

Written evidence submitted by Disabled People Against Cuts, Ellen Clifford (ADY0491)

Introduction

This submission is sent on behalf of:

Disabled People Against Cuts which is a national campaign group led by Deaf and Disabled people. The campaign was set up in response to the disproportionate impact of welfare reform and austerity measures on Deaf and disabled people.

1) To what extent do people in England and Wales have access to good palliative care?

Health and social care provision in England and Wales is extremely underfunded. This includes provision for Palliative care, which requires more investment. Currently, a significant proportion of end-of-life care is provided by hospice charities, which are reliant on fundraising and voluntary donations to survive.

Good quality social care provision is necessary to ensure dignity in living for disabled people, including individuals receiving palliative care. Over a decade of cuts to social care has stripped disabled people of their independence and autonomy. This, alongside society's narrative of disabled people being a burden, results in individuals feeling that the only option available to them is to end their life.

Good quality palliative care and adequate social care provision go hand in hand to ensure dignity in living. The current inequalities in the health and social care system mean that there are groups of individuals who are disproportionately disadvantaged. This creates a significant risk that individuals with life limiting conditions will make the choice to end their lives, not to end pain/suffering, but because it is the only way out of an impossible and undignified way of living.

This is what is happening in Canada now. It is important that the inquiry considers the situation in Canada and hears about cases such as those of Amir Farsoud who was approved for Medical Assistance In Dying (MAID) which he sought not because of the back pain he experienced but because of poverty and fear of homelessness,¹ or of Alan Nichols who was killed despite concerns being raised by his family and a nurse practitioner that he did not qualify and did not have capacity to consent. They reported the case to police and health authorities alleging that mental health hospital staff had improperly helped him request assisted suicide.² The inquiry should also be made aware of concerns raised by human right experts in Canada including Canada's Human Rights Commission.³

2) How can palliative care be improved, and would such improvements negate some of the arguments for assisted dying/assisted suicide?

¹ <https://www.dailymail.co.uk/news/article-11441995/Canadian-man-facing-eviction-accepted-countrys-controversial-legal-EUTHANASIA-program.html>

² <https://apnews.com/article/covid-science-health-toronto-7c631558a457188d2bd2b5cfd360a867>

³ <https://apnews.com/article/covid-science-health-toronto-7c631558a457188d2bd2b5cfd360a867>

Given the advances in modern medicine, there is absolutely no need for anyone to experience or to die in pain. Palliative care needs to be funded adequately so no one has to fear or be at risk of a painful death.

Additionally, awareness raising of palliative care services and provisions is crucial, to address the concerns and fears the public may have around dying in pain.

Access to good quality social care provision is necessary to ensure that individuals are able to live with dignity. As mentioned above, cuts to social care support have resulted in disabled people having to go without support to meet their basic needs, in most cases, due to the financial implications, further exacerbated by the current cost-of-living crisis.

3) What can be learnt from the evidence in countries where assisted dying/assisted suicide is legal?

We need to learn how difficult it is to set limits and safeguards and how once legalisation occurs, how the scope of the law can be expanded through legal challenges and case law. Moreover, we need to learn the extent to which disabled people's lives are devalued and how legalisation encourages the view that disabled people are a burden on society and have a social obligation to terminate their lives. We also need to learn from evidence that palliative care and treatments/therapies to prolong life are undermined and disinvested in following legalisation.

Additionally, we need to learn from countries, such as Canada, where disabled people are choosing to end their lives because they do not get enough support to live. Research suggests that in the vast majority of cases, ending pain and suffering is not the primary reason people are choosing to end their lives. Instead, their reasoning is based on the notion that they are a burden on society, a notion that is perpetuated on an individual, cultural, and political level. Shockingly, there are examples where assisted suicide is being offered as an alternative to adequate living conditions—A recent case involved a disabled person asking for a ramp to enable wheelchair accessibility, and the professional involved asked if they had considered assisted suicide.⁴ In light of this, we need to learn from other countries how easy it is for people to be pressured into (assisted) suicide.

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

Assisting somebody to end their life contravenes the principle of 'do no harm' under which physicians are required to practice.

Additionally, there is an existing distrust of medical professionals amongst many disabled people. This is due to the fact that the vast majority of medical practice is underpinned by the medical model of disability—a model which views disabled people as broken, and consequently of no value to society. Additionally, it is extremely unlikely that disabled people will be able to trust medical professionals to keep them alive when those professionals are, at the same time, supporting other disabled people with the same conditions to end their life.

⁴ <https://www.bbc.co.uk/news/world-us-canada-64004329>

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

None – this must not be an option.

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

Assisted suicide must not be an option.

Disabled people are 2 to 3 times more likely to experience domestic abuse, compared to non-disabled people. This includes coercive and controlling behaviour. It is argued that such coercive behaviours would increase, should assisted suicide be legalised, given the current attitudes towards disabled people in society.

7) 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?

None – This must not be an option.

8) What capabilities would a person need to be able to consent to assisted dying/assisted suicide?

None – This must not be an option.

9) What should the Government's role be in relation to the debate?

We call upon the government to ensure that everyone has adequate support to live without feeling a burden on their families and society, and with the same opportunities as non-disabled people. This includes adequate investment in health and social care (including palliative care), so that no one has to die in pain.

In addition, the cost-of-living crisis, which disproportionately affects disabled people, has significantly eroded the quality and dignity of living for disabled people, who are struggling to afford additional disability-related expenses (E.G., the costs of running electrical equipment), on top of costs of basic necessities such as food and energy. Britain's social security system is less generous than most other high-income countries. Britain is one of only four countries to see a large fall in overall Welfare Benefit Generosity (WBG) over the past forty years with WBG in 2018 more than 10% lower than its 1980 level.⁵ If disabled people are unable to meet their basic needs due to poverty, there is a danger that legalisation of assisted suicide would lead to the most disadvantaged people in society choosing death in response to the inadequacies of the social safety net. Politicians like to say that they are "protecting the most vulnerable". For this to be true, benefit reform is essential before legalisation can be considered.

⁵ Comparative Welfare Entitlement Project (CWEP – Version 2022-01) data: <https://ukandeu.ac.uk/how-generous-is-british-welfare/>

In conclusion, we call upon the government to focus on, and invest in, our right to live, rather than our right to die.

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