

## Written evidence submitted by Dr Philip berry (ADY0111)

I write this as a consultant physician who has published on the subject of assisted dying (AD) in a peer reviewed medical journals (1, 2). I am a supporter of A and work with terminally ill patients alongside palliative care teams. As such, I have tried to avoid a polarised position. Latterly, I have been concerned about the rapid extension of AD legislation to non-terminal conditions, for instance in Canada. I believe a law restricted to terminal conditions can and should be passed in the UK. As discussed in section 1 below, we must ask ourselves whether anxieties around socio-economic factors will result in infinite delay and a continued inability for society to accommodate the needs of those who wish to maintain control over their timing and manner of their death. In the second section, I explore the principle of a right to a private life, as explored through other end of life legal cases.

1 - Berry PA. From Empathy to Assisted Dying: An Argument. *Clinical Ethics*. 2013;8(1):5-8.

doi:10.1177/1477750912474765

2 - Berry P. Giving dying people what they want *BMJ* 2013; 347 :f4982 doi:10.1136/bmj.f4982

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### *1. Reflections on the Canada experience*

Since medical assistance in dying (MAiD) became legal in 2016, over 31,000 Canadians have died by lethal injection or self-administered prescription. It is clearly a 'successful' policy, as the number of patients dying in this way appears to confirm a previously unmet need. It is important to note that the criteria for MAiD were liberalised in 2021, such that terminal illness was no longer a pre-requisite.

However, accounts have now come through about patients who were driven to MAiD not because of intractable symptoms associated with terminal illness, but because of despair related to socio-economic circumstances. An investigation by Alexander Raikin (Dec 16th 2022) appears to confirm that non-medical factors are accepted by MAiD physicians as valid reasons to seek an assisted death, and are in fact discussed openly in training seminars. Raikin provides slides from an on-line meeting, and highlights the relevant sentences in the cases that were discussed. The article highlights individual cases where patients have been open about their motives for seeking death, such as Les

Landry who wrote on his application, “I turned 65 [and] lost all m[y] disabilities benefits and now a senior in poverty. I am not going to live my life like this.” Raikin criticises MAiD proponents not only for considering these factors, but actually championing the fact that Canadian law has drawn attention to their importance. Raikin writes,

*It’s as if the situation offers a silver lining. Reel [a MAiD practitioner] excitedly talks about the problem as an “extraordinary lever” to lobby for improved welfare. Gibb-Carsley’s [another participant] slideshow concludes, “trust in the evolution of this field of practice,” meaning the practice of euthanasia. “Your Assessments provide a rare opportunity to hear from the typically disenfranchised patients about their experiences.” The subtext of this sunny euphemism is that giving a voice to the voiceless will, for many, ultimately mean killing them.*

How can I, as a supporter of assisted dying, reconcile these quite concerns with the ongoing campaign to legalise assisted dying (AD) in the UK? It is a moment to reflect and consider whether, after all, those who oppose AD have been right all along. Are we happy to continue that support while watching thousands of vulnerable people slide down a slippery slope in Canada?

Inevitably, one seeks to rationalise the observations from Canada. However many stories are exposed, the number remains tiny compared to those who were granted a peaceful death for the right reasons. Next, it seems reasonable to assume that the vast majority of doctors involved in assessing applications for MAiD do so objectively, professionally and with patients’ best interests uppermost in their minds. It is too much to conclude, surely, that there is some awful national conspiracy among the ranks of MAiD practitioners to rid society of the vulnerable or those who ‘cost’ too much. More likely, they are a volunteer group naturally predisposed to respect applications, and who look not to block but to facilitate the wishes of those who wish to die within the law. Finally, the possibility that negative reports about MAiD are written by journalists or commentators with pre-existing agendas must be considered; it is important, for instance, that authors declare their religious position, as any views that are grounded in faith or doctrine may not be applicable to those who do not believe.

Despite all of the above, if individuals are applying to MAiD for the wrong reasons, and successfully gaining assistance in dying, it must be accepted that the law is not functioning in the way it was intended. There are no sensible advocates of AD in the UK who would agree that poverty or isolation are valid reasons to die.

Here is an uncomfortable question: Does AD law need to be 100% safe (i.e. each case clearly and solely driven by physical symptoms)? This question may sound perverse ('Of course it does!' will be the most common response), however we know that although zero risk and zero harm are the ideals for any new procedure or pathway, they are probably unrealistic. In the UK we have Never Events, medical accidents that people have invested years of effort in order to eradicate, yet still they occur, week on week. We need to be clear on where AD sits within the tolerance for risk. Surely, we cannot lump AD in with all the other 'treatments'. Maximum security *is* required, for it is final, irreversible and exists on an entirely different moral plane. It sits in its own, exceptional category of healthcare.

Next, we must consider suffering. Without being drawn into complex philosophy or Kierkegaardian reflections on the human condition, it can be argued that patients who experience physical symptoms associated with terminal disease suffer on more than just that level. Assisted dying laws are naturally written to account for the symptoms of physical illness, but the application of those laws must be able to accommodate other forms of despair that accumulate around ill-health. This is not to say that anxiety about money or accommodation should feature in the decision to allow AD, but it would be naive to imagine that patients making an application will have no other concerns. It is incumbent on physicians to appreciate the patient as a whole person, and to understand the whole situation. To do this, questions must be asked about social and economic factors. Having obtained that information (for instance, anxiety around large credit card bills) it would be quite artificial not to document that or consider it as a part of the complete picture.

The greater challenge is trying to understand whether that anxiety, which may be unrelated to the disease but which is part of the patient's life, is driving the person towards death. It would take a very skilled psychologist or psychiatrist to determine that. I can imagine some hesitancy around forcing that question during an assessment for AD; the person has made an application and their capacity to do so is presumably unquestioned; is it right then to press them on how much of their motivation derives from socio-economic factors? In order to guarantee that social factors are *not* a factor, it will be necessary to screen patients who apply for MAiD such that those with difficult (and not easily reparable) economic circumstances were excluded. This could in itself be unethical. This point is made in Raikin's article. Ellen Wiebe, a 'poster child for Canadian medical death' (Raikin's words),

*...declined requests to be interviewed for this article. Asked for comment about her statements in the seminar, she responded: "It is rare for assessors to have patients who have unmet needs, but it does happen. Usually these unmet needs are around loneliness and poverty. As all Canadians have rights to an assisted death, people who are lonely or poor also have those rights."*

This is an intriguing rebuttal. Poverty and isolation exist. We cannot exclude those who experience such social disadvantages.

As I write this, I feel uncomfortable. Am I trying to justify an allowance for those in a difficult financial or social position to successfully leave a world that has not been kind to them or delivered success as most of us would identify it? What kind of doctor would do that?

Ultimately, supporters of assisted dying must decide if their almost sacred respect for autonomy, and their insistence that autonomy supersedes other considerations, outshine the warning lights that are flashing in Canada. We must answer this question and others if we are to press on with an assisted dying law in the UK.

- Do we accept that suffering is more complex than pain or fear of an uncontrolled death, and those complexities should be allowed to drive someone towards an unnatural death?
- Are we comfortable that physicians will bring their own values to the screening process?
- How will we respond when stories about patients who shortened their existence for reasons other than ill-health appear?
- Are we content, as a society, to pass a law that is not *absolutely* safe? Are the hidden harms of *not* passing a law greater than the risks of passing it?

I do not pretend to provide answers here. This reflection is in anticipation of the questions that are bound to be directed at campaigners for AD in this country. Stories from Canada will colour speeches made by MPs who oppose a change in the law. Answers and assurances are needed if the UK is to join the growing number of countries where terminally patients can exercise the ultimate choice.

## *2. The right to a private life, with reference to previous judgements on end of life decisions*

How far does the right to 'private life' go? Noel Conway, who had motor neurone disease, felt that his inability to arrange an assisted death without fear of his 'assistant' being prosecuted, was an intrusion on his right to private life. He was barred from taking steps to manage his death in the way he would like. His legal team argued that the current law results in someone with severe physical disability such as his being discriminated against. Thus, they proposed that two articles of the European Convention of Human Rights (ECHR), 8 and 12, are contravened by the 1961 Suicide Act.

Article 8 has been examined in relation to end of life issues several times over the last few years. Most recently, the Janet Tracey case touched on it from a quite different direction – was her right to private life infringed by medical staff who did not engage her in discussion about a DNACPR notice?

It is interesting to look at the Tracey judges' reasoning in the light cast by Noel Conway's situation. Firstly, do DNACPR decisions have anything at all to do with assisted dying (AD)? I would say yes, insofar as discussions and decisions around CPR relate to what goes on in the last hours or minutes of life. They relate to patients wishes as regards dignity, and how their body is physically handled. They reflect a patient's attitude to mortality, and whether they feel ready to die without final, heroic measures (of course, we know that the CPR decision does not ultimately rest in the patient's hands, but their view on it remains of paramount importance).

The judges in the Tracey case thought so too, for they invoked the case of Diane Pretty (see below), confirming that from a legal perspective there is a degree of overlap. They begin by setting out the case against the medics (embodied in this instance by the 'secretary of state' [SoS]);

The claim as now advanced against the Secretary of State is that he breached Mrs Tracey's article 8 rights by failing to publish national guidance to ensure (i) that the process of making DNACPR decisions is sufficiently clear, accessible and foreseeable and (ii) that persons in the position of Mrs Tracey have the right (a) *to be involved in discussions and decisions about DNACPR* and (b) *to be given information to enable them so to be involved, including the right to seek a second opinion.*

The Tracey case was about consultation, what was *said* (or not said), rather than about what was done or not done. So in this regard, extrapolating to Noel Conway's situation is of limited value. However, the judges are sympathetic to the barrister who is presenting the case against the SoS;

*Mr Havers QC submits that article 8 is engaged by a DNACPR decision because it concerns how an individual chooses to pass the closing days and moments of her life and how she manages her death: see Pretty v UK (2002)*

And,

*It is a decision which concerns a patient's personal autonomy, integrity, dignity and quality of life.*

They seem to accept that Article 8 is highly relevant to end of life scenarios.

Then the view of the opposing barrister Mr Sachdeva, is explored,

*He submits that it is not sufficient to say that article 8 is engaged simply because the decision which is under consideration impacts on the physical integrity and autonomy of an individual. But he has been unable to identify the criteria by which to determine whether article 8 is engaged by the withholding of medical treatment.*

But this is rejected in a powerful paragraph from the judges,

*In [our] judgment, however, none of Mr Sachdeva's submissions justifies the conclusion that article 8 is not engaged by a decision to impose a DNACPR notice. A decision as to how to pass the closing days and moments of one's life and how one manages one's death touches in the most immediate and obvious way a patient's personal autonomy, integrity, dignity and quality of life. If there were any doubt as to that, it has been settled by the decision in Pretty.*

We know that Diane Pretty failed in her attempts to prove that a right to choose death was not the same as a right to private life – she took it to the House of Lords and the European Court of Human Rights.

As A.C. Grayling summarised in this article,

– – *Mrs Pretty's lawyers based their arguments on the most important rights in the [European Human Rights] Convention: the right to life, the right to be protected from inhumane treatment, and the rights to privacy and freedom of thought and belief. They argued that these rights give Mrs Pretty the right to choose when and how to die. The grounds they put forward were, first, that a right to life includes a right to die; second, that if Mrs Pretty is denied the chance to end her life before it becomes intolerable she would in effect thereby be subject to inhumane treatment; and third, that*

*her rights to privacy and freedom of belief give her the autonomy to decide what to do with her own life.*

*The judges disagreed with all these arguments, saying that they ‘stand the whole purpose of the Convention on its head’ on the grounds that the Convention’s provisions aim at protecting and sustaining life, and that because ‘death is the antithesis of life’ the Convention accords no right to die nor to choose when and how to die. --*

Back to Tracey; other cases involving successful applications that Article 8 was contravened are covered, including one in which a DNACPR decision was made and diamorphine given [Glass v UK (2004)], and a case where an abortion was requested by a woman who suffered from such bad myopia that she did not think she could cope with the pregnancy. The judges recall that in this case, *The [European Court of Human Rights] also reiterates that “private life” is a broad term, encompassing, inter alia, aspects of an individual’s physical and social identity including the right to personal autonomy, personal development and to establish and develop relationships with other human beings and the outside world.*

Article 8 is therefore seen to extend to aspects of personal identity that are clearly relevant to a person approaching the end of their life.

Evidence from The Equality and Human Rights Commission is then reviewed, which emphasises that any decisions based on the quality or value of life must be led by patients, *Mr Wolfe QC, for The Equality and Human Rights Commission, emphasises the difference between (i) medical issues (such as whether CPR might work) which are matters for the clinicians to decide and (ii) questions relating to the welfare of the patient in the widest sense (including social and psychological issues) which are essentially for the patient to decide. It is for the patient and not for others to say that a life which the patient would regard as worthwhile is not worth living...*

Later, the Tracey judges bring the NHS constitution into the argument; it says, *“You have the right to be involved in discussions and decisions about your health and care, including your end of life care, and to be given information to enable you to do this. Where appropriate, this right includes your family and carers.”*

Finally, in the ‘OVERALL CONCLUSION’ , they refer to,

*...autonomy, integrity, dignity and quality of life of the patient. It is accordingly critical to good patient care. The duty to consult is of course part of a clinical process. That process is individual to each patient albeit that it is informed by good clinical practice.*

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