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Preamble:

As a severely disabled person I was strongly opposed to Assisted Dying until I sat on the Commission on Assisted Dying (2011-2012). The evidence that emerged from this Commission resulted in me changing my mind. Evidence-based policy making should sit at the heart of everything. I would be very happy to give oral evidence to the Enquiry.

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1. Introduction

- a. It is important not to conflate 2 very different issues. Ineffective social care and poor practice in the use of Do Not Attempt Resuscitation (DNAR), tragic as they are, need to be addressed. But opposing Assisted Dying Legislation will not achieve this.
- b. On the contrary, effective safeguards that balance autonomy and protection are more likely to improve the DNAR process and have a positive impact on Social Care. Evidence for this comes from Victoria (Australia) that facilitated the constructive engagement of the disability community in drafting the legislation.

2. People/Organisations that have changed their mind

- 1. Disability Rights UK were opposed to Assisted Dying as recorded in 2 tweets from Not Dead Yet in 2015 <https://twitter.com/notdeadyetuk/status/641337374878887937> and in 2016 <https://twitter.com/notdeadyetuk/status/697541038639071234> . This is supported by the Witness Statement of David George Foster, 26 June 2017, that was presented to the High Court listing Disability Rights UK as a member of Care Not Killing, a Christian alliance opposed to Assisted Dying. Further support illustrating opposition is on DRUK’s website from 2015 <https://www.disabilityrightsuk.org/news/2015/september/our-position-proposed-assisted-dying-bill>
- 2. Now, in the Disability Rights UK E-Newsletter dated 23rd July 2021 states: Kamran Mallick, CEO of Disability Rights UK said “Disability Rights UK currently has a neutral position.”
- 3. Disability Rights Oregon Executive Director, Bob Joondeph confirmed in a letter dated 14th February 2019, that: “Disability Rights Oregon has never received a complaint that a person with disabilities was coerced or was being coerced to make use of the Oregon Death with Dignity Act”.

4. Lord Carey, former Archbishop of Canterbury. "The moral (and, for me, the Christian) case for a change in the law is irrefutable. Covid-19 has forced us all to rethink our certainties about death and dying. How can a country that cares so deeply for victims of this virus be so indifferent to those who, at the end of life, suffer indignity and intractable pain?"
5. Dr Taj Hargey, Muslim academic and Imam, "Forward-looking Muslim scholars and liberal theologians promote individual thinking that is relevant to modern Britain. This religious focus embodies all aspects of human rights including to die with dignity at the end of life with assistance through an act of compassion".ⁱ
6. Archbishop Desmond Tutu said: "Terminally ill people 'should have right to choose a dignified assisted death', on his 85th birthday. Desmond Tutu has said he would like the option of ending his life through assisted dying as he called on politicians, lawmakers, and religious leaders to take action on the issue."ⁱⁱ
7. Former Chair of the Committee on Ethical Issues in Medicine at the Royal College of Physicians. "As a doctor I used to think palliative care was the answer. Now I realise that keeping people alive can be unspeakably cruel"ⁱⁱⁱ
8. A newspaper article about Lord Rix stated, "The actor Lord Brian Rix has changed his mind to support assisted dying after his terminal illness left him wanting to end his own life. Lord Rix, once one of Britain's most popular stage and television actors, was a campaigner for people with learning disabilities and the president of Mencap."^{iv}
9. Dr David Grube, who practiced family medicine in Oregon before retiring in 2012, once opposed aid-in-dying. But he said that as more states have legalized aid-in-dying and no evidence has emerged that patients are being pressured into the process, more people are becoming comfortable with the idea. "It's like same-sex marriage," said Grube, who is the medical director of Compassion and Choices. "Forty or 50 years ago, I didn't even know what a homosexual was. Now I see people in loving relationships, and that's great."^v
10. Ann Jackson, the CEO of the Oregon Hospice Association from 1988 to 2008 said: "I really did believe that good palliative care could address the needs of people who were dying...The main thing I've learned is that that is not true. We may be able to address pain and symptoms, but we cannot address the futility some people feel at the end of life, the suffering they feel over their loss of autonomy. Hospice care cannot allow people to control their lives if they are going to deny them the right to die at a time of their own choosing."^{vi}
11. At the same time, the Oregon Hospice Association did campaign against law changed but then dropped its opposition when they saw the law was working well.
12. Nick Boles, former MP, has also changed his mind, he said "Every year hundreds of other people face the prospect of great suffering at the end of a terminal illness suffering that cannot be alleviated by our wonderful palliative care nurses and have no legal means of doing enough to stop it."^{vii}
13. Andrew Mitchell MP said: "I was so adamantly opposed to assisted dying until I heard stories from so many of my constituents. Often with tears pouring down their faces, they have given me deeply

intimate details of the last days of someone they loved but who died a miserable and sometimes very painful death. I have changed my mind.”^{viii}

14. Lord Low stated: “Being disabled myself and a lifelong campaigner for disabled people’s rights, I can testify that not all disabled people are opposed to assisted dying. Recent proposals for assisted dying legislation contain more safeguards against disabled people being officiously treated as terminally ill against their wishes than exist now. Assisted dying legislation is about giving people choice and control at the end of life. This is what disabled people campaign for in every other aspect of life. Why would they not also wish for it at the end?”^{ix}
15. Notable disabled people including many disability activists support Assisted Dying^x
 - a. Stephen Hawking (1942-2018) Renowned cosmologist and theoretical physicist said: *“I think those who have a terminal illness and are in great pain should have the right to choose to end their lives, and those that help them should be free from prosecution.”*
 - b. Hugh Gallagher (1932-2004) Paralyzed from age 19 until his death at 71; drafter of the Architectural Barriers Act of 1968, the nation's first federal disability rights law, which led to the broader accessibility provisions of the 1990 Americans with Disabilities Act said: *“As a disabled person who has fought for my civil rights I see assisted dying as a matter of personal autonomy. I make the decisions. While I do not believe that I would ever make use of assisted dying, I believe it would be a comfort and support knowing that it is available.”*
 - c. Andrew Batavia (1957 - 2003) A disability rights activist who helped draft regulations for the Americans with Disabilities Act. In 2002, he co-founded Autonomy, Inc., to represent persons with disabilities who wanted choices and control over their lives, including the option of medical aid in dying for those who were terminally ill.

3. Key Messages

1. A terminally ill person requesting an Assisted Death is not choosing between living and dying. They are choosing between 2 different ways of dying; either enduring avoidable suffering or a peaceful death surrounded by family and friends celebrating life.
2. Disabled People opposing Assisted Dying often do so because they see it devaluing disabled people’s lives. They fail to recognise that opposition on the grounds of disability devalues us even more profoundly by ignoring our diverse voices and refusing to respect our autonomy.
3. Disability alone (without terminal illness) will never meet the eligibility criteria set out in the proposed UK legislation.
4. Most disability groups do not oppose assisted dying for terminally ill adults, but some high profile groups do (Box et al, 2021)^{xi}
5. There is no hierarchy of Human Rights. The rights of Disabled People are no more important, or less important than the rights of Dying People to autonomy, choice, and control.
6. Future generations will look back at the horror we subjected dying people to. They will read of bereaved relatives and ask why parliamentarians failed to act; why institutions insisted our law was adequate, paying no attention to the evidence; why the voices of dying people were ignored.

7. The argument for assisted dying is fundamentally about giving people choice and control at the end of life. It is curious that those who campaign for choice and control in every other aspect of disabled people's lives balk at it being given to terminally ill people at the end of life.
8. Currently during the last few days of dying with a terminal illness: "Some will vomit faeces. Some will retch at the stench of their body rotting. Some will suffocate over several days as their last moments are disfigured by terror," Dr Brill Crawley (Palliative Care Consultant).
9. Currently dying people and non-dying people, (e.g., those in a permanent vegetative state or with locked-in syndrome, or people at the end stage of motor neurone disease, Multiple Sclerosis, and many other conditions) can refuse treatment such as oxygen, chemotherapy, or dialysis. If they are not receiving medical treatment, they are permitted to stop eating food or drinking water and this results in a long, slow, cruel death. But this is the only option they can take if they want to die.
10. In 2018 Mavis, 80, helped husband Dennis, 81, overdose in pursuit of an assisted death to escape his suffering from terminal cancer. Mavis also overdosed and was hospitalised. Dennis died. Mavis was imprisoned for 30 hours still wearing her hospital gown. She endured an 18 month court case, whilst grieving for Dennis, until found innocent. After Dennis's death, 5000 miles away in Oregon, Frankie, and Charlie, married for 66 years, died peacefully in their sleep. Frankie, 88, had unbearable heart disease and Charlie had prostate cancer. They were dying, but they were able to take control by the legislation, so they took their medicine and died.
11. Charlie Kentish WW2 veteran developed terminal cancer 3 days before his 94th birthday. He begged for help to end his life, but because of the law, he went unheard. He spent months unable to swallow or live life on his terms. He died in his garage after taking his life.^{xii}
12. Research shows that those with cancer are at a high risk of suicide. About 2.5 times higher risk than the general population. Experience demonstrates that Assisted Dying significantly restricts suicide amongst dying people. Once empowered at the end of life people aren't forced to end their lives by violent means, afraid and alone just to end their suffering.
13. There is an irrefutable moral and ethical case for assisted dying but there is also logical one. Opposing assisted dying because of speculative concerns about how safe or unsafe it might be are hypocritical when we consider protections around current end-of-life choices. These have far more potential for abuse and harm for disabled people, which must not be allowed to continue (e.g., DNAR abuse, outsourcing the problem to Dignitas, coercion resulting in suicide, and doctors making decisions without transparency or oversight).
14. Moving decision-making power away from clinicians to individuals and promoting the importance of a shared understanding at the end of life (which is what an assisted dying law seeks to do) will protect not threaten disabled people.
15. 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.^{xiii}

16. "Assisted Dying harms no one and benefits those who make their request to take prescribed medication. This is achieved by spurring conversations about their end-of-life options, including hospice and palliative care, and it leads to better use of them" Dr Omega Silver former president of the American Medical Women's Association.^{xiv}
17. Having access to Assisted Dying does not mean that you must follow it through, but it does mean that the reality of its availability releases anxiety, gets rid of fear and significantly improves your quality-of-life for as long as it lasts. It is like an insurance policy; people know it is there if they need it. Many more request assisted dying then use it in Oregon.
18. In 2021 Mr Hancock wrote to Sir Ian Diamond, the National Statistician, asking whether he has any figures on the number of Britons who kill themselves after being diagnosed with a terminal illness. Why is he interested? The answer is that he apparently wants to pursue a subject that many believe goes to the heart of what kind of society we believe ourselves to be. Should we allow doctors to help people to die? Mr Hancock wants a new debate on the matter and thinks Sir Ian's figures could inform it.^{xv} Article by John Humphrys of the BBC.
19. Dr Bill Crawley, Palliative Care Physician: "Suicide is dreadful for the relatives when they find the body and travelling to Dignitas requires you to die early because you need to be fit to travel".^{xvi}
20. Opponents of Assisted Dying claim that we must protect 'vulnerable people' from coercion and that a new law would remove existing protection. However, the opposite is the case. If there is any coercion under the current legislation that pushes people towards suicide, there are no protections until the individual is dead. Surely coercion is better identified in advance and prevented rather than after someone is dead?
21. The Journal of Medical Ethics reported a study of the Oregon Assisted Dying act that: "showed no evidence of heightened risk for elderly people, women, people with low educational status or poor people, disabled people and chronically ill people, people with psychiatric illnesses, or ethnic minorities. Most people who seek out and Assisted Death are aged 65-84, white, well educated, have medical insurance and have cancer"^{xvii}
22. Science Direct reports that 20% of GPs report using Continuous Deep Sedation but it is well known and well recognised that a significantly higher proportion use it. This results in the "Doctrine Of Double Effect" as GPs can justify increasing morphine doses to kill the pain whilst at the same time killing the patient without risk of breaching the Suicide Act 1961.^{xviii}
23. Being unconscious for medication to treat intractable pain is the same as being dead, and Continuous Deep Sedation induces unconsciousness just as Assisted Dying causes death. So, the "Doctrine of Double Effect" does not establish a moral difference between CDS and Assisted Dying.

24. In the Supreme Court British Columbia, Justice Lynn Smith concluded that a system with properly designed safeguards could prevent vulnerable persons from being induced to commit suicide by family whilst permitting, fully informed persons acting voluntarily to receive Assisted Dying.^{xix}
25. Paul Blomfield MP was close to tears in the Commons as he told fellow MPs that his father took his own life after a terminal cancer diagnosis. “He had always said that he would rather end things than face a degrading death.” July 2019^{xx}
26. Prof Paul Cosford, Medical Director at Public Health England was aware that his lung cancer would end his life. He had never smoked. He demanded control over his final days. “I might have a diamorphine pump, the idea of having an extra vile in the fridge to me to use is appealing.”^{xxi}
27. Dr Henry Marsh, acclaimed neurosurgeon with terminal cancer speaks out for assisted dying “... Opponents to assisted dying oppose an enquiry because the evidence is so strong that their hypothetical arguments against it don’t hold water, they will lose the debate.”^{xxii}
28. Tom Shakespeare’s note on the 3 types of disabled people – dying, progressive & stable but impacted by the ageing process is important as it relates to assisted dying. The Commission on Assisted Dying recognised the importance of this distinction and in its final report stated: “The intention of the Commission is to... establish a clear delineation between the application of assisted suicide for people who are terminally ill and others with long-term conditions or impairments. The adoption of this distinction in any future legislation would send a clear message that disabled people’s lives are valued equally.”^{xxiii}
29. A research study in the Journal of Medical Ethics “DROs need to be involved in the policy debate so that the crucial perspectives of PwD are heard and addressed. This is an important message for countries around the world that permit, or are considering legalising, assisted dying”^{xxiv}

4. Oregon Death with Dignity Act Data Summary Report 2020

Summary

The Act requires the Oregon Health Authority (OHA) to collect information about the patients and physicians who participate in the Act and to publish an annual statistical report. In 2020, 370 people were reported to have received prescriptions under the DWDA. As of January 22, 2021, 245 people had died in 2020 from ingesting the prescribed medications, including 22 who had received prescriptions in previous years. Demographic characteristics of DWDA patients were similar to those of previous years: most patients were aged 65 years or older (81%) and white (97%). While cancer still accounted for most underlying illnesses (66%), patients with heart disease (11%) outnumbered those with neurological disease (8%) for the first time in 2020.

5. References

ⁱ https://www.youtube.com/watch?v=4L_SnC7w13o&t=7s

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ⁱⁱⁱ <https://www.thetimes.co.uk/article/why-i-changed-my-mind-on-assisted-dying-0phq6d2t7gh>

^{iv} <https://www.independent.co.uk/news/people/lord-brian-rix-assisted-dying-suicide-bill-terminal-illness-a7178766.html>

^v <https://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2018/03/09/aid-in-dying-gains->

momentum-as-erstwhile-opponents-change-their-minds

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- xxi <https://news.sky.com/story/assisted-dying-medical-director-with-incurable-lung-cancer-calls-for-a-review-of-existing-laws-12086205>
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