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> *'...The practice of MAiD in Ontario is most common among elderly, community-residing patients with cancer, neurodegenerative disease or end-stage organ failure who are in the final months of life. Our findings that Ontario residents who received MAiD were frequently already followed by palliative care providers suggests that MAiD requests are unlikely to be the consequence of inadequate access to palliative care in Ontario. Recipients of MAiD in Ontario were younger, wealthier, more likely to be married and substantially less likely to live in an institution than the general population of decedents, suggesting that MAiD is unlikely to be driven by social or economic vulnerability.'*

See Dr Downie *et al*, 'Early experience with medical assistance in dying in Ontario, Canada: a cohort study', CMAJ February 24, 2020 192 (8). Available at: https://www.cmaj.ca/content/192/8/E173