
Euthanasia: Searching for the Full Story

Timothy Devos
Editor

Euthanasia: Searching for the Full Story

Experiences and Insights of Belgian
Doctors and Nurses

 Springer

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Foreword 1

The authors of *There's Another Side to Euthanasia* are commendable. Their powerful book proves that 18 years after the Belgian law on euthanasia was passed, and in the midst of a rather broad consensus about the subject among the media and public opinion, the need to challenge popular beliefs remains. Giving fieldworkers the opportunity to express their doubts while describing their experience gives weight to the arguments. They forget about the false conflict between advocates of an ethic of autonomy and promoters of one of vulnerability, and similarly, avoid the inflated antagonism between people who can be “compassionate” with someone else’s suffering and the “unbending” defenders of the ban on killing. Providing facts and genuine experience which prompt their reflection, the authors offer their unassuming testimony before asserting their convictions. Thus, unbiased by ideological preconceptions, the style flows with neither pathos nor arrogance. People who choose to perform euthanasia are not stigmatized. On the contrary, their tactfulness is conveyed for instance when a colleague’s refusal to take part in euthanasia is respected and the medical team makes sure they are not present at the lethal injection. Although not stigmatized, people in favour of euthanasia may feel challenged by these bold testimonies which run against the tide of popular thinking to follow people’s inner voice of conscience.

Undoubtedly, people who choose to perform euthanasia examine their conscience too when appraising their course of action, and we may not doubt their authenticity. Neither do we have any reason to doubt the integrity of those who exercise their right to conscientious objection by refusing to take their patients’ lives: one cannot accuse someone who ratifies the Hippocratic Oath of holding outdated moral or religious standards. Yet, we notice that conscientious objection is under pressure when an author writes: *“The present-day message of liberal societies is to discredit conscientious objection in the name of tolerance. In other words, a ‘tolerant’ health professional is expected to carry out everything that is demanded of them without any personal thinking. Doesn’t tolerance run the risk of becoming tyrannical if it prevents a carer from working with their conscience, and renders illegitimate any personal deliberation on the meaning of what is right and good?”* Furthermore, during an inspection, Community inspectors have ordered a hospital, whose charter stipulated euthanasia was not to be performed on their premises, to update the document and lay down a euthanasia protocol. If conscientious objection is reduced in this way to a merely individual dimension, it is watered down to simple tolerance

for a personal weakness or a worrying inability to abide by the common decency. Too often, the conscience issue boils down to a subjective feeling, a personal opinion, or even “*a perverted sense of duty*”, and one easily forgets that, in order to be legitimate, conscience needs to be “enlightened”. It needs mentioning that the authors of the testimonies in this book manage to provide a number of perspectives which are easily overlooked when euthanasia is performed, such as: Why is euthanasia wrongly referred to as a “*natural death*”? Why is the doctor's identity concealed in the case of euthanasia “*whilst it is explicitly documented in any other significant medical act?*”

The main argument of the promoters of euthanasia is well known: when a patient's request has been accepted, their unappeasable suffering must be relieved. Refusing to alleviate their pain would be tantamount to lacking compassion and restricting their freedom. But such reasoning, often with heartfelt articulation but also in good faith, contains a major flaw: it denies the complexity of the underlying issues. On the one hand, “unappeasable suffering” has so many different facets that it is not easy to define precisely. Moreover, a wide range of methods to relieve suffering are now available, including palliative sedation. On the other hand, can someone's freedom to acknowledge that they see no alternative way to escape unbearable suffering be regarded as a real freedom? These two issues are worth pondering.

What is compassion? Stemming from pity, compassion can lead to damaging attitudes when, overwhelmed by emotion, it misses adjustment and refinement by an enlightened conscience. “This (adjustment) means that the carer does not completely identify with the other's suffering nor acts exclusively from the patient's perspective; but that they can consider the other's predicament in earnest.” Speaking about “deceptive and therefore dangerous pity”, an author calls to mind the warning by Stefan Zweig in his beautiful novel *Beware of Pity* or the one by Antoine de Saint-Exupéry: “all too often have I seen pity go astray” while another author writes “compassion means being alongside another person in their ordeal”.

Authentic compassion does not involve suppressing one's own emotions which tend to surface when one's mind is quietened. “Such was the experience of a qualified doctor, who once told me he had performed euthanasia several times in the care institution where he works. His eyes filled with tears as he confessed that some nights he wakes up in a sweat, seeing the faces of the very people he has euthanised in front of him.”

What a truncated understanding of the patient's self-determination overlooks is that there can be no freedom outside the relationship that binds the patient and doctor. Freedom that relies on the presence of another person is totally different from the individual freedom a person exercises, for instance, when taking their own life. In the latter, they are separate from society, face to face only with themselves. But when a patient summons the medical profession into a deadly pact, they change the “therapeutic alliance” into a “legally binding agreement”. One can therefore consider this a “perverted fusional relationship”. “We are no longer dealing with free and responsible autonomy, but with the desperate act of two people trapped by helplessness.” Surprisingly, although autonomy is generally thought to have been

conquered by the patient, the recounted testimonies suggest that “with the normalisation of euthanasia, a new form of paternalism has entered the Belgian medical world. Indeed, in the end, it is the doctor who decides whether or not euthanasia will be granted.”

An advantage of these testimonies lies in how they illustrate that what is sometimes referred to as current excesses of euthanasia (psychiatric cases, existential suffering, euthanasia for children, advance decisions of euthanasia, etc.) are in fact a direct consequence of a law that has breached a dam. When a crack opens up in a sea wall, waves cannot but widen it even though, at the start, people naïvely thought they could seal it off.

A warning by Robert Badinter, former French Minister of Justice in the government of President François Mitterrand, comes to mind. Against the public opinion of his time, Badinter had been the architect of the abolition of the death penalty in 1981. And later, overcoming all political divide, this man from the left fully endorsed Jean Leonetti, a moderate right-winger and kingpin of the 2005 French law (on End of Life). For Robert Badinter, law does not only have a repressive value but, above all, an expressive one which conveys a society’s ethical values. And he says, on these, one law commands all the others, the law that forbids the intentional killing of another person, even out of seeming compassion. I would like to add that forbidding does not equal preventing, but points towards an anthropologically structured benchmark. Indeed, transgressing the law does not necessarily mean denying it, but when transgressing becomes embedded in the law under the alleged purpose of supervising it, it is no longer a transgression. And here is what I have learnt from Aristotle and Paul Ricœur: Transgression falls under the authority of the courts, not of the law.

The testimonies reported in this book are forward-thinking and prophetic: they are the words of “Resistance fighters” and watchers who do not believe that euthanasia can be a medical or a caring act, neither can it be a neutral option. As I said before, euthanasia does not complement palliative care, it ends it; it is not the pinnacle of care and support for the patient, it discontinues it; it does not relieve the patients, it takes their lives.

Nantes, France

Jacques Ricot

Foreword 2

A main argument of the advocates of legalizing euthanasia is that the decision to be euthanized in jurisdictions allowing this is a purely personal decision of the individual concerned and does not affect anyone else. This claim is often expressed by the most vocal, educated and powerful people in a society as, “If you object to euthanasia you don’t have to use it, but you have no right to prevent me from doing so and my accessing euthanasia does not affect you. It’s no one else’s business.” This book challenges that claim by documenting first-hand evidence, mainly from healthcare professionals, about how euthanasia has affected them and the institutions in which they work.

The Failure to Present “the Full Story”

As the title of this book, *Searching for the Full Story*, indicates, the full story that needs to be told and taken into account in deciding whether to legalize euthanasia is not being told. There are two sides to the euthanasia debate, but, in post-modern Western democracies in decision making about legalization, one side, that in favour of legalization, receives far more airtime and attention in the public square and media than the side opposing legalization. There are many converging reasons why this imbalance is occurring, including the ease with which the competing cases can be made.

The case for legalizing euthanasia is easy to make in contemporary post-modern Western democracies, especially those in which moral relativism and utilitarianism are the main philosophies informing the dominant worldview of a given society. Moral relativism takes a stance that nothing is absolutely or inherently wrong, rather what is right or wrong all depends on the circumstances and the individual person’s preferences. Utilitarianism in the context of euthanasia proposes that euthanasia is a means that has an outcome or end of reducing suffering and, therefore, can be justified and is ethical.

In these societies, overwhelming primacy is given to the value of respect for individual autonomy—this approach is often called “radical autonomy”. In prioritizing the conflict in values that euthanasia presents between respect for individual autonomy and respect for life, the former prevails. Moreover, the

discussion and analysis of the impact of legalizing euthanasia is limited to only the present time—this restriction can be called “presentism”.

The pro-euthanasia case is promoted and buttressed by stories of “bad” natural deaths—those where great suffering is experienced—and “good” euthanasia deaths—those where suffering is promptly and completely eradicated through the intentional extinguishing of life itself by using euthanasia.

The media, which overall has a bias towards legalizing euthanasia, are especially prone to presenting euthanasia as a topic for discussion in the public square in the manner described above, that is, with a focus on an individual suffering person and only taking into account the immediate impact in the present of providing that person with euthanasia.

The case against euthanasia is much more difficult to promote, not because it is weak—it is not—but because it is much more complex.

This case requires looking not just to the present but also to our “collective human memory”—that is, history—for lessons from the past and to our “collective human imagination” to try to anticipate the full and wider consequences of legalizing euthanasia.

While the individual person and their wishes and respect for their right to autonomy are always important considerations, they are not alone sufficient considerations, if we are to make wise decisions as a society whether or not to legalize euthanasia. That requires taking into account the immediate and long-term wider ramifications of legalizing euthanasia and authorizing physicians, and in some cases nurses, to end the life of another person through administering lethal medications with a primary intention to cause death. These ramifications include the effects on healthcare professionals and the healthcare professions; on the institutions in which they practice, such as hospitals and aged care homes; on society and the shared values on which it is based and which create the glue that bonds us as a community; and even on our global reality. There is a dearth of literature in this regard. *Searching for the Full Story: Experiences and Insights of Belgian Doctors and Nurses* makes an important contribution to starting to fill these lacunae.

Feminist scholars have developed a concept of “relational autonomy”, which recognizes and takes into account that even though I might have a legal right to decide for myself what should happen to me, for example in relation to euthanasia, what I decide affects others besides myself. The personal accounts of the authors of their encounters with euthanasia, in each of the chapters of “*Searching for the Full Story*”, powerfully demonstrate the truth of this insight.

Of particular concern in relation to the wider impact of legalizing euthanasia is the possibility of it being “thrust on” or “seeping into” the lives of fragile and vulnerable people—those who are poor, uneducated or least vocal, and those who are elderly or living with a disability. The COVID-19 pandemic has provided horrific examples of neglect in many of our countries—even criminal neglect—in the everyday care and treatment of such people, which should be a warning that we cannot afford to trivialize or underestimate the dangers of the abuse of legalized euthanasia in relation to them.

Range of Disciplines and Experiential Knowledge

Two of the notable features of the book include, first, that each of the chapters is written by a different professional from a range of disciplines relevant to deciding about legalizing euthanasia and assessing its impact on individuals, families, communities and societies. The majority are practising healthcare professionals—oncologists, a psychiatrist, other physicians including a general practitioner, nurses—specializing in the care of terminally ill and dying patients and, importantly, a philosopher-ethicist with expertise in this domain.

A second notable feature is that these authors communicate experiential knowledge, a very important human way of knowing that often cannot be reduced to a mathematical formula or weighed or measured and for that reason may be ignored or rejected as irrelevant in decision making. That is a very serious mistake.

Issues Raised by Legalized Euthanasia

Here are just some of the issues, selected at random, to which the book alerts the reader.

We found heartbreaking the story in Eric Vermeer’s chapter, “The Slippery Slope Syndrome,” of the nurse whose husband asked her to arrange euthanasia for him, but not to tell him the identity of the doctor who would provide it or on which date. Her grief, as recounted by Vermeer, after her husband was euthanized is palpable:

Finally, together with the doctor, we agreed on a date but since I had promised to say nothing to him, I was not able to say to him, “I love you,” or “Thank you”...The day of his euthanasia both of us died... he physically and I mentally.

She melted into tears and I [Vermeer] had no other words but silence.

We note, to avoid confusion, that this story is not an example of a slippery slope, but of profound human grief.

Expansion and Normalization Through Giving Priority to Autonomy

Vermeer’s chapter shows the very rapid change to normalization of euthanasia as a way to die once it is legalized. As more and more jurisdictions introduce it, this normalization process will accelerate. Any restrictions on access to euthanasia are challenged as breaches of rights to personal autonomy, the right to decide what should happen to your own body and life, and such challenges are consistent with the primary justification for allowing euthanasia, namely, giving respect for personal autonomy priority over all other values and considerations.

Canada legalized euthanasia (called MAiD—medical aid in dying) in June 2016. In a recent Quebec case the judge ruled that the requirement in the law, that the person’s death to be “reasonably foreseeable” in order for them to qualify for euthanasia, was unconstitutional.¹ In February 2020, the Canadian Government introduced a bill, which includes a provision deleting this requirement from the Criminal Code provisions governing access to MAiD. There have even been reports that the Canadian euthanasia law will be challenged on the grounds that placing any conditions, such as requiring a physician’s authorization, on mentally competent adults having access to euthanasia is unconstitutional on the grounds that they breach these persons’ constitutional Charter rights to life, liberty and security of the person.

Philosopher Willem Lemmens in his important chapter “When Conscience Wavers” challenges the view that euthanasia has been normalized in Belgium on the grounds that, first, it unavoidably involves transgressions of long-established principles of medical ethics and that such breaches can never be normalized. Second, he rightly observes that, whatever the law might be, there will always be some physicians who cannot, in good conscience, accept euthanasia as ethical or appropriate medical treatment. Lemmens also demonstrates the inherently problematic character of the legalization of euthanasia by identifying the risks and harms it creates to important shared societal values and what goes wrong in its practice.

Suicide and Social Contagion

Research shows that suicide can be contagious. This phenomenon is sometimes called “social contagion”. For example, when a young person commits suicide there can be a cluster of copycat cases. We know that a single case of suicide can affect over 100 people, some with grief and others with contagion. Moreover, in Australia, for instance, suicide is the number one cause of death in persons under 35 years of age and the government is committing large financial resources to provide what they hope will be remedial measures. Suicide rates have risen in at least most, and possibly all, jurisdictions that have legalized physician-assisted suicide or euthanasia.

There does seem to be social contagion in post-modern Western democracies with respect to legalizing assisted suicide and euthanasia, themselves. We could call it an epidemic or even pandemic of legalizing euthanasia. The acceptance of euthanasia by many societies is not an accidental or isolated phenomenon; it is an outcome of a major “cultural change”, as psychiatrist An Haekens notes in Chap. 4, “Euthanasia for Incurable Mental Suffering”.

Haekens’ discussion of empathy is so important it bears repeating, especially because at the heart of the euthanasia debate is disagreement between the two sides

¹ *Truchon c. Procureur général du Canada*, 2019 QCCS 3792

of the euthanasia debate regarding what is the most compassionate approach to those who are dying:

The notion of empathy merits some further reflection. Edith Stein [1] established a distinction among different levels of empathy. She distinguishes being immediately shaken by an emotion, “emotional contagion,” and corrective empathy, the evaluation of one’s own capacities for empathy. True empathy is only possible when this corrective movement of conscience has been applied to emotional contagion. This means that the caregiver will not totally identify with the other person’s suffering and will not be supposed to have to act from the patient’s point of view, but that he will be able to look truthfully at the other’s situation. Only then will he be morally justified to take care of the other person. It is important to be aware of these different levels of empathy, particularly in the context of a request for euthanasia on account of mental suffering.

Euthanasia is Incompatible with Palliative Care

Many authors discuss palliative care, the benefits it offers and how euthanasia and palliative care are philosophically and in practice totally incompatible. Options at the end-of-life are presented by those in favour of euthanasia as a choice between suffering, including the suffering engendered by over-treatment, and euthanasia, rather than presenting palliative care as a true alternative to both suffering and euthanasia. This non-disclosure raises the issue of whether an informed consent to euthanasia has been obtained if the full range of palliative care options and the gamut of risks and benefits of both approaches to suffering have not been disclosed to the patient.

Loving Accompaniment Until Natural Death

What the analysis, insights and stories found in this book make clear is that death has its own time and a “good” death requires loving accompaniment of the dying person from a wide range of people, including family and friends and professional caregivers. Some important experiences cannot be time compressed if they are to maintain their integrity and authenticity. Dying is one of these.

Euthanasia eliminates future possibilities for finding meaning, giving to others and receiving selfless gifts of love from them that the period of natural dying can offer. Euthanasia is a harmful effort to compress this period of natural dying and, although presented as being meant to benefit only the dying person, support for euthanasia can result from others wanting to shorten the period of their “watching and waiting” for the person’s death, which can be an experience of suffering for them. This approach was succinctly summed up as follows by a prominent Australian politician who is in favour of legalizing euthanasia: “When you are past your ‘use by’ or ‘best before’ date, you should be checked out as quickly, cheaply and efficiently as possible.” However, human beings are not products and a family,

community or society is not a supermarket selling life from which a person can be evicted. Commodities can be valued and substituted for something of equal value, but human value is beyond price and, therefore, cannot be managed “cheaply and efficiently” as a commodity.

The “Mystery of Death”

An antidote to this approach is to regain our perception and respect for the “mystery of death” to which Julie Blanchard refers in Chap. 8, “Resisting”:

In Belgium, where euthanasia is decriminalized, as in France, where it is not, it has happened to me that it was the family that requested it for a loved one. The main problem for those concerned is time, the time it takes for the illness to bring life to its end, as well as the time for the death throes. As Patrick Baudry says very rightly: “The death throes is not merely a bundle of physiological mechanisms leading to death. It is a psychological and spiritual process that in large part escapes us. To speak of it only by its symptoms would be to make it a final illness. But we are precisely summoned by the presence of a mystery” [2].

Many people in secularized Western democracies are deeply fearful of mysteries, probably, in part, because they cannot feel that they are in control of them. To deal with this fear and the intense anxiety it evokes they use what social psychologists call a “terror reduction mechanism” or “terror management device”. They convert the mystery to a problem and seek a technological solution to the problem. So the *mystery* of death becomes the *problem* of death and a lethal injection—euthanasia—is the technological solution that solves the problem of death.

Conclusion

We are only starting to understand the complexity of the issues legalized euthanasia raises, the uncertainties it involves and the breadth of its potential consequences. The authors of the chapters in *Searching for the Full Story: Experiences and Insights of Belgian Doctors and Nurses* make important contributions in this regard and show us that we have much, much more to learn. Legalizing euthanasia is not, as pro-euthanasia advocates argue, just a small incremental step on an ethical path we have already taken. It is a radical rejection of the most fundamental value on which we base our societies, that of respect for human life. Respect for human life must be upheld at two levels: in society in general and for every human life without diminution of worth based on disease or any other factor. Euthanasia contravenes both levels of respect and ruptures the story we tell each other and buy into to create the glue that bonds us as a society—the story of our collective humanness and what that entails. We believe that history will judge the euthanasia debate as having been the single most important societal values debate of the twenty-first century. Knowledge is essential if we are to make wise decisions about whether or not to allow

euthanasia, and *Searching for the Full Story: Experiences and Insights of Belgian Doctors and Nurses* contributes very important information and insights to our fund of knowledge in this regard.

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