

22 November 2023

Ms Maeve Ní Liatháin Clerk Joint Committee on Assisted Dying Leinster House Dublin 2 D02 XR20

Dear Ms Ní Liatháin,

Please find attached my opening statement to the Joint Committee on Assisted Dying. I will present a summarised version of this statement to the Committee in my introductory 3 minute presentation.

I would also seek to have permission granted for Tom Curran to attend my presentation as a guest.

Tom Curran is @ < tom.curran@hotmail.com > or 087 256 2714 Redmonds Cottage, Killahurler ARKLOW, COUNTY WICKLOW, Y14 DX03

Is there a list of others who will be presenting to the Committee at this time? Please confirm receipt, and advise if further information detail required before my attendance.

Should you or the Committee have questions in advance, I may be contacted at the below.

Yours sincerely,

Philip Nitschke, PhD MBBS

Philip Nitschke

Director & Founder Exit International PO Box 37781 Darwin NT 0821 Australia

Exit International BV Postbus 283 2000 AG Haarlem NL

Ph NL. +31 6309 66992

contact@exitinternational.net
www.exitinternational.net

#### **Preamble**

On 22 September 1996, I helped the first of four terminally ill patients to die under Australia's *Rights of the Terminally Ill Act*. These were the world's first voluntary, legal, lethal injections.

This law of the Northern Territory of Australia was enacted to allow terminally ill Australians to ask for medical help to die.

The law passed in the unicameral Parliament of the Northern Territory by just one vote: the vote of Wes Lanaphuy, the Aboriginal member for Arnhem in the parliament who said "I'll never use such a law, and I don't think any of my people will, but I do not think I have the right to prevent others for accessing this option".

In the 1990s I was working as a doctor in Darwin and was one of the very few members of the medical profession who supported the introduction this law.

While most Northern Territorians thought the *Rights of the Terminally III Act* made good common sense, the Australian Medical Association, and the church were vehemently opposed. Doctors argued that was a slippery slope that would destroy the patient /Dr relationship; the church said it was a violation of God's law.

The Territory law lasted only 8 months before a conscience vote in the Australian Federal Parliament overturned this world first legislation. The conservative Catholic Member of Federal Parliament in the Melbourne seat of Menzies, Kevin Andrew, boasted that his private member's bill had set the movement back 25 years. He was not wrong

A year later, Oregon in the US introduced it's legislation, similar to that of the NT, and in 2001 my new adopted homeland of the Netherlands passed its *Termination of Life on Request and Assisted Suicide (Review Procedures) Act*.

It was not until 2017 that the Victorian Parliament would enact another assisted dying bill in Australia.

Switzerland has allowed assisted suicide based on altruistic motives since 1937.

# **Guiding Principles**

In the current assisted dying legal framework, there are two principal paradigms of thought and practice: the medical model and human rights model. I shall address each of these in turn.

### 1. The Medical Model

Most jurisdictions in the world have (rather blindly in my opinion) implemented a medical model style law. With the usual medical model, a person can only legally get help from a doctor to die, if they have been diagnosed with a terminal illness and have been deigned to have less than six months to live (or 12 months is the medical diagnosis is neurological).

My involvement in the right to die movement over the past 27 years has taught me that any framework that creates an exclusive 'club' of people with a distinct qualification criteria ends up discriminating against far more people than it will ever help. By its very nature far too many deserving people will find that they do not quite qualify to use such a law: they will not be sick enough, or their diagnosis will have an ambiguous prognosis.

People like the late partner of my good colleague and friend Tom Curran, Marie Fleming, provide a good example. With a diagnosis of progressive MS, Marie's neurologist could never say when she was likely to die. Tom tells the story that Marie could have died in two months, two years or 20 years. No one could say. A medical model law excludes people like Marie.

But this is not all that troubles me about the medical model. The other is the power of the medical profession to decide who gets to have a good death and who doesn't

With doctors in the prime gate-keeping role, a medical model assisted dying law sets the medical profession up as the arbiters. Yet dying is not a medical process. Illness may be medical, but dying is not. We are all going to do it, regardless of whether we have the person in the white coat by our bed or not.

And there is another point, with doctors as the arbiters, the patient is left with very little decision-making power. Not only must very sick people jump through hoops to qualify to get help but unless they can find kindly doctors to prescribe them the much-needed lethal drugs, their quest to end their suffering will fail

As Dutch journalist, Henk Blanken, wrote in *The Guardian* in 2018 in an article titled 'My death is not my own: the limits of legal euthanasia':

The right to die has been discussed for so long now in the Netherlands that we have come to believe we each have the right to die when we want. But when push comes to shove, the patient is not the one who decides on their euthanasia. It is the doctor who decides, and no one else.

Tom Curran is currently campaigning for Marie's Law – perhaps this committee can turn its attention to the qualifying criteria like we have now in the Netherlands, 'unbearable suffering'. This small but significant step puts a little bit of control back with the patients - people – who need it so much. Such a move would also allow very elderly people who have a range of 'poly-pathologies' (all those small but serious health issues that come with old age) to ask for help to die.

As public health consultant Dr Lucy Thomas argued in the *British Medical Journal* in October 2020:

[by medicalising] 'what constitutes an acceptable reason for ending life, and with doctors as the arbiters and administrators, ... extends medical authority rather than enhancing patient autonomy, with deeply damaging unintended consequences. [It is only by moving outside the medical frame' that 'the fundamental ethical and practical dilemmas' can be brought 'into focus, facilitating serious discussion about how society should respond to people with mental capacity and a consistent desire to end their life prematurely'.<sup>1</sup>

## 2. The Human Rights Model

In contrast to the medical model of assisted dying is the human rights model that informs the law in Switzerland. Under the *Swiss Penal Code* (see Art. 115 StGB), any person can be assisted to die, as long as the motive of those providing the assistance is altruistic in kind.

In Switzerland, there is no requirement that the person receiving the assistance has been diagnosed with an illness of any kind. This allows for what the Swiss call 'Balance Sheet Suicide' (BSS), whereby a person's quality of life is understood wholistically. For example, under the human rights model, it is myriad quality of life indicators that are considered in the context of a person's request for assistance to die.

For 104-year old Australian, Professor David Goodall,<sup>2</sup> who I took to Switzerland in 2018 for an assisted suicide, it was factors failing eyesight, increasing frailty in terms of mobility and a feeling of existential angst (as he outlived his generation and felt a stranger in his own world) that, collectively, motivated him to want to exit on his own terms.

The experience of very old people such as David Goodall are not the exception. The only thing exceptional about this man is his decision to speak out and make public that he should not have to argue that he was 'sick' in order to get help to end his completed life. There is a silent majority for whom their experience resonates strongly.

<sup>&</sup>lt;sup>1</sup> Lucy Thomas, 'Demedicalisation: radically reframing the assisted dying debate', *British Medical Journal*, 30 Sept 2020 at: <a href="https://doi.org/10.1136/bmj.m2919">https://doi.org/10.1136/bmj.m2919</a>

<sup>&</sup>lt;sup>2</sup> Philipp Jenne, 'Australian, 104, dies in assisted suicide in Switzerland', *Associated Press*, 10 May 2018 at: https://apnews.com/article/163b479bf625469b84189fb84ec339ad

# The Swiss Human Rights Approach: Legal Outline

At a practical level, the Swiss law works as follows:

- The person receiving the assistance must have mental capacity
- The action which brings about the death must be initiated (controlled) by the person themselves.

In Switzerland, mental capacity is assumed. Only if a person has been diagnosed with a psychiatric or neurological condition, will he/she need to be assessed by a psychiatrist. The doctor stays 'in reserve on the bench': only called upon when needed.

In regard to the second point of 'ownership of the action' again there is no central role of the doctor in administering the lethal drugs. The person must take the cup to their lips, or activate the IV infusion themselves.

Of course, the prescription of the pentobarbital remains the task of a medical professional . However, there is no requirement under any Swiss law or regulation that prescription substances must be used. I would encourage the Joint Committee to take note of this absence of proscription of the method of death.

That the Swiss approach has worked effectively since 1937 makes this model an important subject of critical inquiry in the context of devising effective voluntary assisted dying legislation for Ireland.

#### Method of Death?

One further issue I would like to raise concerns the actual means that will be used to bring about a peaceful death.

In 1995, as I was preparing for the implementation of the *Rights of the Terminally III Act*, I could have employed any method of death. With only Switzerland existing as an example (if one excludes the protocols of capital punishment in the US), I had to figure things out for myself: what drug(s) would be best and in which combination and potency.

Back then the barbiturate, pentobarbital, was still on the prescribing schedule. The 'Deliverance Machine' which I had built for my four patients to allow them to initiate the process that would end their lives used the drug combination of pentobarbital, a curare analogue, and potassium chloride to provide the peaceful, elective death of my four patients. This machine allowed the patient to control the process, changing 'euthanasia' (where I would do the killing) into assisted suicide. This machine is now on permanent display in the British Science Museum in London.

While Switzerland still uses pentobarbital in assisted suicide (often with an anti-emetic), recently the US have created the D-DMAPh drug mixture that offers a faster TTD (time to death) when taken orally than pentobarbital. D-DMAPh stands for: Digoxin, Diazepam, Morphine, Amitriptyline and Phenobarbital, and is as effective, and cheaper than pentobarbital.<sup>4</sup>

This shift in the US has been driven by the global lack of availability of pentobarbital because of its use in capital punishment lethal injections,

Where oral administration is impractical or impossible and where intravenous access is difficult, a hypoxic death using nitrogen gas should be considered. The 'Sarco' 3D-printed, euthanasia device is currently undergoing final trials in the Netherlands before deployment in Switzerland.<sup>5</sup> Indeed the Sarco was developed when I was approached by UK lawyers for Tony Nicklinson, a man with locked in syndrome who could not readily use oral or intravenous drugs. Devices such as this have a useful and proper place in this discussion. Providing a reliable death within a responsible legal framework should not exclude such options in any proposed Irish legislation.

-

<sup>&</sup>lt;sup>3</sup> https://www.scienceandsociety.co.uk/results.asp?image=10323706

<sup>&</sup>lt;sup>4</sup> Dr Lonny Shavelson of the Bay Area End of Life Options group is an expert in this field. See: https://bayareaendoflifeoptions.com/2016/04/06/bay-area-end-of-life-options/

<sup>&</sup>lt;sup>5</sup> See: www.Sarco.design

### In Conclusion

The Republic of Ireland has a unique opportunity to forge a new, more equitable and more sustainable path in regard to assisted dying law.

By thinking beyond the medical model, Ireland is well placed to make laws that benefit the majority, rather than the select few who are *sick enough to qualify* for a law which by its very nature is exclusionary, rather than inclusionary. Such a law would honour fully the courageous legal battle (and the memory) of Marie Fleming.

An approach based on the Swiss model would serve Ireland well in the longer term. I cannot stress enough the importance of a wholistic approach to and end of life choices law in Ireland; especially given the changed lifecourse in modern, western societies where we are all living longer but 'sicker' lives.

Without choice over when and how their lives can come to a dignified end, older Irish people (not only the terminally ill) remain hamstrung. They *deserve better*. Ireland has a golden opportunity to *do better*.