Linguæ &
Rivista di lingue e culture moderne

Francesco Sani

Euthanasia and the Right to Die: the Ultimate Taboo

https://doi.org/10.14276/l.v26i2.4750

2 / 2024

ISSN 1724-8698

Urbino University Press
Università degli Studi di Urbino Carlo Bo

Francesco Sani

Independent Scholar
francescosani.fs@gmail.com

Euthanasia and the Right to Die: The Ultimate Taboo

ABSTRACT

In the many years of legal attempts in the English, Scottish, and Italian parliaments to overthrow a thinly-veiled hypocrisy surrounding the right to request medically-assisted dying for those whose life has become intolerable, there has been a wealth of discussion as well as misinformation on the topic of 'a good death'. In my contribution I will attempt to show how this taboo-laden 'ethically sensitive topic' has parallels in these two nations: through a narrative that encompasses parliamentary legislation, dictionaries, and other sources, I will endeavour to explore the shifting concept of suicide through the centuries, including the way in which death is seen to belong to the individual or to society. It is ultimately by freeing death of cultural structures that we can look at assisted suicide for the terminally ill, for example, as a question of human rights against inhumane suffering, rather than something taboo that must remain underground.

KEYWORDS: Death; assisted suicide; euthanasia; dying; taboo.

1. Cross-Cultural Issues and Why Assisted Dying Matters

Allow me to begin on a personal note: having lived between Italy and the United Kingdom since I was a teenager, I developed multiple perspectives on certain issues, one of which is how death is seen and dealt with. About twenty years ago, I was putting my bilingual abilities to good use by assisting the

Associazione Luca Coscioni on several translations and edits in connection with, among other initiatives, the Second World Congress for the Freedom of Scientific Research (2009). Through this, I became interested in the ethics debate on assisted suicide, looking at how legislative reforms had been attempted or were being pursued in the parliaments of Italy, England, and Scotland: why, I wondered, were legislators across two countries and three parliaments unable to reflect public opinion on assisted dying? Was regulating this issue in medical or private settings so taboo as to be virtually untouchable?

The narrative of assisted suicide and euthanasia prohibition can be summarised by its association with the archetype/spectre of the killer nurse/doctor: the Lucy Letbys and Harold Shipmans of this world are one of the nightmares that all legislators want to avoid. The reality, of course, is that one cannot legislate one's way out of murderous intent – it will often find a way – and that by closing the debate or brushing it under the carpet one may potentially endanger patients. Much has been said, for example, about the unwanted double-effect of opiates such as morphine, even though it seems that myth must be carefully separated from reality (Faris, Dewar and Dyason 2021): hypothetically, if a doctor unintentionally hastened a terminally ill patient's death through excessive morphine administration, would this be seen as malicious intent? Would it be on the same plane as active euthanasia?

It is the lack of specific legislation, campaigners may argue, that leaves many vulnerable to a bad death, rather than introducing assisted suicide into the healthcare equation. Yet, an ethical hypocrisy of brushing difficult issues under the moral carpet seems to persist: just as we see with sex work, any fruitful political discussion on subjects considered taboo is often shirked. Where something is known to exist but remains illegal, it causes harm at both an individual and a societal level. A sex worker in a country where selling sex is illegal might be unable, for example, to report violent clients to the authorities for fear of prosecution: regulating sex work, though problematic in appearing to legitimise the sexual exploitation and trafficking of individuals, may at least give those involved some agency. In the same way, a family member helping a terminally ill patient ending their life, with their written request and consent, in a country where assisting and abetting suicide was illegal, would likely refrain from declaring their involvement out of fear of prosecution, whereas regulating

this practice would allow the process to fully surface from the shadows of shame.

Creating a culture of covertness and taboo does not sow the conditions for protecting individual autonomy and bodily rights; rather, it pushes these issues underground along with the lives of those dealing with them; where something is hidden by guilt and shame, there grow illegality, malpractice, and harmful behaviour. Recent issues around the revisiting of *Roe v. Wade* in the United States have parallels to the aforementioned: legislators who cannot reconcile their ideological convictions with the bodily reality of womanhood, that is, the need to have control of one's reproductive rights, are more inclined to deny legal abortion than allowing it. Liberal laws tend to benefit many more people than prohibitive ones: the central tenet is that I may not agree with *x* but I will not deny you the right to it. For example, I may not agree with eating meat, but I would not deny meat-eaters the right to enjoy it. The latter could be applied to any number of human areas:

- how one should dress in public;
- how one should educate one's child(ren);
- how one should love and make love;
- how one should be religious, that is, one's faith;
- how one should behave with people of a different gender;
- how one should communicate at home, i.e. in what language one should do so.

The list is probably endless, and illiberal rulers down the ages have intrigued historians by coming up with countless new modes of interference into people's private lives, new lists of prohibited behaviours, and new things to ban from 'orthodox' morality.

As I looked at attempts to reform the law in the parliaments of Westminster (London), Holyrood (Edinburgh), and Montecitorio (Rome), I came across figures such as Lord Joel Joffe, Baroness Mary Warnock, Debbie Purdy, Dianne Pretty, Dr. Anne Turner, Loris Fortuna and Margo MacDonald. The last name is important to me because in 2010 I was fortunate to interview her regarding her Assisted Suicide (Scotland) Bill (2013), not long before she eventually succumbed to her incurable illness (2014). In the interview, Margo MacDonald highlighted how support for a reform to assisted dying was usually high in the political world – until, that is, a new election cycle loomed closer,

and the fear of the electorate's judgment would set in. She was clear that her bill would only apply to those patients who were *compos mentis,* which would be one of the checks and balances to avoid situations where someone without mental capacity would be taking this route. Many others have tried setting up goalposts between a patient's initial request and final access to assisted suicide, proposing similar checks and balances to ensure protections for vulnerable patients. Despite such efforts many bills have failed, with opponents invoking the 'slippery slope' argument, which warns that legalising assisted dying is only the first step toward active euthanasia – where a medical professional intentionally causes death by direct intervention.

Opponents of assisted dying, such as Care Not Killing and other anti-euthanasia groups, weaponise data from countries that permit assisted dying by spinning it in such a way as to imply flaws in the process and that in so doing imply that the rise in requests for assisted dying is somehow irrefutable proof of a euthanasia epidemic. Committees in the British Parliament have heard evidence from key witnesses and experts who have offered factual knowledge of the assisted dying models enshrined in the legal system of countries such as Holland, Switzerland, and the American state of Oregon; some have even travelled to those countries to gather first-hand evidence in an attempt to remove any doubt over those legal frameworks. The reality, whichever side of the debate one may be, is that there is no hidden truth: while assisted dying must be scrutinised for abuse there must be enough trust in it lest those countries that want to legislate on it may forever hesitate.

At its core, assisted dying is about patient autonomy: patients and healthcare professionals involved in this option generally agree that it gives patients peace of mind, especially for those in the case of terminal, incurable illnesses. It would allow the people in question to choose the timing of their death, often at home, saying goodbye to one's family without fear of legal prosecution for them; it would also prevent them from resorting to extreme methods (e.g., jumping from a window) or having to die sooner than intended (e.g., by having to travel to another country to legally access assisted dying, which has to be done before one is too ill to make that journey).

2. Pain Relief, Sanctity of Life, and Dying Mores through the Ages

In discussing assisted dying, one of the counterarguments often brought to the fore is the following: were there to be better and universal palliative care for the terminally ill, there would be no need or desire for assisted suicide. However, the truth is that, on the basis of what we currently have in place, this ideal will likely never be fully realised. There will always be individual situations where pain relief methods are inadequate for a particular scenario and/or where a patient may not wish to spend their final days in a drug-induced stupor but opt for an early exit while still fully conscious and able-minded. The palliative care ideal shares much common ground with that of assisted suicide: both hold dear the patient's quality of life, meaning, the desire to make a person's final months, weeks and days as comfortable, pain-free, and tolerable as possible. This is the idea of a 'good death', an exact translation of the Greek word *eu-thanasia*. While laudanum and other opiates were historically available to some, it was only in the twentieth century that medical science made possible the prolonging of life beyond what was previously conceivable. As a result, we have come to witness cases such as those of, for example, Terri Schiavo, Piergiorgio Welby, and Eluana Englaro, all of whom were kept alive by artificial ventilation, nutrition, and hydration. These cases have provoked deep feelings and debate both in their respective countries (the US and Italy) and abroad: what does 'quality of life' or a 'good death' mean for someone who is terminally ill or in a permanent vegetative state?

Another landmark case is that of the Italian disc jockey Fabiano Antoniani, a.k.a. DJ Fabo. After a car accident left him blind and tetraplegic, he chose to die at the Swiss Dignitas facility, with the support of Marco Cappato from the Associazione Luca Coscioni. His death sparked a judicial journey up to the Italian Constitutional Court, with the latter absolving Cappato in 2019 of any wrongdoing and urging Parliament to legislate on the issue of assisted suicide. Unlike Schiavo, Welby, or Englaro, DJ Fabo was not dependent on life-sustaining treatments like artificial ventilation or feeding tubes, which could be removed to bring about death. Instead, he faced the prospect of a blind, immobile consciousness for the rest of his life, with no prospect of ever returning to a life that, for him, was worth living. An ethical legislator should

have no qualms with the idea that the state should allow someone in that predicament to choose to die on their terms, and that life should not be forced on them.

The history of pain relief, as I mentioned above, included opium and its derivatives as well as other medicinal herbs; however, artificial breathing, nutrition, and hydration did not exist. As a result, neither did the medical dilemmas we now face such as deciding on the fate of a patient in a permanent vegetative state who had not previously laid out advance directives to inform medical staff on what their wishes would be in that situation. As medicine creates more possibilities to sustain life, we are able to delay death and, by this course of action, we also engender more nuanced ethical conundrums. In Western culture the concept and practice of dying have taken many shapes; while there are parallels in the physicians' desire to relieve their patients' suffering, the idea of people ending their own life has often been cloaked in ideology. In ancient Greece and Rome, suicide may have been acceptable in specific situations, for example women under threat of rape or losing a loved one, or men about to be captured by the enemy in battle or sentenced to death by the state. From Syrinx the nymph to Seneca the senator, honourable dying in so-called classical antiquity had poignancy and some tolerance, something that we also see in philosophy – for example in the writings of Plato, who even in earlier works such as *Phaedo* did outline scenarios where the unyielding tenet of suicide as reprehensible could meet with some moral compromise. Indeed, the idea of life as a divine gift occupied the mind of many more than just the ancient Athenian philosophers: in the aftermath of the fall of the western Roman empire, the establishment of Christian theology shaped the mediaeval moral universe in such a manner that its increasingly doctrinal thinking wove its way into all areas of daily life, from eating and drinking to fertility and, inevitably, dying.

In the Augustinian universe, as seen in his *De civitate dei* (413- 427 AD), that Platonic interpretation of suicide was reinforced while the scholar focused the early mediaeval mind on viewing the ending of one's life as a crime against the divine: for the following millennium, that is from the fifth century AD to the fifteenth, Christian ideology filled the vacuum left by the fallen Roman empire while the Church of Rome increasingly viewed itself as sole executor of God's

will on Earth. However, Christian political activism gave its blessings to many ills, under the banner of God's work, from witch hunts and torture to 'holy' wars and massacres. The question is: how could this be reconciled with the banning of suicide as a sinful act? How could Christianity be uncharitable to one's decision to end one's life but allow, for example, burning *suspected* heretics at the stake? How could Crusaders be given carte blanche to kill and maim but people fighting a personal battle with heartbreak or ill health be condemned to burn in infernal eternity for ending their life? We may not find it possible to reconcile these views all too easily, therefore we may want to focus less on suicide and shift our gaze to dying intended as a process: here we find a great deal of detail to help us find some answers.

In the late-mediaeval tome, the *Ars moriendi*, we have a fifteenth-century summary of the general thinking on the subject of dying: the title, which in the Caxton translation of that time became *The Art and Craft to Know Well to Die*, offers advice on what should be done at the dying person's bedside; this, of course, included specifics on praying rituals. What is perhaps unsurprising is the way in which human death, like other human endeavours at the time, is the relinquishing of one's life back to the deity, as though it were on loan for the time of one's existence, reinforcing a belief that what is paramount is our preparation for that return journey to the spiritual world, to the afterlife. The concept of a 'good death', therefore, was not seen as a matter temporal but a matter spiritual: the dying must be spiritually prepared according to the rites established by doctrine, which included prayers and atonement, lest they should find themselves cast into eternal damnation after having passed on. The bed, therefore, was a different place for the living and the dying: while in life, especially for the wealthier, it may have been adorned by fine linen to signify status, in death it did away with those fineries and became unadorned, stripped back to basics, signifying that the dying person renounced material concerns and eschewed greed. This image of the "honest bed" (French, Smith and Stanbury 2016), that is, a bed that symbolises the good reputation of a household and its virtuousness, was part of mediaeval iconography and reinforced the symbolism of dying as an abandonment of earthly materialism.

What is also interesting is that death occurred mostly at home, meaning that unless one had died in battle or at sea or in other such scenarios, the

expectation was that one would have the time to prepare oneself for dying in one's own bed (or equivalent). This is in sharp contrast with what post-war industrialisation brought about in twentieth-century life, where the increasing medicalisation of birthing and dying stripped those moments of the home-centred rituals that had been continuously in use across western cultures from mediaeval times to pre-industrial, agrarian societies. It will suffice to look at the *wakes*, still used in the second half of the twentieth century and within current memory in several parts of Scotland such as the Outer Hebrides, where the deceased would be kept in their home for one or two nights to give the community an opportunity to come and pay their respects. In these small communities, another example being in pre-evacuation St. Kilda, when a person departed from life then all work and schooling would cease and be suspended for as long as the wakes and funereal rites were in process: death demanded a collective pause for unity and reflection.

The medicalisation of dying, with hospitals replacing homes and a meaningful community, has signified a profound change: with surroundings stripped of personal symbolism or memory, the deathbed is immersed in the neon light of a ward, with no belongings, animals or even flowers allowed, all of which in the name of better physical care for the sick. "Dying is removed from the home to the hospital and is dissected into little bits. Those monumental reminders of death, the dying themselves, the sick and the aged, are systematically hidden from public view." (Tierney 2011). This removal from sight, this erasing of public dying happened non-linearly across countries and history, but in the case of the two cultures that I inhabit it has been an almost universal shift as agrarian customs were gradually giving way to post-industrialised mores. "Remembering death is one of the most rooted taboos of our time. Our society exorcises the fear of death with contradictory attitudes [...] which causes both an emotional and rational devaluing of death itself". (Salvestrini, Varanini and Zangarini 2007, VII; my translation). The deathbed of a hospital or hospice is not the 'honest bed' of mediaeval memory: if we wanted to generalise, we could almost conclude that the former is concerned with the body physical whereas the latter with the body spiritual. The contradiction of our time is that on the one hand we have shed the devout mourners' preoccupations at the mediaeval deathbed, while on the other we are

so afraid of openly discussing death that governments of many advanced industrial nations cannot adequately legislate on medically-assisted suicide: we have removed the old taboo of suicide but made a new one out of assisted suicide.

3. How 'Good Death' Definitions Changed after the Middle Ages; a Euthanasia Timeline

Given that classical antiquity, as indeed Roman emperor Augustus (63BC-AD14) had wished for himself, valued a good death in the sense of kind, gentle, and painless, and had indeed a term for it (*eu-thanasia*), how did that meaning almost disappear out of language for a millennium? Or rather, how did dying become concerned chiefly with the health of one's soul? The scope of my inquiry here does not aim to answer this particular question: having seen how Christianity dictated the morality of the dying, I am satisfied to leave this interrogative unanswered; instead, I wish to investigate not only how from the early sixteenth century the term euthanasia began resurfacing and reconnecting to its classical ancestry but also how a more human-centred *Weltanschauung* and medical advances added more ethical nuance to it thereafter. To assist me in this task I will mainly refer to one article (Paoli 2019) resulting in a brief chronology of changing usage and shifting attitudes.

> 1516: In Thomas More's *Utopia*, "voluntary death" is mentioned as a means to escape "torturing, lingering pain, without hope of recovery or ease". (Biotti-Mache 2016)

> 1580: In the *Lexicon græco-latinum novum* by Johannes Scapula we can see both Euthànatos and Euthanasìa, in Greek, each of them translated into Latin as 'good and happy death'.

> 1588: "[...] In the *Vita del sereniss.mo S.r Guiglielmo Gonzaga duca di Mantoa, et di Monferrato &c. Descritta da Lodouico Arriuabene*, [...] it is written of the man's death, who [...] 'died of a very peaceful and pleasant death [...] which he [Augustus] [...] called Euthanasia". (Paoli 2019; my translation)

1605: Francis Bacon in *The Advancement of Learning* wrote: "I esteem [...] the office of a physician not only to restore health, but to mitigate pain [...] not only when [it] may conduce to recovery, but when it may serve to make a fair [...] passage. For it is no small felicity [...] *Euthanasia*". (Biotti-Mache 2016) This type of euthanasia was referred to by Bacon as *exterior* in that it concerned the body rather than the soul.

1723: 'Palliative euthanasia' is found in the *Disputatio inauguralis medica de mortis cura, etc.* by George Christopher Detharding. (Paoli 2019)

1829-1840: In the *Vocabolario universale italiano* (Universal Italian Dictionary), Naples, a theological meaning is recorded for euthanasia: "Happy death or sweet passing and tranquil and in a state of grace". (Paoli 2019; my translation)

1879: In his *Diphtheria: its nature and treatment, varieties and local expressions* Sir Morell Mackenzie writes: "Some [...] have maintained that even [...] where the patient is dying from dyspnoea, tracheotomy should be performed with the view of promoting the euthanasia. It is true that death from syncope or gradual exhaustion is much less painful than [...] from apnœa". (Mackenzie 1879, 96)

1905: "Alfredo Panzini, in his *Dizionario moderno: supplemento ai dizionari italiani* [Modern dictionary: supplement to the Italian dictionaries] prints the term Euthanàsia [...] thus defined: '*the good, the peaceful death* thanks to medical actions that take away the pain of agony with drugs'". (Paoli 2019; my translation)

1963-1994: "In 1963 the Zingarelli [dictionary] [...] 9th edition [...] expressly states that the term [euthanasia] [...] denotes the 'anticipation, by painless means, of death for an incurable patient [...] tormented by his illness; denounced by the Church, defended by some doctors and biologists'". (Paoli 2019; my translation). Seven years later, in the 10th edition of the same dictionary "the definitions are inverted, indicating that the meaning from the medical context has become established [...]: 'Euthanasia 1 (med.) Quick closure, by any means suited to causing death painlessly, of a pathological process with a hopeless prognosis accompanied by suffering deemed intolerable'." (Paoli 2019; my translation) Finally, in the 12th edition in 1994 "we read: 'euthanasia 1. (med.) Pain-free death caused in cases of fatal prognosis and of suffering deemed unbearable. *Active e.* by administering certain substances *Passive e.* by withdrawing medical treatment'". (Paoli 2019; my translation)

Through this brief timeline we see, both in the Italian and the English sources, a moving set of goalposts from the mediaeval preoccupation with the

soul's condition at death's door to the Renaissance's human-centred concern for easing the patient's suffering in a more open debate around a good death. Beyond the Renaissance, we start noticing a more medicalised usage of the terms, which reflects a move away from the theological to the physical. Of course, dictionaries do not always reveal society's attitude to a particular concept: just because there was a word for something, and it did not have a negative descriptor, it does not mean that the practice of it was favourably viewed by people at large. For example, using an adjective to describe someone's ethnicity could be seen as neutral on paper, but in practice that word may be loaded and used in a derogatory tone; also, a word used as an insult may be reclaimed by a victimised group as a badge of identity, thus reinforcing the inability for us to understand the true firepower of that word if going simply by its definition within contemporary glossaries. This means that euthanasia may now be more precisely defined in language, but it does not necessarily reflect the strong feelings and ideological opposition to it: indeed, people practising it, like doctors who carry out abortions, may be in danger of being eyed with suspicion in a culture where either those practices are officially illegal, or they are legal but are undermined by many obstacles in clinics and hospitals (for example, with regard to abortion, through the practice of widespread 'conscientious objection' on religious grounds).

If dictionaries only yield part of the information about various societies' attitudes to a concept across time, what should we consult to gain a better appreciation of that concept's cultural context? In the case of death and dying, including suicide (with or without help from a medic), how could one have the finger on the pulse of societal attitudes? News outlets and media sources may satisfy most of our questions in this area; however, given that the origins of modern newspaper publishing are put to the early years of the eighteenth century, what would we look at going further back in time? Overall, written literature extends much farther back, which is very fortunate as it allows us to trace not only the belief systems of the authors but also, through their eyes, those of the societies of which they were a product.

If we look at the last seven hundred years, we will find much writing about dying: from Giovanni Boccaccio (1313-1375) and the deadly plague scenes in his *Decameron* to Vittoria Colonna (1492-1547) and her sonnet XXII, *Quando*

Morte tra noi disciolse il nodo (*When Death the bond between us had released*) dealing poetically with the grief of losing her husband; from Æmilia Lanyer née Bassano (1569-1645) and her physical depiction of the dying Christ in her *Salve Deus Rex Judæorum* (*Hail God, King of the Jews*) to John Donne (1572-1631) and his Holy Sonnet 10, *Death, Be not Proud*, where he elevates humanity while debasing death's power; and on, from Johann Wolfgang von Göthe (1749-1832) with the suicidal young man in *Die Leiden des jungen Werthers* (*The Sorrows of Young Werther*), where only death cures love's ills, to Ugo Foscolo (1778-1827) and the suicide of a young man, lovelorn and disillusioned by unachievable political aspirations, in *Le ultime lettere di Jacopo Ortis* (*Jacopo Ortis's Last Letters*) – with both of these works carrying the echoes of that most celebrated play from 1597 featuring the double suicide in Verona of a young couple in a forbidden relationship.

The list continues through the centuries, with examples such as *Sappho's Last Song* by Giacomo Leopardi (1798-1837); *Cold in the earth – and the deep snow piled above thee* by Emily Brontë (1818-1848); *Because I could not stop for Death* by Emily Dickinson (1830-1886); the war poems by Wilfred Owen (1893-1918); *Elm* by Sylvia Plath (1932-1963); *Football season is over* by Hunter Thompson (1937-2005); and many, many more. What the last two have in common, incidentally, is that both authors committed suicide; indeed, while Leopardi's ill-health and suicidal thoughts did not push him too to end his own life, his writings can be scrutinised for clues about his thoughts on his own demise, just as one could with those of Plath and Thompson.

An earlier poet who, like Leopardi, did wish for a way out of ill-health, physical deterioration and suffering, was John Keats (1795-1821): in his 1819 poem *Ode to a Nightingale* he wrote:

> My heart aches, and a drowsy numbness pains
> My sense, as though of hemlock I had drunk,
> Or emptied some dull opiate to the drains
> [...] Darkling I listen; and, for many a time
> I have been half in love with easeful Death,
> Call'd him soft names in many a mused rhyme,
> To take into the air my quiet breath;
> Now more than ever seems it rich to die,
> To cease upon the midnight with no pain [...]

Upon arriving in Rome in late 1820, with hopes that a warmer climate would alleviate his tuberculosis, he only worsened: taking up lodgings in what is now the Keats-Shelley Museum on the Spanish Steps, he endured a hundred days of a weakening body and of blood loss through coughing. The illness that killed his brother Tom came to scythe him too into death's arms, while his friend James Severn and his doctor nursed him as best they could, day and night. What Keats asked for, that is, laudanum (opium in an alcoholic solution), was not given to him for fear that he may use it to commit suicide; however, it would have greatly eased his pain, something that the last line of the quoted excerpt makes abundantly clear. The poem was written the year before he undertook the journey to Rome, already suffering from the effects of 'consumption' (pulmonary tuberculosis), an illness that was only defined as such in the immediate years after the poet's passing.

The British philosopher and House of Lords Peer, Lady Warnock, titled her co-authored book on euthanasia *Easeful Death* in memory of Keats and, we could add, of the inhumane suffering during the later stages of his terminal illness. In it she writes: "By what moral argument can we justify [...] keeping those people alive who sincerely want to die, when their life is, in their own eyes, not worth preserving?" (Warnock and Macdonald 2008, 137) She continues thus: "It is not irrational or morally wrong for people in some situations to be, like poor Keats, 'half in love with easeful death'" (ibid.). She also goes on to say that escaping pain is not the only reason for seeking an early exit: "Those who beg for death [...] may also be motivated by the desire not to spoil [...] the life they have lived by lingering on in a state of hopeless dependence and lack of dignity" (ibid., 138).

Warnock had seen Lord Joffe's 2002 Assisted Dying Bill repeatedly defeated in the House of Lords, and from the final vote in 2006 there would be no further bills on the subject until Lord Falconer's one in 2013, the same year that saw MSP Margo MacDonald's Assisted Suicide Bill introduced in the Scottish Parliament. Mary Warnock saw both attempts fail, as well as MP Rob Marris's Assisted Dying Bill in 2014 (defeated in 2015); after her passing in 2019, another bill on assisted dying was proposed and introduced in the Lords by Baroness Meacher in 2021, but the following year it ran out of time to progress within the parliamentary session.

The current situation is that Lord Falconer has returned to these matters this year by putting forward his Assisted Dying for Terminally Ill Adults Bill, which will get a second reading in November, but, significantly, there are concurrent proposals both in the House of Commons, with news on October 3rd that MP Kim Leadbeater will introduce her Assisted Dying for the Terminally Ill Bill, and in Holyrood, with MSP Liam McArthur's Assisted Dying for Terminally Ill Adults Bill at the first of three stages, with the relevant committee having tabled an eight-week programme for gathering evidence before progressing to the second stage (amendments). Were these not cause to be expectant of forthcoming change, the Tynwald (the Isle of Man's Parliament) passed the first stage of MHK Dr. Alex Allinson's Assisted Dying Bill (2023) this summer at the third reading in its House of Keys, ready for a vote this month in the Legislative Chamber, which means that it could become Manx law in 2025, and the British Prime Minister said that he would not oppose it.

Meanwhile, Italy drags its heels with no proposed laws on assisted suicide: aiding and abetting suicide carries similar punishment in both countries (up to fourteen years' imprisonment in the UK and twelve in Italy), and indeed Italy too has tried spurring Parliament into action through civic action such as a referendum on legalising euthanasia, organised by the Associazione Luca Coscioni in 2021 (and able to garner over 1.2 million signatures) but declared inadmissible by the Constitutional Court the following year. Meanwhile, thanks to the same Court's pronouncement in 2019 declaring that article 580 of the penal code (which dates back to the 1930 *Codice Rocco* of Fascist Italy) was unconstitutional, assisted suicide could be allowed under certain circumstances, and it was left to public healthcare providers such as hospitals, given checks made by the relevant ethics committees in the territory, to make the necessary arrangements for a patient to be enabled to take the necessary drugs to end his/her life.

Following this pronouncement, the first medically assisted suicide that legally took place on Italian soil was in June 2022, with a tetraplegic patient (Federico Carboni) finally being able to have an assisted death through self-administration, via an intravenous pump (and a switch activated with his mouth), of the drug recommended by the ethics committee (Pentothal

Sodium). It should be added, however, that it took two years for Federico to actually have his will fulfilled, with the help of civic action and legal representation from the Associazione Luca Coscioni that included not only taking the regional healthcare agency to court for failing to assess that he had the prerequisites mandated by the 2019 Constitutional Court pronouncement, but also having to issue numerous compulsory warnings to the agency and the ethics committee for failing to fulfil their legal duty to assist him in ending his life. What is even more demoralising is that while this patient was given the green light on medically assisted suicide, the healthcare provider would then give no material assistance for this procedure: Federico and the Associazione Luca Coscioni managed to raise the funds themselves to cover the considerable costs for both drugs and machinery.

Even though the Constitutional Court issued further guidelines in July 2024 (Sentence 135/2024) to extend the term 'trattamenti di sostegno vitale' (life-sustaining treatments) to pharmaceutical therapies and any treatment involving medical staff or caregivers without which the patient could die, the Italian Parliament continues to defy two sentences by the Constitutional Court and to default on its obligations, allowing the legal limbo to saunter on indefinitely: the last parliamentary debate, which examined the legalities of medically assisted death ('Esame delle norme sulla morte medicalmente assistita'), took place in March 2022. Since then, a new government came to office, which again delayed any hope of progress, leaving patients and their families with no certainty over imminent or future choices for how to legally request and access an 'easeful death' within their territory.

4. Closing Statement

In a recent review of US assisted dying (Kozlov 2022) the analysis made of Medical Aid in Dying data from nine states from 1998 to 2020 that legalised assisted dying, showed some interesting statistics, of which I will list five:

1) of the 8,451 patients who received a prescription, 5,329 actually took it and died (ca. 63%);
2) 90% of the ones who took the prescription to end their lives did so at home;
3) 88% had medical insurance and had informed their family;

4) 87% had enrolled in hospice care / received palliative care;
5) 74% had cancer.

These findings shed light on many important factors in legalised assisted death:

1) having a prescription for assisted dying is often done for peace of mind, but not everyone will end up taking the prescription, for a variety of reasons;
2) dying at home is overwhelmingly a factor in where people choose to die;
3) being uninsured is not a prime statistic for those who took the prescription;
4) a high palliative care enrolment shows that assisted dying is not at odds with palliative care;
5) cancer is by far the biggest reason for assisted dying.

In addressing issues around financial pressures or increased palliative care spending, therefore, it seems that a false premise is set. One of the authors examined (Pereira 2011) goes to great lengths in reviewing the assisted suicide model, based on safeguards, and addresses the slippery slope concerns. While dealing with assisted dying is always a delicate matter, personally and societally, the numbers of people affected are still relatively small compared to the general mortality of the populations in countries such as the Netherlands or the USA: taking the latter as an example, in the state of Oregon, 367 people died through assisted suicide in 2023, against over three million (3.09m) in the whole country, making the Oregon assisted deaths 0.01% of the whole country's mortality.

The arguments put forward about an epidemic in deaths, again, do not take into account issues (Cornfield 2023) relating to increased information access to patients about their right to access physician-assisted dying under state law, as well as better reporting by authorities of those deaths as separate from deaths due to, let us say, the patients' underlying conditions. Reporting is an important matter not just for policymakers but also for public perception: if domestic abuse rates are up, is this because previous generations experienced fewer instances of it, or because victims have more agency to speak out and can be better supported? What, exactly, should be classed as a social epidemic, and on what basis?

There are indeed fears of pressures on the vulnerable, but the safeguards in place across laws passed and currently under scrutiny usually require more than one physician to consent to the patient's request and/or a

psychologist/psychiatrist assessment, with some legislation dictating terminal illness with a limited life expectancy period and other restrictions. Debates over assisted dying understandably involve emotional arguments for and against it, some ideologically rooted and others stemming from harrowing family stories: all of these must be heard but it is hard to evidence how much evidence can move legislators to truly shift their feelings on assisted dying at the point of voting.

On a final point: in the years 1998 to 2020 (Kozlov 2022) there were 5,329 medically-assisted suicides in the USA; in the same period and country, there were 1,097 state executions, according to the Death Penalty Information Center (2024). How do we square these two statistics? Can capital punishment, still legal in that country, be looked at with the same prism as physician-assisted suicide? What about the right of death row prisoners to access assisted dying if they met the requirements under state law?

If death is taboo; if it has become invisible to the living; if it resided by the 'honest bed' of mediaeval custom but it now resides by a hospital bed; if, finally, it is no longer in the community but shut away, out of sight; how can we, in any society, converse openly about ways in which to normalise death and better prepare for it? Legislating on assisted dying is only part of the conversation on a good death, as much as better and universally available palliative care should be. In the end, unlike state executions, assisted dying and conversations around it must put compassion for the person at their core. Whether the taboo of dying will soon be a thing of the past, it is too early to tell.

References

Bertelli, Diego. 2013. "Morselli, Rensi, Leopardi e la filosofia del suicidio". *Rassegna della Letteratura Italiana*, Year 117, Series IX (2): 471-84.

Biotti-Mache, Françoise. 2016. "Euthanasia: Elements of Language and History". Translated by Cadenza Academic Translations. *Études sur la Mort* 2: 17-33.

Carroll, Joseph. 2019. "Death in Literature". In *Evolutionary Perspectives on Death. Evolutionary Psychology.* Ed. by Shackelford, T.K., and V. Zeigler-Hill, 137-59. Cham: Springer.

Dholwani, Kishor, Kushal Nandi, and Amrita Chakraborty, *et al.* 2021. "Euthanasia: The Silent Request for Becoming Rest in Peace". *World Journal of Pharmaceutical and Medical Research* 7 (10): 283-90.

Dinkelaar, Bianca M. 2020. "Rational and Irrational Suicide in Plato and Modern Psychiatry". *BJPsych Advances* 26 (4): 229-35.

Faris, Hannah, Brian Dewar, and Claire Dyason, *et al.* 2021. "Goods, Causes and Intentions: Problems with Applying the Doctrine of Double Effect to Palliative Sedation". *BMC Medical Ethics* 22 (141): 1-8. https://doi.org/10.1186/s12910-021-00709-0

French, Katherine L., Kathryn A. Smith, and Sarah Stanbury. 2016. "An Honest Bed: The Scene of Life and Death in Late Medieval England". *Fragments* 5: 61-95.

Graham, Philip. 2021. *Mary War*nock. *Ethics, Education and Public Policy in Post-War Britain.* Cambridge, UK: Open Book Publishers. https://doi.org/10.11647/obp.0278.

Hernández, Isabel. 2021. "Werther e la Moda del Suicidio per Amore." January 14. https://www.storicang.it/a/werther-e-moda-suicidio-per-amore_15031 (7 September 2024).

Kozlov, Elissa, Molly Nowels, Michael Gusmano, *et al.* 2022. "Aggregating 23 Years of Data on Medical Aid in Dying in the United States". *Journal of the American Geriatrics Society* 70 (10): 3040-44. https://doi.org/10.1111/jgs.17925.

Mackenzie, Morell. 1879. *Diphtheria: Its Nature and Treatment, Varieties and Local Expressions.* Philadelphia: Lindsay & Blakiston.

Pereira, J. 2011. "Legalizing Euthanasia or Assisted Suicide: The Illusion of Safeguards and Controls". *Current Oncology* 18 (2): 38-45. https://doi.org/10.3747/co.v18i2.883.

Salvestrini, Francesco, Gian Maria Varanini, and Anna Zangarini. 2007. *La morte e i suoi riti in Italia tra Medioevo e prima Età moderna.* Firenze: Firenze University Press.

Scapula, Johann. 1820. *Lexicon Graeco-Latinum.* Oxford: Clarendon Press.

Skelton, John. 2003. "Death and Dying in Literature". *Advances in Psychiatric Treatment* 9 (3): 211-17. https://doi.org/10.1192/apt.9.3.211.

Tierney, Lisa. 2001. "Changing Attitudes Towards Death and Suffering: A Cultural Perspective on the Euthanasia Debate". Master's thesis, Pontifical University, Co. Kildare, Ireland. https://mural.maynoothuniversity.ie/5193/1/Lisa_Tierney_20140709162726.pdf (23 September 2024).

Warnock, Mary, and Elisabeth Macdonald. 2008. *Easeful Death: Is There a Case for Assisted Dying?* Oxford: Oxford University Press.

Web references

"2022 Death with Dignity, Report to the Legislature: Prepared by Center for Health Statistics Disease Control & Health Statistics". 2023. Washington, United States of America: Center for Health Statistics Disease Control & Health Statistics. June 2. https://doh.wa.gov/sites/default/files/2023-10/422-109-DeathWithDignityAct2022.pdf (11 November 2024).

"Corte Costituzionale: Giudizio di Legittimità Costituzionale in Via Incidentale. Sentenza 135/2024". 2024. https://www.cortecostituzionale.it/actionSchedaPronuncia.do?param_ecli=ECLI:IT:COST:2024:135 (15 July 2024).

Death Penalty Information Center. 2024. "Execution Database". July 18. https://deathpenaltyinfo.org/database/executions (10 November 2024).

Alberti, Piero. 2023. "Right-to-Die Legislation in Italy: A Tale of Two Parties." March 20. https://www.ethox.ox.ac.uk/blog/right-to-die-legislation-in-italy-a-tale-of-two-parties (17 September 2024).

Cappato, Marco. 2024. "Eutanasia tra arte e politica". *Associazione Luca Coscioni*. September 27. https://www.associazionelucacoscioni.it/notizie/blog/eutanasia-tra-arte-e-politica (13 September 2024).

Cornfield, Jerry. 2023. "Deaths Under Washington's Medical Aid in Dying Program Hit New High in 2022". *Washington State Standard*, November 9. https://washingtonstatestandard.com/2023/11/07/physician-assisted-deaths-in-washington-hit-new-high-in-2022/ (10 November 2024).

Coscioni, Associazione Luca. 2024. "Fine Vita, Eutanasia e Testamento Biologico". September 30. https://www.associazionelucacoscioni.it/cosa-facciamo/fine-vita-e-eutanasia (16 September 2024).

Fortuna, Loris, Rossella Artioli, and Franco Trappoli, *et al.* 1984. "Norme sulla Tutela della Dignità della Vita e Disciplina della Eutanasia Passiva." No. 2405. *Atti Parlamentari, IX Legislatura.* Roma: Camera dei Deputati. https://documenti.camera.it/_dati/leg09/lavori/stampati/pdf/24050001.pdf (23 September 2024).

Merthe, Nellie. 2022. "Scottish Funeral Customs". *Graveyards of Scotland*, https://graveyardsofscotland.com/scottish-funeral-customs/ (10 September 2024).

Paoli, Matilde. 2019. "Eutanasia". *Accademia della Crusca*. https://accademiadellacrusca.it/it/contenuti/eutanasia/7955 (24 August 2024).

Regnard, Claud, Ana Worthington, and Ilora Finlay. 2023. "Oregon Death With Dignity Act Access: 25-Year Analysis". *BMJ Supportive & Palliative Care*. https://doi.org/10.1136/spcare-2023-004292.

Sani, Francesco. 2010. "The Proposed End of Life Choices (Scotland) Bill: An Interview with Margo MacDonald, MSP". *World Congress for Freedom of Scientific Research*. https://www.freedomofresearch.org/the-proposed-end-of-life-choices-scotland-bill-an-interview-with-margo-macdonald-msp/ (18 September 2024).