

Euthanasia: Searching for the Full Story

Experiences and Insights of
Belgian Doctors and Nurses

Timothy Devos
Editor

 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by refusing to take their patients’ lives: one cannot accuse someone who ratifies the Hippocratic Oath of holding outdated moral or religious standards.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.

Sydney, NSW, Australia
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Margaret Somerville
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The Slippery Slope Syndrome

1

Eric Vermeer

I am well acquainted with a generalist who, when still young, espoused the cause of euthanasia in the 1980s, distributing, already at that early date, cards to carry on one's person declaring that the holder wished to be euthanized. Nevertheless, she waited until the law was adopted to begin practicing euthanasia. Once she did, she was sick for three days after each instance. In order to overcome this painful contradiction, she consulted psychologists who persuaded her that the cause of her suffering was loneliness, since euthanasia was not at all widespread in her region. Instead of pondering over this poignant reaction of life within her, she has not ceased to persuade doctors to practice euthanasia ...

Hugo R. (close friend)

For more than 20 years I have practiced nursing, first in oncology services, then in palliative care. As a teacher and psychotherapist for the past 10 years, I have had the opportunity to continue working with nursing students in palliative care and psychiatric services, as well as to supervise nursing teams. An ethicist by training, I belong to an ethics committee in a neuropsychiatric hospital. Wearing these different hats gives me the great privilege of encountering patients at the end of life or who suffer from mental illnesses as well as nurses and students who face difficult situations, and to review in the ethics committee clinical situations involving great suffering.

The question of euthanasia comes up very regularly and occasions numerous discussions that are both emotional and engaging.

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1

1.1 The Decriminalization of Euthanasia

Since 2002, Belgian law has permitted euthanasia to be decriminalized under certain conditions. Notably, this law was intended to combat clandestine euthanasia, but one is led to conclude that this has absolutely not been the result. According to a thorough study in *The British Medical Journal*¹ [1], it can be reasonably estimated that half of the euthanasia procedures are still being carried out without being reported. This is not surprising for those who know that someone's death is always accompanied by strong emotions and that decisions are often made on the spur of the moment.

Five years ago, a doctor went so far as to say, in the Senate, that for a long time he had not declared any euthanasia cases and that he did not call in a second colleague to validate the request for euthanasia, as the law nonetheless stipulates.²

The topic has not ceased to be fed by the media who, by playing on emotions, impose on us the idea that in order to die with dignity, one has to be euthanized.

This discussion is taking place in a country marked, as are other countries in Europe, by an increase in serious incurable diseases of much longer duration than in the past. Every year in Belgium, more than 40,000 new cases of cancer are diagnosed, with the prognosis of real healing (remission for more than 5 years) of around 60%; however, in spite of advances in medicine, more than 15,000 Belgians die of cancer every year. To this must be added the upsurge of other diseases labeled as multifactorial (Alzheimer's disease, cardiovascular diseases, cerebral vascular strokes, neuromuscular diseases such as amyotrophic lateral sclerosis, and schizophrenia)—all of them burdensome pathologies that cause a great deal of physical and mental suffering.

¹*The British Medical Journal* conducted a study, using a cross-sectional analysis of euthanasia cases that had been reported to the Federal Registration Commission in Flanders, via an anonymous questionnaire sent through an attorney to general practitioners who had treated a quarter of the patients who died between June 1 and November 30, 2007 (a total of 6927 deaths). This study revealed that only half of the euthanasia cases were officially declared. The questionnaire asked the doctors which of these four treatments had been applied to the patient concerned:

1—withdrawing or not administering a treatment, in spite of its possible effect on shortening the life of the patient.

2—intensifying analgesic treatment, in spite of its possible effect on shortening the life of the patient.

3—withdrawing or not administering a treatment, with the explicit intent to hasten death.

4—administering, providing, or prescribing medical drug doses with the explicit intent to hasten death.

Only the cases where the doctor had chosen the fourth treatment were considered euthanasia. Only half of these cases were officially reported to the Commission.

²“A professor of the University of Ghent, Dr. Marc Cosyns, pleaded on Wednesday before the joint Senate Commissions on Social Affairs and Justice in favor of eliminating the laws on euthanasia and palliative care and integrating them into the law on patients' rights. Incidentally, this same doctor stated that he had not reported any acts of euthanasia since 2011, an obligation that is however stipulated by the law.” (“Intégrer l'euthanasie dans les droits des patients et l'éliminer des lois,” *RTBF Info*—20 Marc 2013, www.rtbf.be/info).

It was thus necessary to initiate discussion about the end of life. But it had to be done sincerely, that is, by involving all who play a part in healthcare and without any preconceived ideas. But that is not what happened. In 2002, Belgium decriminalized euthanasia and at the same time promoted palliative care,³ as though to signify that they were one and the same reality. Yet, if there is a message to put across first and foremost, it is that it is necessary to differentiate clearly between euthanasia, which is the planned process of dying, from palliative care. The latter aims, as is well known, at developing the specific management of physical, psychological, familial, and spiritual symptoms.

However, the definition, in Europe as in Canada, is clear and unambiguous: “Palliative care neither hastens nor postpones death.” It follows that every form of extraordinary measure that postpones death and every act of euthanasia that hastens death is foreign to the philosophy of palliative care.

1.2 Ignorance About Palliative Care

In 2002, the Netherlands began to offer Belgian doctors in Flanders training modules on euthanasia that met with clear success, to the detriment of various forms of training in palliative care, pain management, and analgesia.⁴ Accordingly, many doctors, for lack of training in palliative care, quickly came to the conclusion that euthanasia was the only solution when conditions of physical or mental pain appear to resist traditional treatments.

Healthcare professionals agree in saying that today around 95% of all pain can be alleviated, although 60–65% of patients still die in pain.

The continuing education of doctors needs to be called into question. Would it not be more pertinent to invest in training on the treatment of pain rather than on the way to euthanize a patient in pain?

To think of euthanasia as the only way to relieve intractable pain is hardly the answer sick people expect. I have often had occasion to ask this question of patients requesting euthanasia: “Do you wish to die or do you wish to stop suffering?” In most cases, patients ask for a better quality of life rather than an “end to life.”

Obviously, no one questions the full measure of a patient’s suffering, nor the way they go through it... I do not even question their request for euthanasia, when there is no relief. On the contrary, I react in view of the way the doctor receives this request... I often hear, from doctors favoring euthanasia, that euthanasia plainly signals the admission of medical failure. Because the doctor feels powerless (or incompetent?) faced with a patient’s pain or suffering, euthanasia appears the only answer to give.

This being so, it is just as obvious that there remain extremely difficult situations: a small minority of patients (around 5%) can render the medical team powerless

³The same year also saw the adoption of the law on patients’ rights.

⁴Pain management: the treatment of pain. Analgesia: the reduction of pain. See also the Brief Healthcare List of Terms at the end of the book.

when the pain is so complex and multifactorial. We then have the possibility of having recourse to sedation, in its many degrees.

In the same way that the resolve to sow confusion between palliative care and euthanasia is real, there is also an attempt to amalgamate euthanasia and sedation, whereas they are two totally different realities, on several levels.

In the first place, while euthanasia should never be proposed to a patient, sedation is an option to offer a sick person who is experiencing suffering that is unbearable and hard to manage.

The intent of euthanasia is to induce death, whereas the intent of sedation is to treat one or several symptoms.

The process of euthanasia is to guarantee death by injection of a lethal product, whereas the process of sedation is to administer medical substances that must be adjusted to the needs of the patient through a regular and rigorous evaluation of this process.

The result of euthanasia is death, whereas the result of sedation is a better quality of life.

Those who assert that sedation is euthanasia in disguise commit a gross error.

But let us return to the lack of medical training and let the patients speak; they are the ones who in the end know the truth.

Philippe has been suffering from a myeloma⁵ for three years and comes to the emergency services with unbearable back pain... His reaction seems to be irrevocable: "I'm in too much pain... I want to be euthanized... one wouldn't make even a dog live like this.... For the sake of my dignity, I request euthanasia..." The anesthetist on duty comes quickly and gives him an epidural injection of an analgesic product that works within minutes. An hour later, I see Philippe again in his room and, after telling me his story, he concludes: "Fortunately, they didn't listen to me... but you know, when you're in pain, you're capable of asking anything..." Philippe lived another three years, with his two adolescent sons, and he told me how this time had been necessary for his children's grieving process.

The competence of the anesthetist neutralized Philippe's request for euthanasia. This is how a doctor, with little or no training in how to use the new analgesic molecular drugs, can commit an irreparable act.

1.3 The Trivialization of Euthanasia

The examples of lived experience oblige us to look at reality, just as it is.

Mrs. B. suffers from a kidney cancer that has metastasized to the bones and lungs. She regularly complains to the attending physician of her difficult marital situation with a violent, alcoholic husband. She also suffers from no longer seeing her two daughters, aged 25 and 27, who never come to visit her. After several meetings during which the doctor seems

⁵Kahler's disease, also known as multiple myeloma, is an ailment of the bone marrow induced by the uncontrolled proliferation of a specific type of white blood cell, the plasmocytes. Under normal circumstances, these cells specialize in making antibodies (www.cancer.be/les-cancers/types-de-cancers/my-lome-multiple-maladie-de-kahler).

distraught in face of the patient's great suffering, one day he takes it upon himself to speak to her in these terms: "Taking into account your terminal cancer and your family situation, don't you think that euthanasia would seem the least bad solution?" The patient broke down in tears and the doctor realized his blunder.

Miss V. comes to the psychiatric emergency services after a third attempt at suicide. She has been suffering chronic depression for two years, following the breakdown of her marriage. The nurse asks her: "Do you know that you can request euthanasia?" The patient appears surprised and asks for information. While waiting for the patient to be transferred to a psychiatric unit, the nurse gives her the contact information for the ADMD⁶...

Mr. B. is afflicted with pancreatic cancer with no hope of a cure. On several occasions, the doctor has suggested euthanasia, in a gentle but insistent manner. Mr. B. is tired and asks his family to be present around the clock since he no longer has the strength to engage in this kind of discussion with the doctor...

Mrs. V. has been in a rest and care home for several years and has just had a cerebral vascular stroke.⁷ She remains conscious but has lost the ability to speak. As is well known, improvement in these situations is often possible, especially two or three days after the stroke. At a team meeting, the healthcare assistant who looks after her quite openly asks whole team: "Can't we suggest euthanasia to this lady? She has already declined considerably since her stroke.... The majority of the team opposed this strongly, but this example shows how easily the subject is brought up with an icy thoughtlessness and, above all, outside the legal limits set by the conditions of legal decriminalization.

This is not a question of unique and exceptional cases. It is a reality that many do not want to face. Students, who tell me what they experience in training, sometimes have their wings clipped:

"Is it normal for a doctor to propose euthanasia?"

"If it's a matter of proposing euthanasia to a depressed and suicidal patient, I'm changing jobs right away..."

I am, of course, obliged to answer that doctors and nurses who propose euthanasia are doing so completely illegally. Under the guise of compassion, for certain healthcare personnel, euthanasia is becoming more and more a way, often an unconscious way, of removing oneself from the suffering and distress of a sick person.

1.4 A Perverted Sense of Duty

I do not wish to put doctors on trial, far from it. I hear from doctors who really suffer in the face of the insistent demands and the pressure of certain families. That too is a reality.

⁶Association pour le droit de mourir dans la dignité = Association for the Right to Die with Dignity, part of a global network promoting euthanasia, whose motto is "Choosing your own death: A freedom! A right!"

⁷A vascular cerebral stroke occurs when the flow of blood encounters an obstacle (a blood clot or ruptured blood vessel) that blocks its passage to the different parts of the brain thus depriving the latter of their vital input of oxygen, causing their dysfunction and then death within a few minutes (www.franceavc.com).

But do we take the time to propose palliative care, as the law requires? Do we take pains to go a bit further into the history of the person and to explore his real request?

When I give training in palliative care to doctors, I am impressed to hear some of them tell me: “When a patient asks me for euthanasia, I refer him right away to ADMD... It’s my duty...” My reaction always is to ask in what context the request was made and in what way it was received. The answer is very often basic and primary: “The law permits euthanasia, I don’t see why I would refuse it to him... You have to be tolerant...”

Once again, let us ask the question: What is tolerance? From that angle, do we still have the right to react with our own conscience? Tolerance is fundamental, to be sure, but it implies reciprocal respect and invites dialog. It must not, in any case, supplant ethical inquiry.

Sometimes, simply daring to raise the question about a patient’s real request is sufficient to make healthcare staff feel judged and condemned by their peers.

Whoever seeks to remain *alert* and unified by the values that underlie their practice sometimes hear themselves say: “Who do you take yourself for? Where is your tolerance?” Must healthcare staff be content to perform acts, without consulting their conscience, or do they still have the right to react and to feel that their position is at odds with one situation or another?

The difference between personal conscience, which belongs to private life, and the law, which orders relations within society, is well established in our society. However, the problem is that the relationship between the doctor and the patient belongs to life in society governed by law, to be sure, but also to personal relationships governed by ethics. The risk in this for the practitioner is for him to persuade himself that it is normal to silence his conscience in order to conform to the law.

Worse still: even the conscience clause, which allows the healthcare worker to remain free with regard to what the law authorizes and to not engage in acts that their conscience objects to, is jeopardized.

Brigitte, a nurse, invoking the conscience clause, refused to put in place an IV whose sole aim was to inject a lethal product. She was subjected to pressure by the medical staff and had to justify herself before her supervisor. She ended up leaving the hospital to go work elsewhere.

Stéphanie, a nurse, works in intensive care and challenges the head nurse about a medical order that does not seem to her very coherent. In fact, the doctor was asking her to inject a high dose of morphine via an IV. Stéphanie was very aware that this injection could be fatal for the patient. The head nurse retorted: “If you are not able to give 50 mg of morphine via an IV, you don’t belong in this unit...” She held her ground... She went to see the doctor, who then reduced the dose of morphine, but the head nurse continued to hold it against her...

The current message of liberal societies is to discredit conscientious objection in the name of tolerance. In other words, if a healthcare worker calls herself tolerant, she is obliged to carry out all that is asked of her, without any further thought. Does not tolerance risk becoming tyrannical, once it prevents a healthcare worker from

working in keeping with her conscience, by rendering illegitimate any personal reflection on the meaning of wellbeing and goodness?

Democratic discussion and ethical inquiry appear to be endangered in the area of health care. Some will say that I exaggerate; but, to be convinced, it is sufficient to look at the pressures, indeed the reprisals, that healthcare staff undergo when, following their conscience, they react with their heart.

1.5 Suffering and Silence

It is most important to always come back to the patient, to the reality of their suffering and their request. The request for euthanasia is often due to many factors and encompasses physical pain, moral suffering, and the familial context. It is important to listen carefully to what the patient tells us, and also to know when to remain silent...

In spite of all our goodwill, there is always a gap between the patient who suffers and the healthcare staff who try to reach out to him. It is difficult to acknowledge this, but it is something that we must accept. It is difficult when we experience this gap since it forces us to confront our limits, our poverty, and our vulnerability.

When I was a young nurse and I worked with leukemia patients, I had the privilege of caring for Christophe. He was often very rebellious and 1 day I thought it good to say to him: "You know, Christophe, I understand you..." He answered me: "What do you understand? We are both of us 20 years old... You will live and I will die."

Christophe taught me that I needed to approach another's suffering on tiptoe in word and deed, in great humility. We shall never truly understand what the patient is living through in his distress, and this is where listening and silence sometimes become the only language. Then we can hear another underlying suffering that hides beneath the request for euthanasia.

Mrs. N. was suffering from lung cancer and requested euthanasia. Her wish was heard and taken seriously, but it encouraged me to go further into her history. After a long exchange, she told me: "I weigh 33 kg and I am a burden to society [sic]. Moreover, my two daughters are waiting for me to die so that they can inherit the house..." I asked myself what this patient was really asking for. Was it: "Put me to death"? Or else: "Show me that I still have worth in your eyes, despite my feeling useless and my family distress?" As a team, we opted for the second choice and took the time to accompany this patient, without suppressing her request, which evaporated on its own. She left the palliative care unit after three months and was reconciled with her two daughters.

As healthcare workers, we must always ask ourselves what the patient is really asking for.

Mrs. V. suffers from a metastasized breast cancer and is greatly depressed. Early one morning, as I am bringing her breakfast, she tells me: "I would like to die." And, in the same breath, she adds: "You did put my vitamin B in my orange juice?"

I then asked myself the question: Why is this vitamin B so important, when this woman wishes to die? This very interesting paradox made me understand that when a person tells

me: "I want to die," she is not necessarily telling me: "Put me to death." I was able to deepen my relation with Mrs. V. and she told me: "Don't we sometimes have the right to say we are fed up, that life is hard?" She ended by saying that she was not asking for euthanasia, but that she needed to have her distress heard.

This is why reformulation⁸ is important when there is a request for euthanasia.

Mrs. W. is in a rest home and suffers from loneliness. When her daughter comes to visit, she tells her: "I would like to die since I am no longer useful for anything..." The daughter retorts, tit for tat: "But mom, you are still there to love us!..." Mrs. W. was dumbfounded. She remained silent for a long while, then, with a smile on her lips, said: "Yes, that is true, I am still there to love you, and it's the most beautiful thing I know how to do..."

For lack of training or information, out of concern for a perverted and misunderstood tolerance, out of a desire to answer the request in precipitous fashion, euthanasia has become normal for certain people, banal for others, and even moral for a third group.

1.6 The Economic Context

Along with the human suffering experienced on every level, the political message tells us, time and time again, that cuts need to be made and that healthcare is costly.

Once again, we need to open our eyes and acknowledge that we live in a society that leaves less and less place for aging, frailty, illness, and death... To be convinced of this, it is sufficient to read the report of Canadian researchers at the University of Calgary [2], who reckon that Canada could make large cuts in the healthcare budget thanks to the decriminalization of "medically-assistant dying." Basing themselves on the data and profiles of euthanized Belgian and Dutch citizens, these researchers have estimated that more than 10,000 Canadians could have themselves euthanized every year, which would represent a savings of more than 130 million dollars.

Even if they refrain from promoting euthanasia, we have every right to ask ourselves what the goal of their research is.

In Belgium, Dr. Marc Moens, former president of the Belgian Association of Medical Unions (ABSyM-BVAS), also asks himself: "In August 2016, in the wake of budgetary problems in the area of care for the elderly, a debate began over a policy of euthanasia that is motivated by socio-economic considerations... Euthanasia is already considered a right that can be laid claim to and that can be abused, but mostly it is becoming a duty for the doctor who receives the request." [3].

Closely connected to this politico-socio-economic context, "almighty" medicine, which wants to leave nothing to chance and prides itself on mastering everything, considers letting go to be a failure. Thus, faced with a patient at the end of life, the doctor is tempted to see only these two alternatives: extraordinary measures

⁸Reformulation is one of the keys of palliative care. It consists in ascertaining that what the patient has said has been understood by reformulating what he said and asking him if that is what he wanted to say.

or euthanasia. In both cases, the doctor remains “master of the situation” and leaves no place for an acknowledgment of the limits of man and medicine.

Thus, the slippery slope syndrome is very real. In the domain of end of life, euthanasia is effectively and illegally proposed by healthcare staff, even if the legislature pretends to ignore it. In matters of mental and moral suffering, the slide is even more flagrant.

1.7 Euthanasia in the Psychiatric Context

In late 2001, the commission that worked on the bill of law on euthanasia had asserted without any ambiguity that “the psychiatric suffering of the patient alone could never lead to euthanasia. The groups in the majority recognized that patients afflicted with dementia or psychiatric disorders did not fall within the bounds of the projected law’s application” (Descheemaeker Report submitted in the name of the Justice Commission) [4].

Today, the seventh report on the registration of euthanasia cases states that 108 people were euthanized for psychiatric causes such as depression, early dementia, borderline personality disorder, bipolar disorder, schizophrenia, obsessive-compulsive disorder, anorexia, etc.

This practice raises an enormous number of questions, given that the evaluation of “unbearable and unappeasable” mental suffering is extremely subjective. How can the irreversibility of moral or mental suffering be validated?

Thus, a 48-year-old psychiatric inmate was euthanized in prison in September 2012. “The question everyone is asking is whether the inmate would have made his decision if he had received proper psychiatric treatment,” Dr. Moens stated [5].

The case of Laura is still more telling. Laura, 24 years old, suffers from chronic depression and requests euthanasia. Three doctors confirm that her mental suffering cannot be reversed. One month later, the period required by law for euthanizing a patient who is not terminally ill, Laura clearly asserts to the doctor who comes to euthanize her that she no longer wishes to die.

It is evident that the person who suffers mentally has no perspective on the future and cannot imagine that she will be better in a few weeks. Laura’s case reveals, once again, that no one can validate mental suffering as irreversible.

The conditions of decriminalization state that the patient must be “capable and conscious.” How are the real capacity and consciousness of a person suffering from a psychiatric pathology to be verified? The first symptom of a patient deemed *psychotic* is the loss of the sense of reality. Can we then endorse her request, knowing that her perception of reality is altered? We know that in psychiatry the dominant element of people suffering from psychiatric disorders is the loss of their vital impulse. Thus, the primary goal of psychiatry is to develop effective strategies to put a person back on her feet and give her back the will to live. Is not there a risk of imploding the core principle of psychiatry by accepting euthanasia on account of mental suffering?

A young bipolar female has made a second attempt at suicide. The doctor on duty talks to her about the possibility of having herself euthanized. The patient becomes angry, for she does not want to die: "Don't you see that I am just a piece of crap? My adoptive parents have rejected me and I am alone in the world!" The doctor had not understood that these attempts at suicide were calls for help ...

The loss of hope, a feeling of incomprehension, and loneliness are the principal motives for requesting euthanasia in psychiatry, according to documents of the Federal Commission for the Control and Evaluation of Euthanasia [6].

Medication is not the only means to help patients overcome mental suffering, even though they are extremely important and necessary. When we work at the narcissistic reevaluation of people, a path to living can be cleared... Obviously, human and financial means need to be made available, but psychiatric care professionals also need to be convinced.

Gilberte suffers from Huntington's disease and requests euthanasia. The doctor consults a colleague, as the law requires, and a month later the patient is transferred to a hospital that performs euthanasia. At the moment of the act, Gilberte has a crisis of anguish and categorically refuses to be touched. She ends up returning to her unit after telling the doctor: "It was my children who convinced me I no longer had any quality of life."

How do we look upon vulnerability and who are we to evaluate another person's quality of life?

In the mind of common mortals, the dominant opinion, broadly conveyed by the media, identifies euthanasia with dying with dignity. It is true that each of us has, according to our history and filtered through our subjectivity, our own conception of dignity. But does not society incite us to orient our concept within the restrictive framework of autonomy and self-determination, thereby signifying that dignity is lost with physical decline?

Do not we need to rediscover the ontological concept of dignity as extolled by the Universal Declaration of Human Rights? A human being intrinsically has dignity, whatever the contingencies of his life, handicap, suffering, or dependence. As a human being has dignity due to being human, he never loses his dignity; it is irreducible. This objective dignity certainly does not prevent a suffering human being from experiencing a real feeling of indignity; but in that case, is not it a job for us, the healthcare professionals, to try to transform this feeling?

Mrs. R. comes to a palliative care unit after long months of hospitalization in an oncology unit. The oncologist's report is unambiguous: this patient is at the end of life and will die within the coming days. We take the time to accommodate her; we offer her a bath, which she willingly accepts. We ask her what her favorite music is and she tells us she likes the accordion. We find a CD that plays while she is bathed and we sense that Mrs. R. is relaxing. We suggest make-up and nail polish and, when she comes out of the bath, her daughter exclaims: "My, how beautiful you look, mom!" And she replies: "It's not the make-up that's made me beautiful, but the kind regard of the nurses..." Mrs. R., who was supposed to die quickly according to the oncologist's prognosis, left the palliative care unit after six months in the hospital, to return home, surrounded by her loved ones.

1.8 After Euthanasia

We speak very little about the people who go on living after being directly affected by the euthanasia of a loved one.

One day a nurse came over as very aggressive at a lecture I was giving on euthanasia. I took the time to listen to her and I learned that she had just experienced the euthanasia of her husband. In the final stage of terminal cancer, he had asked her to choose the date of his planned death, without her telling him. The patient was at home on an IV, and the doctor came by every day. This nurse was in great distress. This is what she told me: “My husband was euthanized and I am not even certain that he met the conditions of decriminalization... He was indeed suffering, but the medication relieved his pain ... For days and days, I asked myself what was the right day to make him die, but I could not even speak to him about it... 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 had no words to offer but only silence.

It seems more and more obvious that the grieving process is much more difficult when death has been given intentionally. The more natural death is, the more natural the grieving process is as well... I think that we will speak again, in the future, of the *survivor syndrome* for the loved ones who survive the euthanasia of a relative. How many feelings of guilt are laid bare in support groups for people in mourning?

1.9 The Euthanasia of Minors

What is to be said about the euthanasia of minors? In any case, it causes a good deal of ink to flow, even in, and especially in, the medical profession. In Mumbai, in India, in February 2014, the International Congress for Paediatric Palliative Care brought together more than 250 experts from 35 countries. The question of the euthanasia of children obviously came up and these pediatricians as a body decided to send a message to the Belgian government, inviting it to “reconsider its recent decision with the utmost urgency.” This was their message: “We believe that all children (neonates, children, and young people) have the right to the best quality of life. When they have life-limiting conditions they have the right to high quality palliative care to meet their needs... We believe that euthanasia is not part of children’s palliative care and is not an alternative to palliative care...” [7].

The question of euthanasia for minors is extremely tendentious since the child does not know what euthanasia means. Thus, euthanasia has to be explained to the child, so as to make it possible for him to request it. But is not informing him about the possibility of putting an end to his life already a way to proposing it to him? How will the child understand what medicine is proposing to him? Very likely it will be this: “To eliminate this revolting pain, we would be able to eliminate you...”.

In this specific context, euthanasia has a very violent crudeness. I had the opportunity to work in an outpatient hospital where children were treated for various

illnesses, including cancer. I was always edified by the way these children lived their illness. There was suffering, to be sure, but also a kind of joy, and furthermore I never heard talk of euthanasia.⁹

The law tells us that children must be “capable of discernment.” What does this eminently subjective expression mean? At what age is one capable of discernment? 5 years? 8 years? 10 years? 12 years? But do not we all know people 50 years of age who are still not capable of discernment?

There is a risk in unconsciously inducing the request, as much in the children as in the parents. Thus, in a pediatric oncology unit, a child was saying that he wanted to be like a bird and his mother asked herself whether her boy was not in the process of requesting euthanasia [sic]. Obviously this interpretation was not taken seriously, but it nonetheless crossed the mother’s mind! That is what is insidious. Euthanasia has been so trivialized that it is now understood to be implied when there is no request for it.

1.10 The Euthanasia of Remorse

The trivialization of euthanasia manifests itself in matters of identity and the socio-familial context.

We have all heard of Nancy, a girl who had only a “garret over the garage” for a room. Her parents reproached her for not being a boy. Her mother regularly told her: “If only you had been a boy...” Here is what this mother told a reporter from ‘Het Laatste Nieuws’ [8]: “When I saw Nancy for the first time, my dream was shattered... She was so ugly... I had given birth to a monster, a phantom...” While the three boys in the family could relax after school, Nancy had to do the housework. “I have three sons, a husband, and a job. It’s logical that a girl ought to help with the cleaning, isn’t it?” she stated.

Much later, Nancy wanted to become Nathan. First she underwent hormonal treatment, then a removal of the breasts and a phalloplasty. Nancy, now become Nathan, said: “When I looked at myself in the mirror, I was disgusted. My new chest did not correspond to my expectations and my new penis had the look of a reject. I did not want to be a boy in a man’s body, and even less a monster...”.

Nathan requested euthanasia. In conformity with the law, three doctors deemed that Nathan’s suffering was unbearable and irreversible.

Before his death, Nathan wrote a letter to his mother, who replied to the reporter: “I will certainly read it, but it will be filled with lies... For me, this chapter is closed. His death means nothing to me. I do not feel any pain, any doubts, any remorse.”

The request for euthanasia must always be heard and received with infinite respect. It is a cry that needs to be expressed, and it is because we offer room for the expression of this suffering that the suffering can take on another face.

How many patients have told me that they wanted to be euthanized, sometimes at the very moment their illness was diagnosed! Then, along the way, a little like the

⁹The documentary film by Anne-Dauphine Julliand, *Et les mistral gagnants* (2017), shows the extraordinary resilience and appetite for life of seriously ill children.

stages of grieving, they no longer asked for death but looked for a certain quality of life, and that involved a multitude of factors.

Our society extols the right to die with dignity, but the question is biased. It is not the right to die that is in play, but the right to “make die.” The law always regulates acts in which the will is involved; it has nothing to say about a natural state of affairs.

Is palliative care not the most beautiful and the most sublime way to experience dignity? Palliative care is not a way to make people die, but a way to help them live to the very end.

A doctor told me lately that it was monstrous not to euthanize people who were tired of living. This will probably be a future stage in the conditions for decriminalization: allowing the euthanasia of a person who is “tired of living.” Who, finally, is monstrous? The person who is disfigured by illness and tormented by suffering? Or the one who proposes death in any circumstance?

I leave it to Jean Rostand, the eminent biologist and historian of the sciences, to conclude this reflection: “When it becomes habitual to eliminate monsters, the smallest defects will be seen as monstrosities. From suppressing what is horrible to suppressing what is undesirable there is but a small step... This cleansed, purified society—this society without refuse, without blemish, where the normal and the strong benefit from all the resources that until now the abnormal and the weak have consumed—this society would reconnect with Sparta and delight the disciples of Nietzsche. I am not sure that it would still deserve to be called a human society.” [9].

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The Doctor Turned into an Instrument

2

Catherine Dopchie

*It takes nine months for a person to be viable and fully formed
yet it takes only 60 seconds to die!*

Dr. Jeanne B. (doctor in palliative care).

Being a doctor is my vocation; it is my calling to be an active member of society, to have my place in the world. It is not an end in itself, but a way to exist and to flourish personally and in solidarity with others. I am deeply convinced that I have a mission to combat illness with skill, to support the sick and their loved ones with all my heart, and to experience the compassion that alone makes it possible for us all to live together.

Given all this, since the therapeutic relationship is a human relationship, I am convinced that the doctor must be completely committed, with the three dimensions that constitute his being. He engages his body by the expression on his face, the way he speaks, and the movement of his hands; but he engages also with his heart, by his ability to experience emotion, his sensibility, and his intelligence; and lastly, he engages with his mind through his will and his liberty. In all this, he is called to open himself to the other person, all the while respecting her as different. In answering this call, he labors so that the life that dwells equally in both of them may flow within them, between them, and beyond them, and so may weave the bond of humanity that binds all of us. That way, the doctor can reach out to a sick person in a human way, in the entirety of her suffering. He can help the sick person to get moving again, to evolve, so as to heal whatever in her body or mind needs healing, but he can also help her get beyond her losses and reorient her expectations.

C. Dopchie (✉)
Tournai, Belgium

Independently of the treatments we give, sometimes without our knowing it, simply because we open the door to the life within us, good things pour forth from this inner life whose goodness we cultivate. If a person agrees to detach herself from the superficial, if she refocuses on what ultimately counts, she nurtures what is perennial, what transcends the relationship and gives a taste of eternity. A lasting human society is built.

Isabelle is 62 years old, with sparkling blue eyes and a smile from ear to ear. For her husband, her children, their spouses, and her grandchildren, she is the conductor of a family symphony who cannot help but touch those who meet her. Mistress of her life, sure of her choices and resolves, she knows how to guide her little world gently and firmly. In two weeks, jaundice fell upon her like a storm from a summer sky. Unfortunately, its cause is a particularly aggressive cancer of the pancreas that has already spread to the liver. The prognosis is extremely somber. The liver is functioning very poorly, allowing at best a very low dose of chemotherapy, which may be sometimes difficult to tolerate and whose effectiveness seems uncertain. Is it wise to undertake it? Isabelle takes in the news by shedding a few tears that are quickly wiped away and by letting her "better half" hold her hand without saying a word. In one evening, she's made up her mind that there is to be no question of dying: her son is getting married in three months—she's got to get better and be in shape for the wedding. In this chaos, scientific truth shall not have the last word. Isabelle's resolve is wholehearted; the only thing she can do is to silence this damn cancer that wants to interfere with her plans. Everything will go well. With teeth clenched under a revived smile, Isabelle suffers, alone and in silence, the anguish of a dying person that is imposed on her. Mirroring her resolve, without a word said, each of her loved ones obeys the mute order and puts up a good front. The love that flowed so well freezes. Like a colorless, odorless poison, death insidiously settles among them. I suffer to see them like that. Confident in her strength, I suggest to Isabelle that she does not repress the reality of serious illness, that she give it a place in her life and in that of her loved ones. Happily, Isabelle lets herself be guided and agrees to open the door to another way of being. Instead of being the one who shows the way, she learns to listen to the advice given to her. Instead of confining herself to the role of the strong woman who controls everything and imposes a smooth and joyful ambiance, she is willing to both relinquish control and fight on. Accepting her vulnerability implies acknowledging her finiteness. But finiteness is scary. It implies saying good-bye, leaving those one wants to protect. This requires time and inner struggle. Progressively taming reality can allow ties to be firmed up more, to show confidence in loved ones, to leave messages, and to find peace. In these situations, the doctor is inspired by the hope that the sick person may experience a transformation of her life, may accept it and make it her own, to regain the wholeness that opens her to inner healing. Isabelle dares to freely speak the truth. She learns to cry with her loved ones and to let them cry, without for all that becoming discouraged. She becomes willing to not control everything, all the while remaining herself. Bestirring herself to prepare both her son's wedding and her own burial, she makes more room for those she loves and who love her to support her, to surround her, and to care for her.

She learns how to receive in addition to how to give, to welcome whatever happens instead of denying it. This is stimulating and salutary for her and her loved ones. Thanks to this new equilibrium, like a reed that bends but does not break, she expresses even more vividly her personality that is so full of life and will leave her imprint in the hearts of her loved ones to remain there forever, devoting the end of her life to snubbing the death that wanted to crush her. Drawing on this new wealth she discovers in herself, Isabelle finds the necessary force to snatch enough time in remission to let her be truly in shape for her son's wedding. Then she dies quickly but in the joy of a shared victory.

The lessons she taught confirmed the reality of “a life fully lived right to the end,” not only for her loved ones but also for the healthcare professionals, and for me in particular. The tiny spark I gave lit a fiery blaze that shone far and wide. Through alert listening and loving presence, I experienced how, if one simply gives of oneself in this therapeutic alliance, there is a chance of touching the mystery present in each one of us. Mutual self-giving can be painful, or at least destabilizing since such giving often has the feel of powerlessness. One is tempted to flee rather than to live. That is what I would risk doing if I believed that I could not rely on anything. I would then flee to protect myself and remain effective. I would succumb to the temptation of wanting to manage the problem one way or another. But then I would cease to see the sick person. I would see only her illness and her suffering, which repel me. Yes, everything depends on how I see the sick person and how she sees me. Her truth, which escapes her, just as my own escapes me, can only be approached in the communion of our two frailties. This requires confidence and perseverance. Ordinarily, we seek independence, for we think we are free only by being independent. We seek effectiveness, strength, and autonomy, devoted as we are to individualism. As death approaches or when illness brings it to mind, we become aware that this way of seeing things alienates us from our nature and weakens us rather than strengthens us.

Unlike Isabelle, Corinne struggled for five years, with long remissions and relapses. But just like Isabelle, she has a fiery temperament, she is decisive, independent, and combative. She clings to her autonomy in deciding and acting. Losing her hair, or part of her lung or liver, is nothing as long as she can attend to her business and live without depending on others. Her oncologist, who works in the same hospital as I do, has just told her he can only offer to keep her comfortable. She does not want to go home. She wants to stay a while at the clinic. My colleague requests her transfer to palliative care, with no particular plan. She acts a bit distant toward me, but is polite and smiling. She keeps to technical questions—symptoms, explanations, and medication—and does not pick up on any hint I offer for a deeper dialog. I am at her side for a few days only. Very quickly she understands that the fatigue that is starting to hinder her mobility and makes even getting dressed an effort is here to stay. She understands that the appetite she has lost will not return. Without the palliative care team’s knowledge, she makes sure that her referring oncologist will keep his promise to euthanize her. She informs her loved ones; it has to be done quickly. The referring oncologist, who knows that the palliative care team does not practice euthanasia, remains silent about this plan and asks his patient and her loved ones to do the same. They avoid the idea of possible support and concentrate on imagining what they view as inevitable. For them, there is only useless suffering. The patient is in a hurry. I am absent that day; my oncologist colleague is replacing me and is a little overloaded. Without saying a word to the palliative care team he has just left, he asks a nurse on the oncology team to free a room and get the patient so she can be euthanized. Without stating any reason, the nurse in oncology telephones the palliative care unit to say she is coming to get the patient. The healthcare staff in palliative care find these odd doings disturbing. For her part, the patient appears calm. She has got what she decided on, what suits her; the rest means nothing to her. Upon my return, I am pained to see my team treated like furniture. In this assignment, I feel amputated. Nonetheless, I met this patient’s expectations within the framework she defined: I thwarted whatever physical symptoms there were and I did not force upon her a relationship she did not want. She knew that I did not perform euthanasia and freely chose not to speak to me about her difficulties. Yes, at that moment in any case, the only possibility she could see to maintain what she considered her autonomy was to stick to this image of

herself that she had forged and shown to everyone else, that of the patient in charge. As for myself, it was my duty to take in and let resonate in me the mute cry of her suffering, her revolt, her denial, her anger, and her discouragement, even if nothing was said or shared. In the Belgian medical context of the decriminalization of euthanasia, I had no choice but to accept this interpersonal void and let her choose an induced death.

This way of applying the law on euthanasia is widespread. To me it is abusive. Originally, the law removed the fundamental prohibition of killing, but only in certain circumstances deemed extraordinary. The legislature confirmed that killing—even out of compassion, even at the express request of the patient—remained a grave act that the doctor could perform only in an exceptional circumstance. This law sought to protect the doctor against possible indictment. But its application was quickly extended. Thus, in what way did Corinne, in fearing the progressive loss of her autonomy, display suffering that was making her lose her dignity? Or that of those who supported her?

In giving citizens the so-called right to choose when their life is no longer worth living, society turns the doctor into an instrument.

Euthanasia has become a life plan, and the doctor is asked to grant the citizen what she asks of him. Instead of considering euthanasia a transgression, an evil that is tolerated under strict conditions, current ethical thinking seeks to impose a new paradigm of care, under which the doctor must consider it a lesser evil, indeed a simple therapeutic option, in planning care in advance. As for myself, it is only by means of my right to conscientious objection that I can attempt, at the bedside of a sick person, to shed light on the situation from another perspective. This is possible only if the patient leaves me free to do so, because euthanasia has made it difficult to talk about and maintain this perspective. To make myself more available to the person who truly requests euthanasia, I must overcome my own fears and ground myself in my values in order to risk the encounter, to dare to venture into unknown territory, where I will be defenseless, at a loss for an answer, where I will have to give yet more of myself, relying on what lies deepest in me, on the spark of life that sustains me. None of us has created himself, and so I know that this spark also dwells in Corinne, as in every human being. I know, not from theory but from experience, that the spark of life remains alive and can help us. It beckons us to give ourselves up to it with confidence and to let drop the image of what until then we had thought ourselves to be, like an empty shell. Is not that what it means to live? To dare to place real confidence in our untapped resources, without looking to hang onto the image we have constructed of ourselves over time. The doctor knows he must remain by the side of the suffering person, to help him realize he can find himself anew instead of losing himself, that he can again be himself, even if he is different, even if he is afraid he will not be recognized. The person whose suffering seems unbearable and unappeasable sees herself trapped where she thinks she can no longer live. Her suffering reaches out to me in the deepest place of my own frailty, where I too experience my powerlessness as an impasse. The person who is at the end of her rope is a call to me, a summons. The only way, for both of us, to get out of the impasse where suffering wants to trap us, is to recenter ourselves, not on our achievements, not on the quest for a solution, but on our common humanity, our

complicity as allies, by making our relationship strong and loyal, by being willing to live through the difficulties together. The person who is suffering will feel she has been reached out to only if the person who cares for her lets himself be touched where he too is fragile and vulnerable, where he accepts that he too can live through this suffering. Supporting the person is more important than solving a problem, without for all that forgetting that “expertise is the foremost solidarity.”

Accepting this fragile situation provides an opportunity for us to approach the intimate and mysterious place where the life force flows in us like a free gift.

If I consent to be powerless, in a spirit of silence, struggle, confidence, and patience, I can let well up in me a life-giving spring that makes me a better person and allows me to show another person that I have faith in her. It is often from the powerlessness I take on that in my heart there arises the compassion that can reach the suffering person and give her new strength. A shared peace, a gift of life for both of us.

This is what Corinne refused. By turning in on herself, she demanded a contractual commitment rather than a therapeutic alliance. All that is left is the confrontation between the right to request euthanasia and the right to accept or refuse to carry it out. Since Belgian society imposes this confrontation on me, the exercise of these rights must at least respect the vulnerability inherent in human nature. The person who suffers and experiences the feeling of no longer being able to live must be acknowledged in her suffering. Yet are not certain sick people, in a situation of extreme frailty, often exploited for the benefit of a macabre ideology? It in fact is not rare that the press depicts them as horrors to be eliminated since they call into question the concept of an ideal life without suffering, our society’s utopia, which contradicts our life in the flesh. If, like Corinne, the patient sticks to her point of view, to the point of repelling any dialog, there remains only loneliness, on one side and on the other. The therapeutic relationship can only be cut off. And humanity swept aside.

But is this what to expect of a doctor? To step back when he has left only what is essential, his humanity, to place at the service of the person who is suffering?

Should one infer that our country has imposed on us an act that denatures our profession?

In any event, insofar as I am involved, given how I view my medical commitment to the therapeutic relationship, I do not feel respected. It is as though I were but a machine equipped with some good software, producing an act that issues from the meeting of an intellect and a will. Besides, the law does not even require that the doctor know the person he is to euthanize; he must only verify that the person belongs to the “euthanizable without prosecution” group. This law is deluded about its foundation: it purports to be the exercise of a right to autonomy, whereas it is only a conditioned reflex in the face of a double impasse: the impasse of the patient drowning in her suffering as though she no longer has it in her to exist, and the impasse of the doctor locked into the omnipotent efficacy that the other person demands of him.

It is not a question of a responsible and free autonomy but rather of a desperate act of two people trapped in powerlessness.

The resolve to promote autonomy as an absolute good results in a perverse fusion where the roles of master and slave are interchanged.

The sick person, reduced to her suffering, thinks she knows what is good for her and wants to impose her vision. The doctor exists only in his capacity to respond to the patient's expectations. He loses his own identity and commits an act of mistaken mastery to fulfill the other's aggrieved wish. The way they have defined themselves, one cannot continue to exist without the other; they are accomplices forever.

Attempting to take control of the situation by an act that interrupts life is for me false compassion since it denies the fact that the person always remains a force for the good to be protected, whatever her situation—a person with whom, together, we jointly form humanity. Of course, inducing death effectively turns the one who suffers away from a difficult road, but this irreversible act gives the last word to suffering. It prevents the person who suffers from discovering in herself the living force that both renews the one who finds it and strengthens the one who witnesses it. Giving the doctor the power of death over the utterly defenseless person who requests it of him pushes him into a position where he becomes the idol, the one who can do everything. This way of thinking forces the doctor to abandon the therapeutic goal of caring for humans as they really are, to veer toward a promise to improve the human condition, which has been conceived as a subjective ideal, detached from reality, freed from any dependence, from any shared point of reference.

This unbridled quest for total mastery, which denies the finiteness inherent in man and denies man as a transcendent being, is appalling since it cannot do other than sacrifice a weakened person in favor of an idealized and abstract image. Suffering in one's own identity is a painful wound that impairs a person's health. The doctor has no solution to offer; he can only accompany the person along her way, in solidarity with her in this suffering that can touch any person. This is the glory of his vocation of caregiving.

If Corinne does not agree to take the journey of seeking what remains of herself after her losses and what truly defines her as a unique and irreplaceable human being, if she refuses to take the risk of waging this fight and if Belgian society gives her the right to find a doctor who cancels this fight before it can start, it is to be feared that the humanity of both patient and doctor will be erased.

The doctor becomes the instrument that satisfies a resolve, the executor of a contract. Through his skill and the power society bestows on him, he masters the natural life from which the patient wants to be freed..., whereas, for me, the doctor is there, with his expertise of course, but also with his whole person, to place himself at the service of the suffering person, in the most balanced interpersonal relationship possible, recognizing each one's limits.

To demand that medicine master all suffering is to reduce it to solving problems, instead of taking an interest in the person who is suffering.

Suffering certainly must be fought with skill and perseverance, but it does not encompass the whole of a human being. The patient cannot be reduced to her suffering; she is more than that. The doctor cannot be reduced to his expertise or his function; he is more than that.

Requesting death and giving it when suffering persists is neither a courageous act nor an act of love, but a flight and a desertion. Courage and love do not lead to these

impasses: the fear of suffering together, turning in on oneself, and turning the other into an instrument. In these difficult cases particularly, but also generally, I plead for recovering and permanently entrenching a humble and human medicine, almost in spite of its effectiveness, a medicine centered on human beings and not on their problems.

From experience, I know that this attitude can give birth to a new inner freedom. For the sick person who is no longer alone, who is acknowledged as a companion for the journey, as someone important, capable of acting and of giving herself in spite of her extreme frailness, it is a matter of seeing the unexpected surface, of discovering unknown resources within oneself, of tending toward inner healing and wholeness of being. For the healthcare professional, it is a matter of being received by the person who needs him, without having anything else to give but the main thing, which is himself. For loved ones also, it is a matter of growing in humanity by remaining present for the person who is suffering: her suffering upsets them, but they acquiesce in suffering with her.

Only the painful confrontation of this reality makes it possible to affirm the existence of the "kalon kakon," that is, the beauty of love concealed in the ugliness of suffering.

Whether we want it or not, all that we experience rebounds in one way or another on those who surround us. To want to escape, by means of a radical technical solution, from the formidable experience of suffering and dying leaves us more and more defenseless, more and more vulnerable, whether we are the one cared for or the healthcare professional, the loved one, or simply a member of society. This growing inability to live with suffering will make people say, more and more, as we are already hearing, that only an induced death, at the chosen time, is a dignified, peaceful death suffused with humanity, and that only the doctor who agrees to induce the death of his patient who has requested it has any heart. Whereas euthanasia is in fact surrendering to fear, to prevailing despair, to the attitude of "what good is it anyway?" that clips our wings.

Lili writes to me: "Before experiencing the accompaniment you offered my mom, I was rather in favor of euthanasia. Now, not any more. Without making a crusade out of it, I know that I would not want it for myself. I have learned, from the final moments lived with my mother, to tame death. It is a wonderful gift, for I no longer fear death now. That is for me the key: if our society had not set death aside by making it a supreme taboo, euthanasia would not exist. And you are not heartless, on the contrary!"

The growing incapacity to live with suffering affects not only our humanity but also our professional expertise and our ethical bearings. Many healthcare professionals today have not acquired or are losing their expertise in dealing with great suffering instead of improving it. Their threshold of tolerance has fallen greatly.

Euthanasia kills not only the patient but also the therapeutic imagination.

Palliative care, as established by Dr. Saunders, has fallen out of favor, whereas it should be better taught and developed. Instead of taking this route toward progress, certain healthcare professionals, notably members of the Commission for the Control and Evaluation of Euthanasia, ask that directors of public health services

henceforth promote the form for the advance declaration of euthanasia, believing that there are far too few people enrolled. Yet we know well that it is difficult to make decisions when the patient is unconscious,¹ and even more so in the current context where the pressure for euthanasia from suffering loved ones can be great. The Commission's request can only lead to escalation, to the point where euthanasia will become a panacea, applied in any difficult situation. Is that the medicine people want for tomorrow?

2.1 The Therapeutic Alliance

In being born male or female, human beings must acknowledge that they are they are not by themselves alone sufficient to express humanity. This complementarity is also to be found in the doctor–patient relationship. For human beings to be, to live, to grow, and to build humanity, they must accept complementarity and dependence. Being a doctor means forging a therapeutic alliance. This has nothing to do with a therapeutic contract that seeks only to place sophisticated technology, applied by a qualified professional, at the disposition of an anonymous client who gives or does not give her consent. In the alliance, there is a promise of loyalty to always provide care in an impartial way. I have witnessed the way in which many men and women, in situations of great distress, have found in themselves resources they were not aware of and that flourished by their accepting difficult circumstances.

Marie-Thérèse is 84 years old. I find her very agreeable. Yet she upsets me in our first meetings. She suffers from a metastasized ovarian cancer and we speak about a treatment plan. In a very crude, flippant way she tells me how she is for eliminating the elderly in retirement homes and the handicapped at birth, all those useless people who can do nothing with their lives. If she becomes helpless, she is sure she will request euthanasia. She knows that I am a conscientious objector to this act, but just the same, she wants me to take her as a patient for chemotherapy. We get along well. At the end of life, bedridden and completely dependent, to gain time, she fights all the forces arrayed against her, telling her daughter: "It's my old age." Reasoning as a woman in good health, she had reduced her body to its organic aspect, but she had no doubt forgotten the fact that a person exists in relation to others, through her body—this frail body that is herself, and not mere matter that belongs to her. Tirelessly attended by her loving daughter, she came to give renewed value to the body that was abandoning her, to maintain her relationships, and to live through them to the end.

Marie-Thérèse and her daughter, and so many other examples I have seen, show a reality that forbids us to despair of human beings. Human beings can evolve endlessly while always remaining themselves, and can do so much better with an alter ego that accompanies and supports them, and they can invent new norms for themselves that integrate their difficulties. Their acknowledged vulnerability becomes a life force that helps them detach themselves from the idea that they had of themselves and that imprisoned them.

¹The advance declaration on euthanasia is a form by which a person "requests, in the event he/she is no longer able to express his/her will, that a doctor perform euthanasia provided all the conditions laid down in the law of 28 May 2002 on euthanasia are satisfied" (www.health.belgium.be).

Jacques is only around 50 years old. A kind of sullenness and listlessness, a fatalistic carelessness along with a certain resourcefulness in social dependency, drew him into a downward spiral of debt from which there seems to be no return. Fortunately, he is taken into the care of the district's social assistance team and a medical institution that supports him in his new hardship, metastatic lung cancer. Unfortunately, the illness has got the upper hand: chemotherapy is no longer effective. In pain and diminished by an inability to function that is getting worse, he needs to be taken into the care of a palliative care team. Little by little, the core of his person comes to the fore; he shows himself to be particularly plucky with the physiotherapist who is teaching him to walk again; he works hard, like an athlete who wants to win the gold medal. He involves himself, to the point of literally being out of breath, in relating to his new "friends," the healthcare staff, the volunteers, or his fellow unfortunates. From this loyal support, he draws the strength he had lost when he was in good health but abandoned by everyone.

Living this medical relationship, where the doctor and patient agree to have a real responsibility for one another, does not deprive them of autonomy, but on the contrary opens a way to an authentic freedom that is cohesive and human. From this abiding fraternal relationship is born the confidence that makes a therapeutic alliance lived out in everyday life possible. That is the humanist medical paradigm that respects the human being, simply because he/she is human, independently of everything else. Suffering and death than lose their false supremacy. Human life is truly respected to the very end, unconditionally. Human society can rely on and remain firm on this sure foundation.

Yes, euthanasia remains a temptation which is right and good to resist.

We can transform death by living it as an act of love, by welcoming our spirituality that comes to the aid of our wounded flesh. It is no doubt this transformation that makes those who care for the seriously ill say they receive more than they give. In the therapeutic alliance, the patient and doctor weave a bond between themselves by both trusting, in the same manner, in the life force that was given them and that unites them, what I undergo by the violence of suffering is transformed by love. By honoring the life received in us, our flesh is reborn from its ashes. This life force can transform everything from within much better than a solution imposed from without.

Annita is seriously handicapped due to anoxia² at birth. Monitoring her is complicated since she hardly speaks. One has to know her well to interpret her symptoms. So the diagnosis comes too late: paralysis of the lower limbs linked to compression of the bone marrow by metastasis. Recovery is not possible, only a treatment that relieves her pain and prolongs her life. Several visits to reevaluate her treatment have made her well-known in the palliative care department, where she is happy. Through interdisciplinary collaboration and ongoing discussion, the team seeks what is good for Annita, while respecting her wishes and her frailty. At the very end of life, greatly weakened, turned in on herself due to incorrect positions³ slowly acquired despite the efforts of healthcare professionals, from the intense gaze of fraternal communion she draws the strength to die calmly, with a dignity that compels wonder and makes those who tend to her stronger.

²Anoxia is a deficiency of oxygen the blood distributes to the tissues.

³The abnormal position taken by a limb or several joints, due to a persistent anomaly of the underlying skeleton or to a long-lasting neurological affliction.

I hope that in reading this you will have understood that its content does not come from theoretical reflection. I am a doctor and it is as such that I express myself. My thinking is rooted in what I experience as a professional in the field.

The doctor is there to “sometimes heal, often relieve, always console.” Yes, to always console, since it is as a human being that the doctor is close to the person that illness isolates, worries, makes suffer, and plunges into doubt. In all these lived experiences of deaths great or small, where life asks only to triumph, but where the light has dimmed, where its fire has turned cold, the doctor and the sick person are two similar links in the same chain. When the body is tired, too weak to be lifted up, the doctor is there to tell his fellow traveler that she is unique and thus irreplaceable and that her dignity is immutable.

With all my heart, I wish the doctor–patient relationship to be a therapeutic alliance and not a contract. Even if I want to be completely dedicated to the person who turns to me, I do not accept being turned into an instrument, trapped in an idolatry that would make me a seemingly almighty savior. Through our presence before one another, patient and doctor, we can make life flow between us and unite us in one and the same humanity.

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When Conscience Wavers. Some Reflections on the Normalization of Euthanasia in Belgium

3

Willem Lemmens

One day when I no doubt needed to have some kind of feedback, I asked a sick person I was accompanying: “What do you expect of me?” He looked at me, then replied: “I expect you to stand firm.” The roles were reversed down to the very words that were spoken.

Tanguy C. (volunteer in palliative care)

3.1 The Embarrassment of the Law

The euthanasia law has been established in Belgium since 2002. The law states that a physician does not commit a crime in intentionally ending the patients’ life when he meets a number of strict conditions. In certain circles, the euthanasia law is still hailed as a major success story, making Belgium an ethical beacon for the whole world. It is often said that euthanasia has been “accepted” by most of the population and that the so-called opposition, which may have existed initially, has melted away. Euthanasia stands as a figure for the “good death” (eu-thanatos), which more and more people choose every year. In the period 2016–2017, for example, 4337 euthanasia cases were officially registered, 2028 in 2016 and 2309 in 2017 [1]. Officially, about 1 Belgian in 20 has currently his or her life ended through euthanasia.¹ It is therefore appropriate to speak of a certain normalization of euthanasia as an integral

¹It remains remarkable that in the French speaking part of Belgium there are significantly less euthanasia cases officially declared than in the Dutch speaking Flanders: for 2016 436 cases vs. 1592, in 2017 517 vs. 1792 (roughly 40% of the population in Belgium is French speaking).

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part of the end-of-life care in Belgium. Apparently, the legislative initiative has achieved its goal.

Yet there are also dissonant voices. For example, there is great concern among psychiatrists about euthanasia in cases of mere psychological suffering. Here according to many experts, in recent years there have been avoidable deaths, patients who were obviously not terminally ill and who could have been treated [2–4]. Sometimes these are young women with complex psychiatric problems and a strong persistent wish to die, who are in a socially precarious situation and clash with the limits of inadequately developed care. Their death often causes a shock to the family and the immediate social environment. In one case, this recently led to a criminal prosecution that came before the courts of assize (the criminal court in the Belgian juridical system that treats the most severe crimes), a case which affected society as a whole and enjoyed massive press interest. The doctors involved were in the end acquitted, but the trial revealed severe concerns about the way euthanasia was in this case offered and executed. In fact, during the trial, it became clear that the law on euthanasia was not respected on several fundamental points and that the control commission played an active role in the initial attempts to silence the concerns and questions of the bereaved family. Despite all these worrisome elements, the doctors went free, after a debate behind closed doors of 8 h by the lay jury. Apparently, in the end, the idea that the autonomous wish of the patient was respected and that the physicians had only good intentions overruled the fact that the euthanasia law was interpreted by them in a very lenient way.

Since the trial, a significant group of doctors have argued for a thorough evaluation of the law.² Within psychiatric care there has been concern for some time: several stories of problematic euthanasia cases are known, even though some doctors simply deny this. How to deal with that? Even if all these cases would appear to be legally justified, is a law that creates traumas among relatives and causes such discussions in society not intrinsically problematic? And what about the legal certainty of the doctors involved? The law is formulated in such a way that any violation results in a murder charge. Was that the intention of the legislator? Observers note that the acquittal of the doctors sends this signal: do not turn a doctor who tries to help into a murderer. Even though he or she may fail to offer euthanasia on some points in an optimal way, there can be never be spoken of murder in case of euthanasia, because the doctors acted with good intentions or, as one says, “in good faith.” This was the official line of argument of the lawyers defending the physicians at the trial on the euthanasia of Tine Nys.

However, as more critical voices remark, these observations raise the thought that the current law looks like a rag of paper, with a purely symbolic function: it cannot really be violated, since it is based on trust in the doctor who commits euthanasia and the belief that nobody asks for euthanasia in a lighthearted way or haphazardly. As long as the doctor follows the correct procedures and faithfully reports every euthanasia case to the monitoring committee, he is fine.

²According to a poll of the *Artsenkrant/Le journal du Medecin* 70% of the physicians in Flanders and 61.5% in French speaking Belgium insist on an evaluation of the law (*Knack*, 31 January 2020).

What is the function of the law? Apparently, the law recalls the need for careful handling of something as extremely important and complex as euthanasia, but at the same time, it wants to give doctors legal certainty. In the aftermath of the trial mentioned, the chairman of the audit committee that was created by the law in 2002 unequivocally says that the role of the committee is to act as a buffer between physicians and public prosecutor. This implies that the only possible violations of the law are limited to procedural negligence and carelessness that can be detected by a purely administrative control committee. What action must be taken on infringements, and what exactly those violations could consist of, remains unclear. This may explain why few physicians or law experts are currently willing to sit on this committee. One doctor already resigned in 2018 because it was clear to him after two sessions that manifest violations of the euthanasia law are being ignored by the committee and swept under the carpet. A letter from this doctor to the parliament, to whom the audit committee is accountable, simply remained unanswered.

In what follows I do not want to delve deeper into the controversies and discussions that continue to take place around the euthanasia law in Belgium, nor do I want to comment on problematic cases that keep popping up. Rather, from a philosophical point of view, I want to try to understand why euthanasia, as a symbol of a “good death,” but also as a lived reality at the end-of-life, inevitably continues to have something unruly and confronts us with fundamental medical and moral questions and problems, next to personal tragedies and trauma’s among families of patients that receive euthanasia. These experiences within the realm of end-of-life care lead to ongoing discussions at the level of civil society, whereby critical voices, asking for a serious and independent evaluation of the euthanasia social experiment, are countered by pro-euthanasia lobbyists who plea for a further extension of the law to people with dementia and a better access for patients with psychiatric afflictions and disorders. These last pleas are fostered by the normalization of euthanasia. However, critics see this as a proof of the slippery slope dynamics that inevitably emerges wherever euthanasia is legally permitted.

Why is the normalization of euthanasia welcomed by some and rather feared by others? Moreover, why should according to the pro-euthanasia experts euthanasia become an integrated part of normal therapeutic practice in the clinic, while others are vehemently opposed to this idea and plea for a more cautious attitude towards the further normalization of the active ending of human life in end-of-life-care? Finally, there is the tricky issue that the *mere possibility* of euthanasia would exert pressure on both the physician and the patient, but also on the whole society as such. Does that pressure indeed exist or does the law, based on self-determination, allows everyone the freedom to choose for euthanasia or not, free from any social pressure?

3.2 Euthanasia: Medical Act or Transgression?

The Belgian law describes the act of euthanasia clearly and elegantly. Euthanasia is, we read, “the intentional termination of life by a person other than the person concerned, at his request ...” It is important that this act is performed by a doctor and

that specific restrictive conditions are met. In fact, the euthanasia law decriminalizes an act that is subject to a radical prohibition in every legal order: the intentional killing of another, the most severe crime a human being can commit. The law therefore clearly states that the doctor does not commit a crime *if* he complies strictly with the conditions of the law. Moreover, an important clause in the law states that no treating physician can be obliged to “apply euthanasia,” although he must explain any refusal and pass on the medical file to a doctor designated by the patient or the confidant (Law on Euthanasia, Chapter VI, Article 14). Apparently, the Belgian law thus respects explicitly the freedom of conscience of the physician, a crucial principle of classical medical deontology.

It is clear the original concept of euthanasia has been considerably curtailed by the legislative initiative: in its original meaning, euthanasia refers to a “good death,” and was classically understood to mean the most optimal way in which a person can say goodbye to life, implying among other things a death free from unbearable suffering and pain. In the nineteenth and twentieth centuries this concept evolved: by euthanasia one increasingly understood a medically induced death, initially from the idea that some “unworthy” forms of life may be terminated by a physician based on his medical judgment and skills.³ In fact, euthanasia in this sense could be offered for a wider range of cases than just unbearable suffering and pain, as the Nazi program Aktion T4 testifies in a gruesome manner, where euthanasia was welcomed as the “good death” for some 200,000 persons with a handicap or a psychiatric affliction [5]. This has also led to the bad connotation that the concept of euthanasia still has in some countries, especially in Germany.

It must be emphasized: crucial in Belgian legislation (such as in the Netherlands and Luxembourg) is the clause that the life-ending act is performed by a doctor *at the explicit request of the patient*. That euthanasia must be the result of an autonomous expression of will, untainted by pressure or occasional emotional distress, is regarded as the moral core of the euthanasia law: thus, the ultimate right to self-determination, and therefore to a dignified, self-chosen death, is honored. Nevertheless, after 18 years and a few thousand euthanasia cases, the alleged transparency of the law seems in practice hardly realized. How come?

There are two ways of looking at euthanasia as it is practiced today in Belgium and the Netherlands (and recently also in Canada, where euthanasia is rather called Medical Assistance in Dying (MAID)): on the one hand, it can be seen as a strictly medical act, contextualized by a procedural framework, which has become integrated into the normal therapeutic realm of end-of-life care and is thus “normalized.” In contrast, euthanasia can be understood as an act that presupposes certain medical expertise and takes place in the context of the clinic or medical care *but falls radically outside the normal therapeutic practice*. I think there are good reasons for understanding euthanasia in the second sense. Let me clarify this.

Euthanasia always emerges as an action figure when the curative, healing objective of medicine falls short of a limit. It concerns a weighty, always existentially

³For more on the history of euthanasia cf. the excellent study by Ian Dowbiggin, *A Concise History of Euthanasia. Life, Death, God, and Medicine*, Rowman and Littlefield Publishers, 2007.

charged act, in principle performed when a patient is incurably ill and death is imminent, in which a dying process is concluded by a direct intervention. The closer the act is to the moment of a foreseeable death, the more it still seems to fall within the therapeutic space of normal end-of-life care. However, in Belgium euthanasia is also legally possible for nonterminal patients. Euthanasia is then offered to answer the suffering caused by an incurable and untreatable illness or affliction, which is experienced by the patient as a source of unbearable suffering, even at a moment in time where death is not at all imminent or even to be expected. This is especially the case with euthanasia demands for merely psychiatric diseases. Here, the physician leaves the normal therapeutic realm and takes a decision to stop all care and perform a life-ending act based on motives and considerations that are never purely medical. Obviously, if euthanasia is not granted, the patient has all chance to continue his life, while a persistent death wish or suicide threat might still exist. As most psychiatrists admit, at this point the social and existential dimension of euthanasia demands must be highlighted: psychiatric patients that ask for euthanasia do so often under the influence of a detrimental social situation and existential isolation. Significantly, the law in Belgium insists that a physician who considers to positively follow a euthanasia demand should try to consult family members and friends, but only on the condition that the patient gives his or her permission to do so. The law here reveals a possible tension between the *colloque singulier* of doctor and patient and the inevitable social dimension of dying.

3.3 Euthanasia as Transgression

Given all these facets I would call euthanasia a *special, transgressive act*, which one cannot reduce to a purely therapeutic option, possibly replaceable by another, technically speaking equivalent medical act. The word *transgression* can make the eyebrows frown. But in several respects, medicine is a practice that involves transgressions. I would like to make a distinction here between transgressions that fall within the normal therapeutic-clinical practice, and transgressions with an existential and therefore deeply moral meaning.

In a way, transgressions belong to the essence of medicine and are a daily practice within the clinic or clinical care: the cutting of the surgeon, but also the physical examination and screening of the body with complicated equipment is inevitably part of good medical practice. This means that the doctor in the clinic or at the bedside comes in specific contact with the most intimate of the human person: his or her body. It is no coincidence that implicitly felt, or sometimes more explicitly formulated rules apply here, which frame the transgressive nature of medical practice and ensure that patients are treated respectfully. Unmistakably, this also means that the doctor who abuses his transgressive power is expected to perform a morally reprehensible act.

Medically justified transgressions in the clinic and at the sickbed are inextricably intertwined with transgressions with an existential-moral meaning. Here too one can speak of morally acceptable transgressions, which are situated on the borderline

of strictly therapeutic and more person-related attitudes and relations between physician and patient. For example, a physician can in the course of a long-term treatment share in a certain way the privacy and intimate personal history of the patient. Empathy is in medicine very important, and always presupposes a person-to-person relationship of a certain sort between physician and patient. In psychiatry, this is the case par excellence, but not only there: in other forms of prolonged medical care the relation between physician and patient has inevitably this more personal dimension. This affects in a fundamental way the medical, moral, and existential impact of euthanasia.

This should not surprise us. Euthanasia concerns one of the two liminal moments by which every human life is structured and affected: birth and death. It is no coincidence that in every culture these moments, of crossing the border between existence and nonexistence as a corporal human being, beget a sacred meaning. Even in our liberal and highly secularized culture, we remain sensitive to this sacred character of life and death. It is no coincidence that the atheistic liberal political philosopher Ronald Dworkin [6] says that when it comes to abortion and euthanasia, the “sanctity of life” is at stake. He calls the moral questions about abortion and euthanasia inevitably *religiously* charged.⁴ From this perspective, in all cultures, we find strict rules and taboos that regulate our behavior and attitudes towards birth and death. In fact, the purpose of these rules and taboos is double: on the one hand, they serve to protect the community from transgressions that threaten the sacredness of life and death, on the other hand, they structure and symbolize the way members of a specific community are supposed to behave towards newborn or dying human beings.

From the perspective of the physician, euthanasia should thus be considered a transgression in several respects. Giving a lethal injection to a patient, which results in his or her immediate death, implies an inversion of the attitude a doctor has towards his or her patient in normal therapeutic treatment. Here, the iatrogenic power of the physician reveals itself in a dramatic way.⁵ Indeed, the “technical” act of a lethal injection is in the case of euthanasia inevitably loaded with a strong symbolic-existential meaning. This implies that ending a life by euthanasia never can become a normal medical act: if something goes “wrong” at the offering of a lethal injection, it is almost impossible to conceive of this as a merely medical-technical issue. Complaints of bereaved families after a botched euthanasia on one of their beloved ones, as in the Tine Nys case, bear testimony to this. Remarkably, some Belgian doctors seem to take their own “technical” mistakes rather lightly and

⁴“We stand on the edge of a new age of religion, though a very different one from the long religious era that history began to leave behind in the eighteenth century.” I think Dworkin’s conception of an atheistic religious spirit, which sacralizes individual freedom and self-determination is deeply problematic, but it remains significant that he stresses the need to address issues of life and death from a religiously inspired perspective. Cf. also: Dworkin, *Religion without God*, Harvard University Press, 2013.

⁵About the possibility of iatrogenic harm caused by physician, cf. Cavanaugh T. A., *Hippocrates’ Oath and Asclepius’ Snake. The Birth of the Medical Profession*, Oxford University Press, 2018, pp. 18–22, 108–116.

openly avow to consider the offering of a lethal injection a merely neutral medical act.

In fact, when intentionally causing the death of a patient the physician steps outside the normal therapeutic space and his role of healer, who is focused on preserving life and the bodily integrity of his or her patient. When offering euthanasia, the doctor enters the personal existential realm of the patient: he fulfills a deeply expressed wish, without doubt in most cases in good conscience, but also a wish that comes out of tragic and apparently irresolvable dilemma: the patient wants his or her suffering to end and sees no other solution than death. The doctor is therefore addressed also *himself as a person and not merely as a physician*. He must fulfill a most intimate wish of the patient, which is always emotionally charged and expects from the physician to step outside his therapeutic role. The physician is here addressed *as a human being, in his or her own moral integrity*. Obviously, the patient and his or her family expect and hope that the doctor is acting in good conscience when he offers euthanasia and is not merely an executive technician. If this latter is the case, it might make one wonder whether the physician is not causing a deep moral harm, that is hard to discern, let alone to sanction, but that in a way contaminates his whole profession. "It's no small deal, ending a life," a doctor once told me, "It crawls under your skin, it lingers even when it goes well and in a serene way."

Offering or performing a euthanasia act is therefore in the end a deeply morally charged *existential transgression*. It affects the physician inevitably as a human being and gives him or her a power which is from a juridical point of view immense. As the Belgian law on euthanasia indicates, the doctor commits a crime if the prerequisites foreseen by the law are not respected: if so, euthanasia comes down to killing another human being, the gravest sort of transgression that one can commit. No matter how you turn it, the depenalization of euthanasia allows a doctor to break a commandment on which in principle the entire legal order is built. Of course, the aim of the act is in principle humane and shows a deep concern for a crucial goal of medicine as such: the relief of distress and pain. The well-acting doctor is moved here by compassion, he might even see it as his duty to offer euthanasia to a specific patient. However, this does not detract from the charged, weighty nature of the act: euthanasia implies the radical inversion of normal medical therapy.

Because of this transgressive nature, I believe that euthanasia can never be conceived of as a purely procedural act, which follows the logic of supply and demand. Yet, paradoxically, due to its depenalization in the law of 2002 there is a temptation to see euthanasia in this way. In discussions in the civil society in Belgium that view often resonates: "I do what I want with my life, if I ask to die autonomously, no one has business with it, only the doctor I ask. And doctors only have to agree 'yes' or 'no', nobody should further interfere with my demand." This viewpoint implicitly presupposes a very instrumental relationship between doctor and patient: the offering of euthanasia is seen as a service of a merely contractual nature. But is the reality not more complex? Often doctors in Belgium will confirm this, but it must also be observed that many among them seem to experience a sort of habituation towards the very act of euthanasia. They just follow the public opinion that euthanasia is in

fact a sort of right that should be granted by the medical world. But does this normalization not come at a huge price? A doctor who provides euthanasia a dozen times a year or more often, can he still be sensitive to the transgressive nature of euthanasia? One could say: we, as a society have no business with that, we should not be concerned about how a doctor feels about his involvement in the active ending of a human life, nor should we try to estimate the state of his conscience. But is a society conceivable where we become indifferent to the rules and principles that regulate one of the most transgressive acts a citizen can commit? The freedom of conscience of every citizen is of course personal and inalienable, but the rules by which conscience is oriented are collective and should be open to discussion and evaluation.

Pro-euthanasia physicians eagerly defend that in the Belgian medical world euthanasia is always granted and performed with the utmost care and respect for the patient. Moreover, physicians that offer euthanasia always do so in good conscience, so it is said. When one consults physicians and medical experts in Belgium and ask for their experiences with euthanasia in the clinic, they appear to be confident that there is no risk of what Albert Bandura calls “moral disengagement.” [7] But at the same time doctors who are willing in principle to offer euthanasia acknowledge that they sometimes struggle with the role they have to fulfill in actively ending a human life. Some awareness of the transgressive nature of euthanasia remains present. Personal differences in attitude and capacity, but also in moral conviction, stand out here: “I can offer euthanasia to conscious patients who are suffering somatically and who are at the end, but do not ask me to euthanize a demented person.” Or: “euthanasia on psychiatric patients, one cannot ask this from me. I am unable to do that.” “I can only euthanize a patient that I have followed for a long time, and with whom I feel personally connected.” We discern the same sensitivity among doctors when they express in specific cases their conscious objection or remain in principle very reluctant or unwilling to commit euthanasia. These attitudes of reluctance and principled opposition should be respected because they exemplify the awareness of the transgressive nature of euthanasia.

3.4 Between Law and Conscience: Euthanasia and Moral Integrity

I return to the three questions with which I began this reflection.

1. How should we understand the divergent responses to the so-called normalization of euthanasia? To some in Belgium, it goes without saying that a “right to euthanasia” exists, and could even be derived from human rights, or the right to self-determination. The disappearance of the taboo around euthanasia is from this perspective a good thing because it seems to make the dying process manageable and death less-threatening. Moreover, it derives from the most intimate wishes of the individual patient and respects his or her right to self-determination by lifting the irrational and paternalistic taboo on death.

However, as I have argued, euthanasia can in my view never be regarded as a purely instrumental transaction in which only the autonomy of the patient and the willingness of the doctor (possibly supported by compassion) are at stake. Euthanasia always has an existential, moral, and even spiritual meaning, from which it is impossible to make abstraction and which affects the collective mind of a whole society and the end-of-life care in general. The fear of normalization among some is a fear that this weighty dimension of euthanasia and its public meaning will no longer be seen. Our collective morality, where self-determination is so central, threatens to expand euthanasia even further beyond the clinic's boundaries: euthanasia becomes a sort of emblem of clean, self-desired death, even for people who are not terminally ill. Remarkably, the law, which in fact should remind us of the great impact of euthanasia, seems to have an eroding effect here. Our moral culture is being thoroughly changed, but there is also much confusion and uncertainty: the transparency the law was promised to offer, remains a far dream.

2. As a transgressive act, so I would defend, euthanasia inevitably falls outside the realm of normal therapeutic action. Yet there is still a debate between those who think that there is a right to euthanasia, and those who dispute this. Until now, the Belgian law recognizes and protects the doctor's freedom of conscience not to commit euthanasia. Claiming that euthanasia should and can therefore become a "normal" therapy ignores this. If euthanasia is just an extension of good medical practice, there would be no reason not to recognize it as a patient right. But that would also mean that a doctor may not refuse euthanasia if in his or her eyes it appears to be the "best option" from a medical point of view.

But if euthanasia is *a right the patient can claim*, why should it not become an integral part of the medical training? I received the testimony from a young physician whose mentor thought it would be good she would by way of training get involved in a euthanasia case. Happily, this young physician was able to refuse to do so but her attitude becomes less and less accepted by some pro-euthanasia voices. In Canada, bioethicist Udo Schüklenk contends that in a democratic state the doctors' conscience clause must be restricted. "Conscientious objection" should never compromise the patient's rights to have access to certain medical treatments [8]. If euthanasia or MAID is thus considered as a normal medical therapy to which the patient has a right, this would cause an ethical landslide: the freedom of conscience of the physician would be restricted and controlled by the state. Fundamental transgressive acts such as euthanasia and abortion would thus become a public good, available for all. Doctors would turn into a sort of public medical servants.

3. Given the fact that euthanasia is a transgression that affects personal conscience as well as the collective mind of a society, it becomes understandable why it puts, if legalized, such a pressure on individual doctors, their patients, and the whole medical profession. The proponents of euthanasia in Belgium usually ignore this by stressing that no one is "forced" by the law to ask for euthanasia, one just has the option to do so. The euthanasia law is therefore praised for being very liberal: it leaves maximum space for personal choice, so one contends.

Yet, reality is more complex. Doctors testify they experience conflicts of conscience that lead to disagreement, for example, in a group practice. Sometimes patients seem to be under pressure from the family to ask for euthanasia, however subtle. Or they put pressure on the doctors themselves, often in a state of depression and emotional instability and despair. This proves once again that dying inevitably has a social dimension, but also, and more fundamentally, that it puts a heavy burden on a physician's conscience. He or she is pulled from the strictly therapeutic sphere in the direction of a heavily existentially charged decision and act. Just because the claim to his or her conscience is so great, there is a tendency to hide, as it were, behind the purely procedural requirements of the law. This further promotes the normalization of euthanasia, whereby the active ending of a human life is increasingly considered a purely technical therapeutic intervention.

The normalization of euthanasia is further nourished by the media and influenced by public opinion through lectures, leaflets, moving stories, etc. The message of these public stories is always the same: thanks to the euthanasia law dying has become human, bearable, and serene, and unworthy and inhuman suffering can be avoided. Euthanasia is a gift to the patient and helps the medical profession to deal with the end-of-life in a dignified manner. Euthanasia is presented as a completely neutral act that is independent of any ideology and just meets the patient's right to self-determination. At the same time, any criticism of the way in which euthanasia is applied in practice, or the identification of potential problems or abuses of the law, are rejected or minimized with great persistence. Critics of the euthanasia practice in Belgium are presented as conservative, ideologically biased by religion, and lacking empathy and humanity: their attitude is said to exemplify an obsolete and condescending paternalism.

Such a response shows that the euthanasia law and practice itself is not value-free and is based on an ideology of self-determination and radical autonomy. Moreover, it does not square with the facts: there are also in Belgium staunch non-religious and atheist physicians who share the worries and critique of many colleagues concerning the current euthanasia practice, on legal, medical, and deontological grounds.⁶ However, in the mainstream media and increasingly also in the medical world, the normalization of euthanasia goes hand in hand with its sacralization as a symbol of emancipation: euthanasia has become a new way of dealing with human finitude and the mystery of suffering and death. The sacralization of euthanasia in the name of self-determination thus simultaneously makes every reference to the more ancient Hippocratic tradition into a taboo: it can no longer be said or remembered that euthanasia, all things considered, will remain a transgression that is alien to the nature of medicine and the highly ethical calling of the medical profession. Even the doctor who tries to go along with standardization ("I do euthanasia occasionally, but please not too much") might inevitably at some point find himself in a state where he experiences a dilemma or the wavering of

⁶There are good arguments to be given against the legalization of euthanasia or assisted suicide from an atheist and liberal point of view. Cf. for this Yuill Kevin, *Assisted Suicide. The Liberal, Humanist Case Against Legalization*, Palgrave MacMillan, 2013.

conscience. The farther the request for euthanasia—and if granted, the life-ending act—lies from the moment of natural death, the more likely there might arise a struggle of conscience, but also palavers and dissensus between all involved: patients, but also caretakers, physicians, family members. This fatal and never avoidable dynamic is most poignantly exposed in the case of euthanasia for psychiatric patients.

3.5 Conclusion

I conclude with three observations.

First of all, the depenalization of euthanasia puts pressure not only on the medical world but also on society at large. This inevitably might trigger a conflict of conscience for the physician and the entire medical team involved in end-of-life care. But the family and wider social environment might also be affected by this process of normalization and experience pressure to choose for euthanasia or to propose it as the most appropriate way to die.

Secondly, the attempt to make active life-ending actions more transparent and unambiguous through the euthanasia law, and to release the doctor from the pressure of legal sanctions, has led to a new kind of uncertainty, now at the level of the freedom of conscience of the physician. Where the Hippocratic oath used to be a benchmark and a guideline, the doctor now has to look for self-invented or very volatile benchmarks for his or her conscience.⁷ It is no coincidence that recently in Belgium attempts are being made by groups of doctors—for example, the psychiatrists—to formulate additional rules to somewhat frame the transgressive act of euthanasia and guarantee morally responsible decisions in response to an euthanasia request [9]. At the same time, this creates the temptation, pressured by the culture of normalization, to reduce euthanasia to a procedural act, the result of a merely contractual agreement between doctor and patient. In this way, euthanasia is made morally speaking completely neutral. As a euthanasia prone doctor once declared to a colleague: “who am I not to respect the will of the patient? I am not God!”

Thirdly, I think that there are two ways in which the euthanasia law, and the practice it has created, strengthens problematic coping attitudes on the side of physicians who welcome the normalization of euthanasia and try to bring their own euthanasia practice in consonance with their conscience. While unconsciously recognizing the vexing and transgressive nature of euthanasia, they at the same time seem to silence possible conflicts of conscience in two ways. Either they hide completely behind the law and let the procedures, provided for by the law, take the place of conscience: “the papers are filled in correctly, everything is fine.” Another

⁷Arguments in favor of the sustenance of the classical Hippocratic tradition with regard to euthanasia or MAID are given in: Sprung Charles L., Somerville Margaret A., Radbruch Lukas, Steiner Collet Nathalie, Duttge Gunnar, Piva Jefferson, Antonelli Massimo, Sulmasy Daniel P., Lemmens Willem, Ely Wesley, “Physician-assisted suicide and euthanasia: emerging issues from a global perspective” in *Journal of palliative care*, 2018, pp. 197–203.

attitude consists in pretending that one, as a physician, in fact, is motivated by a *pure goodwill*, not contaminated by doubts or afterthoughts: one coincides as it were with one's own conscience and cherishes the illusion that it is impossible to act wrongly. The latter attitude became apparent after the euthanasia trial in Ghent, where the accused psychiatrist, after her acquittal, stated in the press plainly: "Maybe I could have 'saved' Tine if she had come to me 10 years earlier." In other words, the advice pro-euthanasia, and therefore the death of her patient 10 years "too late," is implicitly acknowledged as being somehow a *contingent tragic event*. Unaware of the highly problematic character of her avowal, the psychiatrist openly testifies of her self-indulgence and alleged purity of conscience: she uses her acquittal to openly plea, on television and in newspapers, for an extension of the access to euthanasia for psychiatric patients.

Both the attitude of hiding behind the procedural form of the law and the attitude of self-glorification and alleged purity of conscience ignore in a fundamental way the transgressive nature of euthanasia. Moreover, both attitudes, I contend, derive from the depenalization of euthanasia and the practice inaugurated by this legal regulation. Therefore, it would be highly undesirable to reach as a society a point where doctors are no longer appealed in their conscience—and either reduce euthanasia to a purely procedural semi-therapeutic act or sacralize it as a highly moral intervention. If this point of normalization is ever reached, the freedom of conscience of the doctor evaporates. Perhaps this is the most important lesson to be learned in Belgium after almost 20 years of social experiment on euthanasia: as a transgressive act, euthanasia should always remain controversial and possibly embarrass the doctor's conscience and by extension the entire society. This embarrassment cannot and should not be eliminated by any law or procedural decision. But if this is right, it also cannot be expected that the normalization of euthanasia will ever succeed. The active ending of a human life, even on demand of the patient, will always fall outside the realm of normal medical practice and remain thus the object of possible controversies, clashes of conscience, and deeply felt traumatic experiences, that affect a whole society.

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Euthanasia for Unbearable Psychological Suffering

4

An Haekens

In recent years one observes in the field of psychiatry a growing proportion of persons requesting euthanasia on account of unbearable psychological suffering. The law concerning euthanasia passed the 17-year mark in 2019 and it is evident today that the number of euthanasias carried out on persons not suffering from a terminal affliction is increasing. In the first (biannual) report of the Federal Commission for the Control and Evaluation of Euthanasia (FCCEE), no mention was made of euthanasia for psychiatric reasons. The report for 2004–2005¹ however describes six cases of persons afflicted with psychiatric disorders who were euthanized. The most recent reports number 57 (2018) and 49 (2019) cases. The illnesses cited were depression, bipolar disorders, early stages of dementia, autism, schizophrenia, obsessive-compulsive disorders, posttraumatic stress disorders, borderline type personality disorders, and other personality disorders.

In 2019, polypathology (“*the co-occurrence of multiple chronic or acute diseases and medical conditions within one person*”²) was the second most frequent diagnosis justifying euthanasia, 17.3% of the total number of registered euthanasias

¹ http://organesdeconcertation.sante.belgique.be/sites/default/files/documents/federale_controle_en_evaluatiecommissie_euthanasie-fr./14088500_fr.pdf

² Definition for the first time used in the report: https://overlegorganen.gezondheid.belgie.be/sites/default/files/documents/8_euthanasie-verslag_2016-2017-nl.pdf, p. 39.

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(by way of comparison, in the period of 2012–2013, the proportion was 5.0%). In the report of the FCCEE for 2016–2017 we read that, even in cases of terminal affliction, 82.8% of causes for “unbearable suffering” are of a psychic nature, in this case, dependence on care, loss of autonomy, loneliness, despair, feelings of unworthiness, desolation, diminished social contacts, etc.³

This evolution reveals a shift that is taking place at the heart of our society. The Dutch psychiatrist Boudewijn Chabot, a pro-euthanasia militant of the first hour, speaks of “a worrisome cultural change regarding self-chosen dying with the doctor’s agreement.”⁴ It must be noted that self-determination at the end of life is a diktat that has imposed itself in recent years and that “control of the practice of euthanasia has been lost, because the legal requirements—which doctors still master reasonably in cases of somatic illnesses—have been declared applicable without any restriction for vulnerable patients suffering from incurable cerebral illnesses.”⁵ Moreover, he observes a link between the growing number of requests for euthanasia and “the financial stripping of care” that undermines the quality of life of persons suffering from a long-term mental illness. More and more critics arise, in our country as well, to voice their reservations regarding the practice of euthanasia.

Starting from a particular case we will first sketch the problem of euthanasia, to then expose, on the basis of legal criteria, the various thorny points of this practice, not only on the form but also on the substance of the practice.

Mrs. Jeanine

I recently received a telephone call from a colleague in family medicine. He was greatly concerned. A patient he had been treating for a long time and who lived in a residential care center was insistently requesting euthanasia. This situation was disturbing him, since it was not certain that the lady fulfilled the conditions to qualify for euthanasia. Since she would not take no for an answer he had decided to solicit the second opinion of a colleague. That doctor had concluded that in fact the lady did not fulfill the legal conditions for euthanasia. “Case closed.” But since the lady was not giving in, and in the face of persistent obstinacy, the family doctor let himself be convinced to consider anew the question of an euthanasia. He called a third doctor for a third opinion. That doctor came to the same conclusion: euthanasia on account of physical suffering was not legally possible in her case. On the other hand, he suggested the possibility of euthanasia on account of unbearable psychological suffering, in light of the patient’s suffering caused by her physical decline (poor eyesight, reduced mobility). But to do that required the supplementary opinion of a psychiatrist. That is why the attending doctor was calling me. I found the case doubtful. Yet I sensed how it troubled my colleague and I agreed to visit the lady. She welcomed me cordially and told me why she wanted to die: she was tired of living and expected me to give the green light to her dying. She was imploring my help! I was very touched by her appeal. But was it for me to decide whether or not this woman has the right to die? And was it really a matter of unbearable psychological suffering? I realized very quickly that no way had yet been established to explore or support her psychological

³ https://overlegorganen.gezondheid.belgie.be/sites/default/files/documents/8_euthanasie-verslag_2016-2017-nl.pdf

⁴ <https://www.nrc.nl/nieuws/2017/06/16/de-euthanasiegeest-is-uit-de-fes-11123806-a1563406>

⁵ Ibid.

(existential) suffering. In other words, she was absolutely not “beyond treatment.” It seemed to me there still were numerous possibilities to make her rediscover meaning to her life, in spite of her limitations. The family doctor reacted to my negative opinion with relief. On the contrary, the people surrounding the patient had strong and negative reactions, giving me the feeling that I had “no compassion whatever,” that I was heartless, and that I resolutely lacked empathy. How was I able to refuse this lady in distress the right to die? “Yet that is the purpose of the law, no ...?”

4.1 What Does the Law Say?⁶

The law concerning euthanasia stipulates that at the time of his request the patient must be conscious and competent to make a decision. He must be in a medical situation where there is no prospect of improvement. The patient must display constant and unbearable physical and/or psychological suffering that cannot be appeased and that arises from an accidental or pathological affliction that is serious and incurable. His request must be expressed in a voluntary, reflected, and repeated way, and cannot arise from external pressure.

4.2 A Lack of Prospect of Improvement of the Medical Situation

In the context of euthanasia by reason of unbearable psychological suffering, the criterion that requires “a lack of prospect of improvement of the medical situation” is already problematic. The description is in fact subject to numerous interpretations. For some, the criterion means “medically incurable,” and thus subject to evaluation by the attending doctor: is treatment still possible? For others, the criterion refers to “unbearable suffering” whose evaluation is based on the subjective perception of the patient.

In its recommendations on the requirements for the care to adopt with respect to euthanasia in psychiatry, the Flemish Association of Psychiatry has indicated that there is an urgent need for further specification of the legal criteria for euthanasia for psychological suffering. In those recommendations “no prospect of improvement of the medical situation” is defined as follows: “the affliction is not only serious and incurable but the suffering is also continuous and unbearable and can no longer be relieved. The definition of a lack of prospect of the medical situation does not refer to a patient’s subjective experience but to the absence of possibilities for treatment and the incapacity to relieve the suffering in a more objective medico-psychiatric perspective.”⁷

⁶ http://www.ejustice.just.fgov.be/cgi_loi/change_lg.pl?language=fr&la=F&cn=2002052837&table_name=loi

⁷ http://vvponline.be/uploads/docs/bib/euthanasie_finaal_vvp_1_dec.pdf (available in Dutch only).

4.3 Incurable Disorder

The law requires an incurable affliction, and thus a situation where no treatment is possible. In a psychiatric context, it is particularly difficult to determine that an illness is incurable. In fact, it is impossible for a psychiatrist to say to his patient, “your disorder is incurable,” or “I have enough indications to show the course your illness will take,” or again, “science teaches me that your condition will never improve.” In psychiatry, it is very difficult to predict the evolution of pathologies and impossible to objectify their incurability. With physical suffering it is altogether different: not that exact prognoses can always be made, but in general, and certainly in the case of cancer, there is enough scientific evidence to ascertain that all treatments have been exhausted or to see what still can be considered. There are a number of psychiatric disorders whose evolution remains unknown. On the other hand, there is no connection between the gravity of a patient’s condition and his chances for improvement. Certain people who are in very poor condition for a long time and who have frequent relapses, in spite of many treatments, can get better later. The crux of the matter therefore seems to be that when estimating the incurability of someone’s suffering, the subjective factor cannot be eliminated. Even psychiatrists very favorable to euthanasia in case of mental suffering acknowledge that the notion of “incurable illness” can never be fully objectified in psychiatry... no more than it is possible anyway to describe the suffering unbearable and hopeless on more or less objective grounds.⁸

Healthcare also implies that treatments are available and accessible. This is not necessarily the case in mental health. “The mental health care sector suffers from budgetary thresholds (underfunding, waiting lists), social thresholds (stigmatization, professional recognition), and thresholds having to do with care (for example ‘comfort care’ is still insufficiently developed) that can result in patients suffering psychiatric afflictions not receiving adequate treatment.”⁹ [1].

Confronting questions of euthanasia by reason of unbearable psychological suffering is a new and sometimes confusing phenomenon for psychiatrists. In fact, they have always striven to prevent their patients’ suicides, which is anyway what society expects of them. Patients who suffer intensively and who feel hopeless have always talked about their *taedium vitae* (aversion for life) and spoken these words: “For me, it is not worth the effort.” It cannot be overemphasized how much mental suffering can be burdensome for the people afflicted by it and for those around them. Since forever the task of psychiatrists and other caregivers in the psychiatric care sector has been to give the patient the possibility of expressing his wish to die in order to talk about it with him, to carry the suffering of these patients with them, to endure it together, and to help search for “meaning.” It involves staying by the patient’s side when he cannot go on. It is the job of psychiatrists to deal with one’s own sense of powerlessness. All this derives from the following conviction: “It is always

⁸ http://www.standaard.be/cnt/dmf20171103_03168722

⁹ <https://www.zorgneticuro.be/sites/default/files/general/Ethisch%20advies%2020%20levenseindezorg%20psychisch%20lijden.pdf> (available in Dutch only).

possible. We are not giving up on you.” Psychiatrists today are more and more often faced with a wish to die that manifests itself under another form: “I want euthanasia.” Society currently expects a psychiatrist, in addition to the continued efforts to prevent as many suicides as possible, to answer his patient’s request for euthanasia, and to decide whether his life is still worth living or not. And this with people who are not suffering from terminal illness and who have, in principle, many more years to live.

Concerning euthanasia, in psychiatry, important discussions are nonetheless taking place regarding the handling of the refusal of treatment. What is to be done with a person who is suffering unbearably, for whom treatment is still possible, but who refuses treatment and requests euthanasia? Certain proponents of euthanasia argue that a patient who suffers unbearably, can be treated but who does not feel he has the strength to begin a new treatment, can have access to euthanasia. The question then arises whether the “lack of prospect of improvement of the medical situation” does not come down to the criterion of “the willingness to begin a new treatment” and whether such an application of the law is not an abusive use of it.

The core of the problem resides in the fact that it is impossible to eliminate the “incurability” of an illness. Even psychiatrists very favorable to euthanasia in case of mental suffering acknowledge that the notion of “incurable illness” can never be fully objectified in psychiatry.... no more than it is possible anyway to describe “unbearable and hopeless suffering” on more or less objective bases.¹⁰

4.4 Persistent and Unbearable Psychological Suffering

The criterion of “persistent and unbearable psychological suffering” is not defined by law either. Suffering is by its essence subjective and assessing the suffering of the person concerned can only be subjective, which in turn gives rise to diverse interpretations. It is not easy to define the different forms of suffering. Nonetheless, a distinction needs to be made among inherent suffering, contextual suffering, and meta-suffering.

By inherent suffering, we understand any suffering caused by the pathology itself: the wish to die is in this case a symptom of a psychiatric illness, for example, of depression that leads to despair. Healing from depression will bring the healing of the wish to die. Patients can also suffer from psychotic symptoms, or from inappropriate behaviors linked to an addiction, or from personality disorders.

Next to inherent suffering comes contextual suffering. Patients stricken with serious mental afflictions suffer from the consequences of the disease: the side effects of medication, repeated relapses and hospital admissions, increasing isolation, loneliness, loss of employment, stigmatization, or social regression....

Finally, there is meta-suffering, which is suffering from one’s suffering: experiencing the feeling of hopelessness and injustice of having to live with a serious and long-lasting mental illness. Very often it is about existential suffering. We must

¹⁰ www.standaard.be/cnt/dmf20171103_03168722

dare to admit that we cannot always provide an appropriate answer to this (existential) suffering. Even in mental healthcare, we have made ourselves guilty of therapeutic persistence. It is of paramount importance that caregivers be resolute, reliable, and determined to help the patient and that they stubbornly not abandon the patient. This must not lead to therapeutic persistence: for example, continuous treatment pressure, repeated hospitalizations always proposing more of the same [2].

“Recovery psychiatry” (“*Hersteldenken*”) has already without any doubt contributed to providing solutions to this problem [3]. This approach focuses more on improving the well-being of the patient than on treating the illness. “Recovery appears as a way to live a satisfying life, filled with hope, to contribute to society in a significant way, despite the limitations imposed by illness. Recovery is the origin of a new significance and meaning given to life, all the while overcoming the disastrous effects of a psychiatric illness.”¹¹

In the same way, in psychiatry, palliative care and the care called “crustative” or “oyster” care (care for seriously afflicted psychiatric patients, around whom the healthcare team forms as it were a solid shell or “oyster”, within which these persons feel secure)¹² are paths that need to be further developed, and that can contribute to better care for patients who experience intense psychological suffering.

Moreover, the existential dimension has been neglected for a long time in mental health care [4]. Although caregivers are being involved in the dialogue around the meaning of life, since psychiatric disorders by definition attack the meaning of life, they are not familiar with this existential dimension and are not acquainted with the specific language of the topics related to the meaning of life. Many caregivers feel awkward when they have to deal with them explicitly. However, in recent years we have seen a turnaround. The growing interest in these themes shows an awareness of their importance. There is nonetheless a long road ahead.

In addition, our society shows little inclination to invest more in healthcare for “chronic psychiatric patients”: little interest, little scientific research, little funding.... The progressive socialization of mental healthcare, a positive movement, risks leaving aside this category of vulnerable people: they cannot always call on a network of support within society itself and they carry their stigmatization of “psychiatric patient” as a burden. The result is that it is only with great difficulty that they find “their place” in our neoliberal society.

In public debates, the opponents of euthanasia in cases of mental suffering are reproached for lacking respect and empathy for their patients. But what does empathy mean in this specific context? A patient’s request to put an end to his life (to put an end to his suffering) can sometimes be understandable to the point that a caregiver is tempted to acquiesce quickly, to comply with it. But do we not give the

¹¹<http://www.ispraisrael.org.il>

¹²http://mailsystem.palliatief.be/accounts/15/attachments/NF_12_2016/crustatieve_zorg_geeft_kwaliteit_van_leven.pdf (available in Dutch only).

patient the message that he no longer has any worth? That we are abandoning him in all his vulnerability and despair? That we cannot take it any longer? Is that really empathy? It would be rather a misleading form and therefore dangerous form of empathy.

4.5 What Is Empathy?

The notion of empathy merits some further reflection. Edith Stein [5] established a distinction among different levels of empathy. She makes a difference between being immediately shaken by emotion, “emotional contagion,” and “corrective empathy”, the evaluation of one’s own capacities for empathy. Authentic empathy is only possible when this corrective movement of conscience has been applied. 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.

4.6 Decision-Making Capacity

In examining more closely the criterion “the capacity to make a decision” it has to be noted that this criterion has not been specified in the Belgian law concerning euthanasia. Yet, evaluating a person’s mental capacity remains a very complicated matter. To this day, there is no consensus on how to evaluate a subject’s capacity to make certain specific choices. This difficulty in assessing is still more acute in persons suffering from a psychiatric disorder.

A depression, an anxiety disorder, or a psychotic disorder can alter a person’s capacity to make a thoughtful decision, which however does not mean that because of his or her psychiatric affliction the person becomes automatically incompetent for all decisions [6].

4.7 Conclusion

Obviously, the legal criteria do not provide sufficient guidance to doctors who wish to evaluate a request for euthanasia in a thoughtful way. The law opens the door to numerous interpretations, as practice confirms. We note that the law is in effect interpreted in very different ways, and in certain cases in a very elastic way.

The law allows any psychiatrist to evaluate very complex psychiatric afflictions, whereas he obviously cannot be an expert in all forms of afflictions, such as autism, eating disorders, mood and personality disorders.

In practice, we also observe that certain patients shop around for medical assessments: everyone can consult as many doctors as he wishes, until he has garnered enough positive assessments. Scott Kim [7] adds that, from a foreign perspective, it is striking that in Belgium the procedures leading to euthanasia are clearly less strict than for other medical interventions that are however less radical. Moreover, there is no feedback loop in this domain: it is not possible to draw any lesson from one's errors, since the patients can no longer speak, being deceased.

The problem, in any event, does not arise solely from the law, but equally from the system of control and evaluation, which in our country functions little or not at all. After 17 years and about 18,000 files submitted to the Federal Commission for Control and Evaluation, only one case was sent to the prosecutor. Nor has any interpretation of the data been made or case descriptions published. Lastly, no close evaluation of the commission's operation has ever taken place.

What should we conclude from this? Without wanting to minimize the immeasurable suffering of many patients afflicted with a psychiatric disorder, the current evolution, where requests for euthanasia by reason of psychological suffering are more and more frequent, is a matter of concern. From the viewpoint of the caregiver, it is sometimes "tempting" to quickly acquiesce to this request. Indeed, it is not easy to deal with one's own feelings of powerlessness in the face of so much suffering in the other person, and it is difficult not to give in to despair.

Requests for euthanasia seem to flourish in the current context of society. We can in fact perceive a general change in culture. "Each must be able to decide for himself when he has had enough" seems to have become the new standard of normality. Such a shift is definitely taking place amount the elderly, as shown in the current debates on "life fatigue" and "completed life".

The social context has a determining effect on patients with a psychiatric disorder. Given that our society is evolving toward a society where every vulnerable life is considered unworthy of human dignity (old age, dependence on care, dementia, mental illness, Down's syndrome...), it becomes extremely difficult to give meaning to one's own life once one is suffering a serious psychiatric disorder. The observation that psychological suffering increasingly plays a role in the practice of euthanasia and that this psychological suffering is a consequence of dependency on care, loss of autonomy, loneliness, loss of dignity, or loss of the ability to maintain social contacts, confirms this evolution.

Is not the primary mission of our society to first invest in quality care, in innovative and accessible treatments, in developing "recovery psychiatry," in organizing palliative care and "oyster" care for the most vulnerable patients with a psychiatric disorder? And above all to give them a place in our society?

4.8 The Long and the Short of Mrs. Jeanine's Story

A few months after my visit with Mrs. Jeanine as "third expert" quite by chance I learned that her partner, with whom she had had a long "LAT" relation (Living Apart Together) had passed away. This man had kept many secrets to himself and had always expressed the wish to die after his companion. When he felt, and then knew that his last days were upon him

and that he would no doubt be the first to die, he pressured his companion to request euthanasia so that their agreement regarding their dying might be upheld. After all, he had many secrets on a relational level, and he did not want those secrets to be revealed if he died first....

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People Facing the Question of Euthanasia: Patients, Family and Friends, Healthcare Workers

5

Rivka Karplus

Since the Oregon Death with Dignity Act was adopted in 1997, followed by the decriminalization of euthanasia in the Netherlands in 2001, and in Belgium in 2002, an increasing number of people are requesting euthanasia.

How does a person reach the point of asking for euthanasia¹? What are the factors involved, for the patient him/herself, for family and friends, or for the medical team? The attitude of the surrounding society evidently plays a role via its perception of suffering and illness, as well as the value it sees or denies in fragilized human life. But rather than limiting ourselves to these general considerations, it seems better to start our discussion by seeking to understand the situation of the person him/herself, since it is his/her life and death which are at stake. A doctor may know a disease thoroughly, and even be a specialist involved in clinical research, but will still be unable to predict exactly how the disease **of a specific individual** will evolve. Even if the statistics show that a certain treatment gives a 70% chance of survival, the person receiving the treatment will never be 70% alive and 30% dead; he/she will always be one or the other. And given that suffering is an essential criterion for allowing euthanasia in those countries where it is legal, it seems important that we first try to understand the reality of that suffering.

¹In order to avoid excess wordiness, the present text frequently uses the more general term of “euthanasia” to also include the practice called “assisted suicide” or “assisted dying.” Despite the distinctions which can be made between the two categories, in both we are dealing with the death of a person as a direct consequence of a series of deliberate actions including an active intervention of medical personnel, either directly by prescribing, preparing or injecting lethal product(s), or by prescribing or supplying them for the person to take.

This article addresses and develops certain points addressed in a more general article published in French: Karplus Rivka, *Euthanasie: réflexions d'un médecin*. NRT, 2014, n 136, pp. 596–605.

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5.1 Personal Suffering

This question must be approached with the greatest of respect for the person suffering, and with a deep humility on the part of those trying to understand, who do not themselves experience the same suffering. Nevertheless, if we wish to analyze the situations which can bring a person to request death, we need to understand the nature of their suffering, as *they* experience it. However inadequate categories may be to describe the complexity of human reactions, we can still describe suffering as physical, psychological, relational, spiritual, or existential. Frequently these different aspects overlap or intermingle, particularly in the case of a serious illness.

5.2 Physical Suffering

Physical suffering may present in various guises: pain, disagreeable sensations such as nausea, weakness, respiratory insufficiency, hunger, or thirst. It may also consist in the loss of physical or cognitive function. Certain situations may be perceived as particularly humiliating, such as urinary or fecal incontinence.

The perception of physical suffering can vary according to the circumstances: the same pain may seem unbearable alone in one's room at 2 am and be relatively easy to bear the next day during the time spent with a friend. The perceived duration of pain, both current and remembered, is frequently longer than its objective duration [1, 2]. Other elements can aggravate physical suffering; for example, the helpless feeling of someone waiting to be given pain medication, or the anguish caused by bone pain which is likely to indicate new metastases.

Any attempt to treat physical suffering, especially that which is perceived as unbearable by the sufferer, must take this complex reality into account. We need to be wary of imposing our own, "objective," exterior perception of the degree or duration of another's physical suffering.

5.3 Psychological Suffering

There is a redoubled suffering in the feeling that one's very humanity is somehow wounded or diminished by a disease which limits the ability to act, fosters dependence on others, or causes physical deterioration. Once again, there is frequently a difference between that which is felt by the patient him/herself, and that which is visible to others.

An artist whose hands can no longer function due to polymyalgia rheumatica (PMR) may feel that his incapacity to draw has taken away his means of expression and the gift which gave his life meaning.² A person suffering from fecal

²Most of the examples are based on my experience as a doctor (in hematology, internal medicine, and infectious diseases), frequently with modification of identifying details.

incontinence may feel imprisoned in his/her own house, by fear of humiliating “leaks” if he/she dares go out. The very relationship to the body can change: rather than being the means of life, of encounter with the surrounding world and with others, it becomes primarily the site of suffering.

The loss of physical beauty (and even disfigurement, such as that following a radical operation for throat cancer) can threaten the person’s sense of identity: “Am I still myself?” The question: “Can others still love me like this?” often implies an underlying doubt: “Can I love myself like this?”

The relationship to time also changes, since it is demarcated by the alternance between the symptoms of suffering and the temporary relief given by medication. It is also often composed of waiting for treatment or visits since the patient has very little control of the events in his/her life. Time can end up being perceived as a gradual progression of disease, filled with fear of what lies ahead.

5.4 Emotional and Relational Suffering

Whatever the depth of a human relationship may be, it cannot escape being affected by suffering, especially in the case of a serious illness. This does not necessarily mean that the impact on the relationship will be negative; sometimes illness and its consequences can be an occasion for encounters more focused on essential aspects. But relationships can also be a source of suffering for the patient: the inability to live them “as before” underlines the omnipresence of the illness in his/her life.

For a couple, intimate aspects of medical care, pain, physical changes can all challenge the body’s role in expressing love and sexuality. There are also logistical problems: if a person is hospitalized, the framework limits intimacy...especially when the medical staff may enter the room at any moment³! The sick person may feel he/she is limited to asking and receiving (visits or assistance), rather than retaining any sort of initiative. This dependence can have varying effects on a relationship: one person may require a constant presence to face the anguish caused by his/her illness, another might refuse visits out of fear of being a burden for family or friends.

Lastly, there is the influence of our society where the value of human beings is too often judged in terms of success or “productivity.” A sick person may ask him/herself if such life is “worth” the cost of treatment or the limits the illness places on family and friends. Such questions can lead to an extreme where the patient asks him/herself if it is not “selfish” to spend so much money for treatment, rather than dying and leaving it to family members. The ill person becomes unable to conceive that his/her presence is of far more value to family members than the material legacy.

³ It is important to note that there are creative initiatives which create spaces for intimacy, even in the hospital setting: the cameras sometimes used to monitor patients in intensive care units can be turned off when a partner, close friend or family are present. In other departments, it is often possible to simply ask the team to refrain from entering the patient’s room for a specific time span.

5.5 Existential and Spiritual Suffering

Death is an inevitable part of our existence. We all know this, even if our perception of death itself may vary among societies or by religious belief. A person suffering from a fatal illness is confronted with his/her mortality as an immediate reality, approaching inexorably but with an unknown date of arrival. The loss of independence may lead the patient to try to “take back control” by determining the moment and circumstances of his/her own death [3]. An article [4] on assisted suicides in Oregon during the first years after its legalization shows that close to half of the persons concerned justified their request by at least one of the following reasons: “Ready to die,” “Wanted to control circumstances of death,” and “Saw continued existence as pointless.”

Accumulated suffering can lead to a feeling of existential anguish. Even those who believe in a good and loving God may find it hard to accept the seeming incompatibility between their faith and the daily reality of their suffering, or the internal contradiction between their desire to bear patiently all that “comes from God” and the questions or feelings of rebellion awakened by their illness.

5.6 How Can One Respond to a Request for Euthanasia?

Given the cumulative aspects of suffering we just discussed, it is far from surprising that some people see their situation as unbearable and express the wish to die rather than continue to live in such circumstances. While every person does not necessarily experience all the abovementioned aspects of suffering, each bears a painful burden which diminishes the very experience of living. The wish to die rather than live “like this” can be understood as a fundamentally human reaction, a rebellion against suffering in death, and thus an affirmation of life as it should be. For this reason, we need to be wary of assuming that all those who ask for euthanasia truly wish to die.

Several articles have been published in recent years about the outcome of requests for euthanasia or assisted suicide since their decriminalization in various countries. The abovementioned article [4] describes the results of a questionnaire sent to Oregon physicians on their experience of assisted suicide since the year when it became legal. Of 165 people who requested assisted suicide, 17 (10%) died by that means; 42 (25%) changed their mind; the others were either considered ineligible by the established criteria or died a natural death before completing the process.⁴ The authors noted that people changed their minds more frequently when the doctor prescribed one or more interventions, among them palliative care, antidepressant medication, social workers, or chaplain services.

In the Netherlands, 8.3% of those who died in 2015 had requested euthanasia, and 4.6% did in fact die by euthanasia or assisted suicide [5]. The national statistics show a progressive increase in the annual cases of death by euthanasia since

⁴The article mentions a number of other circumstances, of which some people had more than one.

1990. A 2005 article [6] based on questionnaires distributed to Dutch physicians reports the following results: 44% of euthanasia requests were followed by death by euthanasia, in 25% of cases the person died before receiving the lethal drug, and 13% of those requesting changed their mind. The Belgian data [7] are similar to those from the Netherlands: an article [8] based on questionnaires sent to more than 3000 Belgian physicians in 2009 determined that 48% of euthanasia requests were eventually carried out and that 10% of those requesting changed their minds. These articles do not indicate whether there was a difference in the interventions offered to persons who actually died by euthanasia and those proposed to the persons who changed their minds. Another Dutch article [9] compared the symptoms, as described by their physicians, for cancer patients who died by euthanasia versus those who died without having requested euthanasia. It showed that more of the first group suffered from severe symptoms, and that for certain of these symptoms (nausea and dyspnea) they received less treatment, although pain was treated for all.

What can we conclude from all these statistics? First of all, the frequency of euthanasia requests is steadily increasing in those countries where it is legal under certain conditions [10]. These requests are the expression of genuine suffering: life has become unbearable for these people, who express that in requesting euthanasia. It would however be incorrect to conclude that all those who request euthanasia truly wish to die. Let us first state what seems evident: a person who expresses the wish to die by euthanasia (with the exception of a truly suicidal wish) is not saying that he/she prefers death to life, but rather that death seems preferable to life *under the actual circumstances*, which implies that he/she might well choose differently if those circumstances were to change. The data from Oregon, the Netherlands, and Belgium show clearly that not all who request euthanasia go on to the final act. In addition, the first article would seem to show that various interventions can help the patient to desire to go on living.

This said, we cannot conclude that all those who withdrew their request for euthanasia “changed their mind” due to the proposed interventions. It would be more accurate to say that there is an entire spectrum of reasons why someone could request euthanasia: the desire to die when faced with what is perceived as an unbearable situation, the will to choose the moment of his/her death when facing the unpredictable duration of a terminal illness, the need to know that the option will be there at a future moment where the suffering could become unbearable, or simply the need to express just how serious that suffering is.⁵

⁵ See (among other articles): Li M, Watt S, Escaf M, Gardam M, Heesters A, O’Leary G, Rodin G. “Medical Assistance in Dying—Implementing a Hospital-Based Program in Canada,” *N Engl J Med*, 2017, n° 376, pp. 2082–2088. This Canadian article describes the fact that many patients “change their mind” about euthanasia after their request has been approved. One possible interpretation, suggested by the authors, is that the fact of having received approval for euthanasia gives them a renewed sense of control of their situation—and hence they no longer feel the need to end their lives.

How can we respond to a request for euthanasia? The first step is to truly hear the suffering being expressed: no one can judge another's suffering, and hence none of us have the right to belittle it or to give a simplistic answer. The person who requests euthanasia is telling us the depth of his/her suffering and proclaiming just how incompatible the suffering seems with what life is meant to be. To truly listen means to be willing to hear simultaneously the suffering, the despair, *and* an affirmation of life expressed in the very wish for death. Often, the simple fact of being listened to, in respect for the uniqueness of the person's experience—and thus for his/her inalienable human dignity—can already alleviate the suffering caused by feeling “less human” due to the incapacity or disfigurement caused by disease.

Once it is established that the response involves listening and accepting the person in his/her present situation, it becomes possible to work together with the person to see what can be done to help reduce suffering. Euthanasia does not improve life—it ends it by giving death. But in helping the sick person to define the areas of his/her suffering ways are opened to work together in looking for means to improve the situation. Pain can be greatly attenuated, often virtually eliminated by palliative care. It is possible to choose the most appropriate medications together with the patient, to identify and treat any adverse effects, and to provide him/her with means to adjust the dose according to the situation. For example, a person might choose to be fully awake to receive visits, and drowsier the rest of the day.

For the other forms of suffering, the logic is the same as that for pain: to prioritize listening, to attempt to understand, to relieve suffering as much as possible—always with the greatest of respect for the person concerned and his/her wishes. It is important to work together with the sick person in order to preserve or restore autonomy as much as possible, and to diminish the physical and esthetic impact on his/her sense of bodily integrity. The means will be different for each individual. A parent may choose to save his/her strength to be with the children when they come home from school, and spend the rest of the day in treatment or in bed. Another, nearing the end, may wish to go to a family reunion, visit a favorite place, or simply go out for the evening. A trip to the sea or to the countryside can reawaken an awareness of the world's beauty for someone who has spent months in a hospital room.⁶ Personal care such as a massage, a hairdo, or new clothes may sometimes help the patient to “feel him/herself again.”

When depression is involved, it is important to have a psychological or psychiatric professional accompany the person. If he/she desires it, a hospital chaplain or other religious accompaniment may also help the person to use faith resources to

⁶ Among other initiatives, personal or by organizations, the “Wish Ambulances” in many countries are worthy of note. Their goal is to enable those gravely or terminally ill to take a trip in an ambulance to accomplish a personal wish. In Israel, they are often used to go to holy sites or to participate in family events, but also for child-oriented fun activities or for nature trips. Two of the sites: www.mdais.org/en/wish-ambulance (Israel), www.als.nl/voor-patient/activiteiten/ambulancewens (Netherlands).

deal with his/her reactions or existential questions. Sometimes the mere fact that a “representant” of the religion considers it normal to ask God questions on suffering, or even to feel anger at Him, can be a source of relief and enable dialog. To accompany someone in illness is often to open doors for a person who has become incapable of imagining a better situation—but while making it clear that these are only suggestions, not “stock answers” for a particular situation. Creativity is important to look for little things which may make a difference, or help to surmount a difficult moment.

When impending death seems to be the cause of distress, it is important to understand what this means for the person entering the terminal phase of his/her illness, and to look together for ways to respond. For those who fear the physical suffering of the final moments, sometimes after a painful experience with a family member, it is important to speak frankly of the probable symptoms as death approaches, and what can be done to alleviate them. Often the sick person needs to know that he/she will not remain alone, that family, friends, or the medical team will be present until the end.

5.7 The Reaction of Family and Friends to a Request for Euthanasia

The family and close friends of a suffering person also suffer, inevitably. There is the pain of seeing a loved one suffer, of not being able to give relief, of seeing the progression of illness and the gradual diminution of strength and energy. The relationship itself is frequently affected when the person suffering no longer has the energy to show affection. The situation is even more complicated by the fact that family and friends frequently have multiple roles. They may be the principal caregivers if a patient is cared for at home. At the hospital, they are frequently called upon to assist the staff in daily care, and are also the ones to transmit the patient’s requests or questions to the medical team. They accompany, continuously or intermittently, the person suffering—while doing the best to go on with the other elements of their lives. All of this frequently leads to an immense fatigue: a husband or wife, who has to take care of the children while his/her spouse is hospitalized, continue working as the sole provider, and be present at the same spouse’s side in the hospital, will soon be exhausted. Even if several family members or friends take turns, fatigue is almost inevitable and makes it difficult for each of them to make time for his/her own emotions.

Attention to the suffering of family and friends is an integral part of caring for the sick person. Not to contrast or compare suffering, but in recognition that they are living the experience of compassion in its most literal sense: a presence to the other in the reality of his/her situation, which means a presence of love. Yet the pain of seeing a loved one suffer, or even the ongoing accumulation of fatigue, can lead family or friends to wish, even unconsciously, for death to come and put an end to the patient’s suffering – and their own. Once euthanasia is presented as a legitimate option, the family may, consciously or unconsciously, encourage the patient to turn

to it as a solution or welcome his/her request as a relief. The point is not to judge those in such a position, but to be aware of the inherent difficulties. The Dutch article on the outcome of euthanasia requests [6] gives “pressure of next-of-kin on request” as one of the “reasons for reluctance in granting the request” in 10% of cases—even if in some of these cases the request was ultimately approved.

Two articles about the Belgian situation [11, 12] discuss cases where a person is put to death without having asked for it; most of them cases where the person was either unconscious or suffering from dementia. Not only was the family frequently consulted (79%) when making the decision, but “Unbearable situation for the family” was one of the reasons given in 38% of cases. These numbers show us how necessary it is to remain vigilant, in order not to respond to the families’ suffering at the patient’s expense. It is essential that family and friends be supported and accompanied; they should be helped to see how much their presence and actions are important, and also to recognize their own need for times and spaces of respite.

5.8 How Can the Medical Staff Act or React to a Request for Euthanasia?

Each member of the medical team is first of all a human being trained to care, to heal disease and suffering. Incurable or terminal illness is always difficult, since the healthcare worker is obliged to face what seems a failure to accomplish his/her mission. The experience of facing a severely ill patient and having to admit that there are no more therapeutic options left is always a painful one; and the temptation to take refuge in aggressive yet futile therapy is all too well known. It could be an oncologist who suggests more and more experimental therapies, or an intensive care team which refuses to admit defeat and resorts to more and more heroic measures. This frequently happens to medical teams facing a tragic situation: aggressive cancer in a previously healthy person, a young person with sudden sepsis or a road accident. There is also what could be termed “default” over-aggressive treatment. An elderly or debilitated person may arrive at the hospital alone and confused or unconscious. If there is no information available on the person’s previous state of health, the doctor on call will do what is necessary to save life...and may discover after the fact that he/she performed aggressive resuscitation on a person with advanced dementia or a terminal illness, who would not have wanted the treatment. At the moment, it is often the only possible decision, but afterwards healthcare workers and family may regret having taken excessive measures relative to the condition and wishes of the patient.

While the above-described situation is familiar to most hospital physicians and nurses, there is less awareness that the acceptance of euthanasia by the medical staff may originate in the same feelings which too often lead to futilely aggressive medicine. In both cases, there is a refusal to admit one’s own powerlessness; euthanasia eliminates the suffering by eliminating the patient—and so removes the obligation of facing his/her suffering. When there are no more treatment options to suggest,

and no hope of improvement to offer, it can be very painful for a doctor to daily face the anguish of patient and family. Euthanasia, paradoxically, seems to restore the doctor's authority: if he/she no longer has the ability to save life, there remains the possibility to act... by giving death.

A medical team may also welcome or even encourage a request for euthanasia as a relief from the pain involved in accompanying the patient. Similarly to what was described for futile medicine, the temptation to turn to euthanasia may be even stronger in circumstances which awaken a strong reaction against particularly "unjust" suffering, such as that of a child, or a sudden, fulminant disease. There are also situations, especially frequent when dealing with prolonged illness, where the medical team becomes emotionally involved with the patient, and hence shares the reactions of family and friends—without necessarily being aware of the fact.

In a difficult situation, created by treatment decisions which turned out after the fact to imply futilely aggressive treatment, euthanasia may seem to be a way to "undo the mistake," and can be quietly practiced on patients who are not in any condition to request—or refuse—it.

There are other, often unadmitted motives which may encourage healthcare workers to approve euthanasia: in overloaded hospital departments, prolonged treatment of patients in the final phase of their illness may be perceived as a burden by the staff, or as a problem relative to an urgent need for available beds for those who "really need" medical treatment.

Finally, there is the question, practical yet morally unacceptable, of the connection between euthanasia and the supply of organs for transplant. A letter to the *Journal of the American Medical Association* [13] calculates that among the 2023 persons who were officially listed as having died by euthanasia in Belgium in 2015, 204 would have been eligible as organ donors, and then compares this number with that of the patients awaiting organ donation. Any healthcare worker who has worked in intensive care knows the extreme vigilance employed to keep the team taking care of the patient distinct from that which evaluates his/her for brain death as a potential organ donor. A connection between euthanasia and organ donation creates a risk of distorting the relationship between the treating staff and the sick person, as if the value of his/her life were to be weighed against the good his/her organs could do after death.

Admitting the potential distortions involved and understanding the influence of human reactions can help us to seek alternative paths. If both euthanasia and futile medicine make the patient pay the price of the medical professions' illusions of omnipotence, then our refusal of these means can help us to see the true situation of the person concerned. We will need a great deal of courage and lucidity to be willing to see the true situation of a suffering human being, and to admit the reactions of family and friends provoked by this suffering—as well as our own. It is never easy to move from an active, decisive medical approach to one that listens and accompanies the person, particularly when dealing with protracted suffering. But if we dare to do this, we can learn to look for means of relief for the person's individual, unique suffering, in partnership with the patient and his/her family and friends,

using the resources of both medical knowledge and our shared humanity. The willingness to walk on this shared path *with* the sick person is in itself an affirmation of his/her human dignity. And that is the most essential care we have to offer.

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Surrendering to or Inducing Death: Artificial Feeding as Paradigm

6

Marie Frings

Euthanasia because of loneliness, because of unappeasable suffering, because of the inadequate training of caregivers, because of the lack of personnel, because of family neglect, etc. Euthanasia, presented as THE solution, disguises the real questions that underly this act of death. Once “bandaid” euthanasia is carried out, the miseries remain.

Didier D. (close friend)

Western societies are confronted increasingly to the dilemma of euthanasia. However, as we enter the public debate, we find ourselves in a Tower of Babel of sorts because it is almost impossible to reach a consensus on the definitions of key-words and terms. It is also true that this specific question should not be separated from the larger picture of all other ethical questions related to end-of-life realities. In such a context, I opted to withdraw from the sterile “conceptual” disputes surrounding this essential issue. I returned to my practice of palliative care and looked at these issues through a concrete clinical questioning, the one around tube feeding either in terminal illness or at the *limits inherent to age with its multiple pathologies*.

The subject of tube feeding may seem highly specific and a selective study; it actually reveals itself as a paradigm of all “end-of-life” ethical questions: therapeutic obstinacy, vs. unreasonable and coercive therapies, euthanasia, assisted suicide, abandonment of the sick, informed consent, difficulties with the loss of autonomy, advanced directives, and/or designation of a legal proxy (living wills), quality of life concepts, chemical or physical restraining methods, the subtlety of the act leading to double effect, with unintended consequences.

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The very question at the core of this debate is: what is the cause of death? Did we want to induce it or did we surrender to it as ineluctable? How can we distinguish between “surrendering to death,” i.e., accepting it as part of our human condition with its limits, and “inducing the dying process,” i.e., to kill or to let someone die intentionally, transgressing the prohibition of murder, either in an active and direct way or indirectly by neglecting the positive correlate of the prohibition which is to assist any person in a time of danger. How can we answer? How can we elaborate a path to find a response to these essential questions? Or if we speak of the right to die, how can we distinguish, in clinical practice, between the right to die with human dignity and the right to kill (self or others) on one’s own terms.

But before we reach these existential thresholds, we need to investigate and evaluate the clinical dimensions of the question.

6.1 Framework of this Reflective Study

I have conducted this research on artificial feeding and hydrating in end-of-life cases for many years. In my medical practice in palliative care units and long-term facilities, I was often confronted with what appeared to me as forced feeding. I saw old people in end-of-life situations, literally sated *ad nauseam*, who needed to have the injected liquids pumped back out because they were immediately rejected; some of these old people were restrained in their chairs or beds to prevent them from pulling the feeding tubes away from their nose. As I watched these practices, I came to question their rationale. But, on the other hand, I was debating mentally whether it was possible not to feed a patient, and to forego these feedings. Was this not inducing the death of this patient and therefore engaging oneself in a process of euthanasia? These questions represented a terrifying onus because they had never been part of the academic curricula nor included in any practical training I had received in medical school. What was to be done then? As many others, I started questioning the now common recourse to these feeding tubes. A thoughtful reflection prior to the placement of the feeding tube would have offered the option not to keep it indefinitely on the patient thus sparing all involved from the harrowing questions surrounding the therapeutic scaling back.

I then sought the advice of a geriatrician friend, Dr. Veronique Latteur. She worked in an acute geriatric medicine ward. There, her experience was as frustrating as mine, yet for a different reason: she was appalled by the number of elderly patients undernourished due to the neglect of this basic health issue. She bitterly deplored the lack of teaching in this important field of nutritional support. She was outraged as she observed the patients’ sufferings, and even more scandalized that many caregivers were so unaware of this. She was determined to fight and create a new awareness to address the nutritional needs of the elderly population, as well as to train the caregivers in this field in which the negligence and the indifference were as rampant in the wards as were the damaging therapeutic obstinacy I described earlier.

This is when we started discussing some of our patients' cases. I feel compelled to present some of these cases here below, as "narrative ethics" is becoming more and more relevant in clinical ethics.

6.1.1 Case #1—Madame B. 73 Years Old

This patient is suffering from Alzheimer's disease; she lives with her only daughter, a widow. Mrs. B was diagnosed five years ago, and she has been coming to this geriatric day center six months ago because she is more and more disoriented and she cannot any longer be left alone in the house while her daughter who is a nurse is at work. One morning, Mrs. B. was found in a coma and was rapidly admitted to the hospital. She was diagnosed with an acute cerebral hemorrhage that could not be operated on. She remained in a coma over the next few days and in the absence of any likely recovery, she was transferred to a palliative care facility near her home, but with a feeding tube and, despite the coma, a subcutaneous pump with morphine and sedatives to ensure a continuous sedative state.

What is the meaning of this situation? What can be done for Mrs. B.?

6.1.2 Case #2—Madame F. 90 Years Old

Mrs. F. is quite alert for her age. She is suffering from arthritis and hypertension. She prudently opted to move to a nursing home six months ago to avoid being hospitalized in an emergency and having to endure unwanted therapeutic obstinacy. But then she had a stroke that left her hemiplegic, aphasic, and having troublesome deglutition. She had to be hospitalized. After a month-long treatment, having made no significant progress, she was sent back to her nursing home with a feeding tube. Four months later, her feeding tube "fell off" three times within a week, and was put back in place each time, till her son intervened and refused to let the nurses replace the tube.

What can be done in this case? We know the patient is conscious and most likely understands what is going on, yet she cannot communicate and express herself?

Are we not here with a case of nutritional therapeutic obstinacy? Why? Who decides these treatments? And regardless of who and why, let us ask: "how can we face such a situation?"

6.1.3 Case #3—Madame J. 68 Years Old

"A 68 years old patient is not a geriatric patient," the geriatrician thought as she was on her way to the Emergency Unit of the hospital to take charge of a new patient. This patient was suffering from acute pneumonia, but more worrisome was her weight registered at admission: 31 kilos, or some 68 pounds. The file revealed a complex and dire medical past: the patient had suffered from polyarthritis for the past twenty years, had taken cortisone drugs for years, and her condition had worsened because of the many side effects of the disease and of the treatments over the years. And yet this thick file showed no mention of her weight, nor did it contain any notes on her nutritional status. The doctor fortunately had a solid background in nutritional therapies and addressed immediately and aggressively the

many causes of her patient's undernutrition. Even if her polyarthritis was not curable, the patient was fed through a feeding tube for six weeks. This allowed this woman to gain ten kilos or 22 pounds in two months, and recover a functioning autonomy she had lost for the past two years. This patient was then able to take care of her own daily hygiene, get dressed without help, and even go briefly on a few errands. To imagine that she could have just as well landed in the palliative care unit of the hospital, located next to the geriatric ward, because of her state of severe malnutrition, and would have died a few days after her admission, is indeed food for thought.

These clinical narratives illustrate the multiple questions we must raise, from the most fundamental to the most pragmatic—and in fact, a doctor will always address the latter ones first. It must be restated that the majority of problematic clinical cases concern dependent individuals, having lost their autonomy, and relying on other people to make decisions in their name. This reality creates a vulnerability that places these patients' safety and rights in jeopardy. Confronted with the incapacity of the patients to express their will, the caregivers may at times be tempted to over-protect their patient whom they legitimately want to assist to the best of their ability.

Regarding the clinical questions, I will only treat those linked to tube feeding, and I will set aside the issues related to malnutrition.

6.2 Why Use Feeding Tubes? What Criteria Prevailed? How Efficient Are they? How Did we Come to Adopt these Protocols?

Dr. Veronique Latteur and myself shared our experiences and went on to explore the existing medical publications that revealed a multitude of clinical studies. First, we discovered papers published between 1985 and 1995, on the pros and cons of intravenous artificial hydration in the last days of life, mainly in terminal cancer patients, where palliative care originated. Then we continued to read the research published after 1995, on artificial feeding, its advantages, and the other questions around it, for other medical populations, particularly in geriatrics because palliative care was then extended to other palliative groups and not reserved anymore for terminal cancer patients.

The rapidly growing number of published articles on artificial feeding could be explained by the fact that a larger number of patients were being tube fed, thanks to the improved technical tools used (mostly thanks to the introduction of the tube directly in the stomach through a gastroscopy¹). Incidentally, it is interesting to note that this technique was developed in 1979, in neonatology, for premature babies. After 20 years of increased use of this new technique, way beyond neonatology, it became necessary to evaluate the practices in this field. To understand the scope of this phenomenon we will cite an American statistic according to which the number

¹ Guided by the light of the gastroscope (the camera tube), the doctor can make an incision at the right place to create the orifice through which he will introduce the tube. The orifice created in this manner is called percutaneous gastrostomy.

of Americans over 65 years of age, who were treated with such a tube, skyrocketed from 15,000 individuals in 1988 to 123,000 in 1995, or a 10-fold increase over 8 years.²

What did we want to measure? Studies have tried to remain objective as they looked at the impact of this type of nutrition on the *span of life* gained, but also on the resulting *quality of life* during that time, two criteria that seemingly could show improvement through these feedings. A thorough study conducted on American veterans showed that lives were prolonged in an average by 7 months and a half for a group of 7000 former soldiers who had been fed through gastrostomy in the 1990s, whether in the case of a cancer, a brain thrombosis, or other medical conditions. The study concluded that most patients fed that way were in the terminal phase of their lives since the American medical corps designates the last 6 months of life as “the terminal phase!” Regarding the quality of life, the studies tried to take into account the impact on the bedsores (expected to go away thanks to a higher level of proteins), on the pneumonias caused by inhalation (also expected to disappear in the absence of troublesome deglutition) and the functional status of the patient (i.e., his or her physical and intellectual performances linked to the weight of the person, to name only one factor), all these elements being the main rationale invoked when a doctor prescribes artificial tube feeding.

The patients fed this way represent a wide spectrum of conditions. Some have been largely studied such as the geriatric population, especially the Alzheimer patients, or those who suffer from other neurological pathologies such as Parkinson’s disease, or cerebral-vascular strokes. There are also many younger patients, suffering from rare affections, such as Amyotrophic lateral sclerosis (ALS), also known as motor neuron disease (MND) or other neurological dystrophies. Yet other patients, also tube fed, are more rarely evaluated. It is particularly true of some poly-handicapped children (brain-impaired or suffering from syndromes called “orphan diseases”³) who are often fed this way, or persons in a persistent vegetative state (PVS) after a coma from a head trauma, a medical complication, or an operating room incident. In order to guard against hasty comparisons and avoid mixing situations up, there are other important aspects to consider such as the clinical state of the patient at the time of the placement of the feeding tube. This state can be quite satisfactory when the tube had to be placed “early on” in the disease, to nourish the patient having a troublesome deglutition, as the person was still in a good nutritional state (as is often the case in a certain form of amyotrophic lateral sclerosis); however, most of the time the tube is placed as a last resort, *when there is nothing else to be done* and the malnutrition of the person is in an advanced state, making it most often a futile recourse (with the exception of the third clinical case presented above that constitutes a counterexample). To add a further observation, the deglutition can

²The numerous references to the mentioned studies, and other texts, can be found in the book *Les alimentations artificielles en fin de vie*, Racine, Brussels, 2005.

³An orphan disease is a pathology that does not benefit from effective treatment. Most orphan diseases are rare diseases, the development and commercialization of which are not profitable for the pharmaceutical industry.

be impaired either *totally* or *partially* (still allowing an oral feeding, albeit insufficient, as is the case for Parkinson patients who need extra time to eat). The question of foregoing the tube feeding is obviously more acute in the first situations.

The conclusions of these studies that I evoke here only briefly show that there is little clinical evidence, i.e., few clear answers to our questions. Many grey areas remain. It is also difficult to build an objective knowledge on these populations, as we encounter many problems, ethical and practical, to conduct research studies on them. We do not know for certain that tube feeding leads to the relief—or the healing—of bedsores! Yet, it does not mean this is never the case. And alas, we also observe that even with tube feeding, the patients still contract pneumonia through inhalation.

But it is clear that a patient, while still by and large healthy, suffering a first stroke with troublesome deglutition, can truly benefit from this form of nutrition in the rehabilitation phase. We are not here in an “end-of-life situation.” This is also true in the case of ear-nose-throat cancers, where tube feeding does not pose a problem unless the disease evolves towards its ultimate phase.

For the ultimate phase as such, the remaining grey areas must lead us to act with prudence. We are well inspired to speak prudently about the benefits a patient may receive from tube feeding, as much as we must exercise caution in our interpretations of the studies. The evaluation tends to be a little clearer in the case of patients suffering from advanced Alzheimer’s disease. A large number of studies concur in demonstrating that when the advantages, in life span and in quality of life, and the recurring downsides of the tubes placed on these patients, in particular the need to *restrain* the patient physically (attach the patient), are weighed against each other, the balance is clearly in disfavor of this type of feeding. It is as if the feeding problems were a sign that the disease is very advanced, even if the patient is still mobile. However, let us also remind ourselves that a general statistical data cannot ever establish an individual prognosis. Some of these studies conducted on a population suffering from dementia rightly conclude that tube feeding must not be offered to this particular group of patients, barring a specific reason brought up by the family. The *standard care* for these patients, from a professional point of view, must be *assisted oral feeding*, meaning that the caregivers could and should take the time to spoon-feed these patients, as appropriate.

This allows us to understand the current way of thinking when facing uncertain clinical situations. One seeks to weigh the pros and cons of such a therapeutic option, while referring as much as possible to the latest known objective data. This approach, based on the *ethics of principles*, i.e., on balancing the principles of beneficence and non-maleficence, of respect of autonomy and of justice, already represents a judgment on a clinical situation. This conscious weighing goes beyond ordinary clinical work, as it already implies an ethical reflection. Clinical work leads the physicians to judge a given therapy option as balanced or imbalanced in connection to the expected results (teleological perspective⁴). In other words, scientific studies and clinical experience will qualify a particular treatment in a particular

⁴Perspective taking only results into account.

clinical reality, as *obligatory or optional* (or even sometimes, *wrong*), vis-à-vis the professional obligations (through the prism of deontology⁵); hence, the coming up of more and more recommendations for the clinical practice. Presently, in France as well as in the USA, more and more *Standards-Options-Recommendations* have been published in recent years. These rational and logical approaches, based on the objectivity of clinical studies are most useful, considering the complexity of potential clinical situations and today's large offer of therapeutic options. Thus, from thinking more deeply over our clinical cases, we move on gradually to ethics.

6.3 First Approach of the Ethical Question

Let us come back to the concrete initial question: "Can we forego a tube feeding therapy?" Before all these studies even existed, a vast ethical reflection had already developed in the 1980s. Let us not forget that from the onset of this practice, tube feeding was apprehended not as some random medical treatment, but as a *life support treatment*. This was linked to its technical aspect, even though it is a very simple tool if we compare it to a ventilator or a dialysis machine. But this technical dimension implies de facto a kind of *on-and-off button* that adds an enormous emotional and moral level to the questions related to these treatments. This button turns into a *life and death switch*. Let us also mention that with the increasing number of borderline situations of this kind, linked to the progress in reanimation, a new concept appeared around 1995, that of *treatment of prolongation of the dying process*. And it is in this context that a more fundamental question came up in relation to our subject: "Is artificial feeding a *medical treatment* or a *basic care*?" Are we in a *cure perspective* or in a *care mode*?

This question quickly placed itself at the forefront of a heated debate. After perusing these fascinating publications, and having given much thought to my own experience, I, along with a vast majority of caregivers who paused to reflect on the subject, have rallied, in a first phase, to the following proposition: "Tube feeding is indeed a medical treatment." For me, two types of arguments firmly supported this position. First, a phenomenology-based analysis of this type of feeding written by an American nurse, Jacquelyn Slomka [1], for whom it sufficed to look at this form of feeding to understand that it is part of a medical reasoning. Second, a reflection on the goals of medicine and therefore on the medical responsibility and its limits led me to the following statements: (1) there is no *obligation* to pursue unreasonable therapeutic obstinacy (deontology approach), and (2) the objective to *maintain life at any cost* is not part of the acts that define the medical profession (teleological approach). I have further reflected on this standpoint as I taught it for many years, till various new encounters and seeing other stands taken, in particular surrounding the extreme situations that are the "persistence vegetative states" encouraged me to rethink my position and, eventually, to amend my conviction.

⁵Perspective dealing mostly with the moral duties of the profession beyond the strict legal parameters.

I then adopted a more nuanced position, beyond the constructed dichotomy between care and treatment: tube feeding belongs in a *special niche* between care and cure!

De Vettere sums up the debate as follows:

“It may seem that concern over how we classify nourishment by tubes or lines is a linguistic quibble without importance. But this is not so. The moral judgment of many people is significantly influenced and sometimes determined by how they classify the procedures they are evaluating.

Thus, those classifying intravenous or tubal nourishment as medical treatment inevitably defend the morality of withdrawal whenever it seems unreasonable, and those classifying the procedures as feeding inevitably claim withdrawal is immoral as long as the body accepts the nourishment...

By not describing the procedures simply as feeding, withdrawal of the procedures will not be considered as “starving the patient to death.” And by not describing the procedures as medical treatment, withdrawal will not be considered as if it were simply another case of stopping a medical treatment.

In our analysis of cases involving feeding tubes and lines, we will not classify the interventions in either of the traditional categories of feeding or treatment but in terms of a new hybrid classification that we will call “medical nutrition and hydration⁶” or, more simply, “medical nutrition.”

In avoiding in this definition to describe the procedure as simply “source of nourishment,” we will not see the eventual interruption as an act aiming at starving the patient to death. And because we do not describe the procedure as a mere medical treatment, avoiding the same restriction as in the former aspect, the interruption will not be assimilated to other routine treatment interruptions.” [2].

Finally, behind this proposition, a non-dichotomist representation appears that allows us to look at the situation for what it really is.

Today we do something similar when speaking of palliative care vs. curative care as we pass progressively from the first type of treatment to the second and from cure to continuing care.

This position is notably different from the one adopted in France, known as the Leonetti law considering artificial feeding as a medical treatment. But it differs also from the position defended by those who raise a caveat against the potential consequence of this law to *shorten* the life span of a patient by foregoing his/her feeding through the tube because it is deemed out of proportions and there is no more consent. Those voicing the *caveat* insist that tube feeding be always qualified as *basic care* so that it can never be foregone except in cases when it would be materially impossible to pursue it, in particular among the patients in a persistent vegetative state.

However, for the sake of pursuing our research, we decided not to focus on these extreme and over mediatized situations, also quite diverse, and most likely still poorly understood (they also represent only a slim percentage of the cases where questions of medical nutrition limitations are raised) in order to reflect on

⁶This corresponds to the choice we made in the book *Les alimentations artificielles en fin de vie* (Racine, Brussels, 2005) to speak of “medically assisted nutrition” or, when we include hydration, to speak of “artificial Hydration and nutrition”.

the more common problems. Contrary to the *always basic care position*, the *median position* adopted by many allows, in effect, to keep the question open regarding the eventual foregoing of tube feeding, which may, in some circumstances, be considered as a medical treatment, potentially becoming excessive. This nuanced position also prohibits answering the difficult question of *withdrawing or withholding* of a feeding tube, in a purely medical logic. This leaning towards a more *median positioning* proved itself to be more and more necessary as we faced the large spectrum of clinical situations presented to us, a spectrum that included among others, as mentioned earlier, handicapped children and persons in a persistent vegetative state. This median correction is also helpful so that we never exclude, neither in the resolution nor in the working out of the decisions taken, the *global care, including the accompaniment*, also called *caring*, thus introducing a human dimension, indispensable and decisive, while facing any end-of-life issue.

6.4 Distinguishing between Ordinary and Extraordinary

Historically, in the 1980s, what was at stake in the dilemma *care vs. treatment* was to know whether one could use, in this context, the historical distinction between *ordinary and extraordinary means of treatment*, the distinction that had been prominent for centuries in medical ethics. Indeed, it seems that care can only be interrupted by death, while in the case of treatment one can reevaluate its pursuit according to its efficiency. However, this distinction between *ordinary and extraordinary*—historical contexts are necessary in this debate—goes back to the battlefields of the sixteenth century, where soldiers with gangrened legs from wounds inflicted by a cannonball, refused to be amputated. Were these soldiers suicidal since they risked a certain death by their own choice? And were those who did not operate on them homicidal?

The question was also raised regarding nourishment, as the Canadian Ethicist, H. Doucet explains:

“Already in the XVI century, when artificial recourses did not yet exist, the Spanish theologian and moralist Francisco De Vitoria (...) wonders if a sick person who stops eating because he or she has lost the sense of taste would be considered guilty of a sin equal to a suicide. The answer of the moralist is the following. If the patient has to make herculean efforts to manage to eat because he or she is very depressed and has lost all appetite, we must accept here a sort of impossibility. The patient is therefore exempted, at least of the mortal sin, particularly if there is no hope of life to speak of.” [3].

But for the modern mind, and with the development of medical techniques, this global judgment, that was the distinction between *ordinary and extraordinary means* according to the circumstances of a particular life, was transformed into operational categories. And indeed what was then extraordinary has become ordinary nowadays. This distinction, initially so pregnant, was somehow eviscerated of its subjective and properly moral intensity, to end up being narrowed in simple

medical and technical terms. To simplify, its importance became obsolete, and as a consequence it became reductive.

It is in the purpose of reintroducing the spirit of a global judgment that the distinction was converted and renamed *proportioned—disproportioned*.

However, with the continuous evolution of techniques, questions keep being raised and studies will inevitably proliferate to research an objective weighing of the pros and cons, and establish the *Standards-Options-Recommendations* I mentioned earlier, which are useful to formulate this ethical judgment that I qualify as first level, i.e., the *professional level*.

I quickly realized, however, that this first *professional level* (already partly in the domain of ethics) is often so burdensome if it is done thoroughly that there is a genuine risk of omitting other ethical aspects, namely the patient's voice, the emotions of the caregiver, the role of personal convictions, i.e., *the ethical and anthropological markers* that are a significant part of all these debates, and that in reality are more important than the sole criteria of clinical efficiency. But historically, these elements were prominently present in the distinction between *ordinary and extraordinary*.

What is therefore at stake in the status of artificial feeding is making a global discernment possible that would include some medical aspects, but also moral and religious parameters, properly personal, with the weight of responsibility linked to the imperfection of any serious discernment.

To answer the partisans of a *therapeutic status of artificial feeding* by its counterpart, i.e., *the basic status*, is to remain at the level of a technique-based mentality where such considerations have no place, as Kevin Wildes of Georgetown University explains:

“With the help of family and physician, the patient is the one who weighs risks, burdens, and benefits in light of a treatment’s probable impact. The distinction depends upon the patient’s quality-of-life judgments. The idea of benefit, as understood in traditional teaching, is not merely the conservation of life. The benefit must be worthwhile in quality and duration. To only include the former and exclude the latter is to lock oneself in a partial and incomplete vision of medicine. The approach of modern, scientific medicine has tended to follow a Cartesian model of the human being and to treat the pathological body (res extensa) as a broken machine separate from the person (res cogitans). This mechanistic view of medicine and of the patient has increased with medical specialization and sub specialization!” [4].

So-called *narrative ethics* are precisely contributing to the reintroduction of the nonmedical elements because they are necessary in the process of any ethical decision that deserves to be called such.

6.5 Three Levels of Ethical Judgment

This is how Dr. Véronique Latteur and myself came to elaborate and propose a three-step protocol as a reference for the caregivers confronted to difficult questions related to handling tube feeding.

1. A *professional intervention* with a judgment on the *proportionate and disproportionate*;
2. A *meeting with the patient* (or his next-of-kin or proxy) to find out his/her (their) judgment on the ordinariness or extraordinariness of the proposal resulting from the first step.
3. Finally, the conclusion of the process consisting in a *concerted decision*, with a well-formulated objective, and with reevaluation at a mutually agreed time, in order to favor a process guided with more *common sense*, rather than only by rational criteria, and also a practice including more personal elements rather than entirely dictated by a technical mentality.

Thanks to this framework, one can grasp two delicate situations. First, when a treatment is judged proportionate to the caregivers but appears extraordinary to the patient or the family/proxy. Second, when a treatment is deemed by the caregivers as disproportionate but is found by the patient or the family/proxy as ordinary. Facing that kind of divergent standpoint is very difficult. However, if all parties do listen to each other and communicate well, there are often ways out of the impasse. It does take time and it is a real process whose keystone is the quality of the relationship between the patient and the caregiver.

When the tube feeding is practiced on a long-term basis (as is the case for patients in PVS) and is then largely related to the basic care, the caregiver's conscience, even though more and more familiar with the questions and the subtleties behind all the terms used to express them, knows that he or she is almost forced to wait for a new clinical event (e.g. pneumonia) or an event of a different nature (such as the repeated fall of the feeding tube mentioned earlier), in order to be able to question anew the tube feeding's relevance. We have to recognize that any reflection on a life-sustaining treatment made *cold-bloodedly* or *at a deadline* (e.g. at the expiration date of a hospital stay), will reveal itself as pertaining to another logic. We are then not talking about a practical discernment based on one patient's reality, but we are debating about the value of somebody's life, and that kind of judgment does not honor our humanity, nor does it honor the medical profession, who, actually, has always proscribed this type of considerations in its deontology.

To come back to the distinction between *surrendering to death* and *actively or passively inducing death*, it seems to me that it is only at the end of the process described above, and after having respected each of its steps, that one will be able to speak of *surrendering to death in the respect of life*. The subtle distinction between "do we surrender to death?" or "do we induce death?" is rooted in the following. The former—legitimate—comes at the end of a global process that takes into account the sum of all the dimensions. The latter is the result of a technical conclusion estranged from the complexity of what the patient has expressed, and divorced from the rigorous clinical evaluation done by the caregivers. It is also oblivious of the social component of any human life and of the indispensable markers that are the *fundamental prohibitions*, sine qua non conditions rendering life possible in society.

So that the process may come to its full deployment, long deliberations are insufficient. It requires that some individuals be committed to face those clinical situations, bring these questions to the debate, and be ready to take a stand, by meeting all the parties concerned, particularly the patients because they should always come first.

At this point, let us reanchor these abstract concepts into concrete situations as we go back to two of the patients presented earlier.

6.6 Madame B. or the “Disproportioned Deemed Ordinary”

Despite the fact that the risk of nutritional coercion was quickly raised in the case of Mrs. B., and that a reasonable extension of the evaluation was announced, her daughter, who had a very close relationship with her mom, begged that the tube feeding be continued for her. In these circumstances, we were engaging in an unknown timeline of tube feeding and a nutrition program was proposed along with a transfer from the palliative care unit back to the nursing home, thankfully in an adjacent building. The patient continued to live in a relative stable quietude for about a year, enjoying the good weather during regular outings in her wheelchair, and in the company of her loving daughter. Then, came a pneumonia, “the old man’s friend,” as the old popular expression used to name it; it then allowed the daughter to accept her mom’s death with a reinforced palliative protocol established to that end.

6.7 Madame F. or the “Proportionate Turned Doubtful (Optional) and Deemed Extraordinary”

After three “falls” or “withdrawals” of the feeding tube in Mrs. F.’s case, her son asked for a second opinion regarding her tube feeding. It is when I first met them because the assigned physician was on vacation and the substitute doctor called me for advice.

At this point, four months have elapsed since her stroke and there is no hope for improvement. The son explains to us that his mother has always said that she did not want any therapeutic obstinacy and this preference was the reason she had opted to move to a nursing home. He feels that his mom, who cannot speak, is clearly signaling this same request. A nurse’s aid/auxiliary assigned to her care shares this perception. It is as if Mrs. F. has been “pouting” at everyone for a week and no one recognizes her anymore. I went to see the patient and I tried to establish a contact with her. Being very much disconcerted, I attempted to articulate to her the question that her son and the caregivers had posed to me. I explained that we had put the tube back in place to take time to think it over. After discussing with the substitute doctor and other caregivers, I explained the nonobligatory nature of this treatment in such a clinical situation, and I invoked the available alternative of strict palliative care. In a consensus with the son and the caregivers, we agreed to meet again in two days to discuss it over. I was also told then that this lady is a faithful and devout Christian. I also learn that she has been inconsolable following her husband’s death and she yearned to be reunited with him in afterlife.

At the end of these multiple meetings, it appeared to us that this medical nutrition did not fulfill any therapeutic objective per se anymore and that strict palliative care was the most respectful way to serve the patient; we all went together to explain it to her.

Much to our surprise this lady was transformed as she heard us, she recovered her peaceful mind and was herself again. Her assent to our proposed care appeared clear to us.

We all shared a general sense of relief and we learned a lesson. A week later, following the withdrawal of artificial feeding, and within the protocol of strict palliative care, Mrs. F. faded away into her death, as the light of a candle would flicker out.

I took a risk in my discernment, calling to mind my medical knowledge as well as putting my decision to the test of my enlightened conscience “hic et nunc”, while also trying to focus on what the patient meant to convey to us. I dared speak, at my own risk; it was difficult. It is my opinion that what ensued confirmed the accuracy and justness of my discernment.

It can be said, then, that it is in accompanying the patients and their loved ones, and by articulating such questions through as honest as possible a communication, but also with the daily cares and treatments, that we can progressively discover the *just* responses to these questions however daunting they may initially appear.

6.8 Conclusion

Let us not rush immediately to the ethical questioning. Let us see first what clinical situation we are confronted with, let us evaluate the existing options, and their reasonable expectations, in the light of what science currently affords us. The accompaniment of the patient, to the best of our ability, should be our first priority.

Then, let us enter the moral debate and let us clearly distinguish the following three levels:

- The professional level: the proportionate or the disproportionate. Let us understand well that qualifying an intervention as disproportionate does not mean that the doctor is denying the patient his/her personal dignity;
- The patient’s perspective: the ordinary or the extraordinary. In particular, let us look for the patient adhesion or non-adhesion in case of only nonverbal communication where doctors have a lot to learn from nurses in order to include the personal elements of the patients’ lives.
- The process of working things out together with the two perspectives.

Let us not be absolute in the principle of preservation of life. This obligation must be linked to other obligations: not to harm, not to impose undue burdens, to respect other’s conscience—knowing that self-respect may lead a caregiver to entrust a patient to another physician under *personal conscience clause*—and finally to consider that life is a mystery of which we only perceive a part.

It is in *active compassion* that we will find the just attitude, allowing to *surrender to death in the respect of life*, because *compassion* really means to suffer with.

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The Meaning of Suffering or the Meaning of Life Despite Suffering

7

Benoit Beuselinck

Relieving suffering is for all of us our primary duty, but denying that it can have meaning falls under the failure to provide assistance to a person in danger.

Cecile L. (volunteer on palliative care).

Healthcare staff, who are close to those who suffer, face all the dimensions of health as defined by the World Health Organisation as early as 1946, in the preamble of its Constitution: ‘*Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity*’.

In 2002, a law was passed in Belgium decriminalising euthanasia, under certain conditions, for people who are suffering from an incurable disease with symptoms that are difficult to control, and if all available means to relieve their suffering have been exhausted. In this framework, one thinks in the first instance of refractory pain, asphyxia, or terminal anguish. But other supporters of the law prioritise the total autonomy of the person and feel that people should be allowed to choose their time of death, if and when their life no longer has any meaning to them. From this perspective, euthanasia becomes a matter of the patient’s rights.

Everyday practice of oncology brings us to deal with symptoms and physical suffering in the terminal stage, which we are generally able to control with supportive care. Sometimes however the symptoms are refractory and palliative sedation

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proves to be necessary.¹ On the other hand, psychological suffering in the face of incurable disease, fatigue of lengthy treatments, loneliness, lack of family support, experiencing dependency, and the inability to go on with one's normal life are some of the many consequences of serious chronic illness which cannot be treated with medication. This is a matter of mental suffering that can take the form of depression, but also of existential, spiritual, or metaphysical distress. Psychological and social circumstances can give the underlying physical suffering a very different dimension. For instance, muscle pain one feels after running a marathon can be physically identical to those induced by a car accident, but they will be devoid of psychological suffering.

Thus, in the current practice of medical oncology, we observe that many requests for euthanasia from people suffering severe physical illness are motivated by psychological reasons. The patients feel that their life no longer has meaning. They fear having to suffer in the future. They are disheartened at not being able to manage their life as they previously did. And they do not want to depend on others. On the other hand, for the same reasons, requests for euthanasia can be made by people who, in the absence of any significant physical illness, consider that it is time to draw their life to a close. Autonomy, which has become a main concern, has replaced life as the fundamental value to be respected. Death, administered by the healthcare professional and offered as a solution, little by little replaces solidarity and creativity.

People who work in palliative care know that a request for euthanasia is very often a cry for help. One always has to start by listening to the pain and emotions behind the question and analysing the underlying reasons for the request. In most cases, when the suffering is taken seriously and solutions are offered, the request for euthanasia disappears.

The complaints of the people who are ill need to be heard. Minimising them or brushing them away does not help. Consequently, healthcare staff must be able to respond to physical suffering with scientific skill and knowledge (by administering pain killers in a professional way), but they must also be able to address psychological and existential suffering by drawing on their own humanity. Acknowledging that a person finds themselves in a humanly difficult situation—'What is happening to you is really hard'—is essential to avoid driving them further into distress! It is the only true help because when the person feels they are being understood, they can see themselves from the outside and come out of their despair.

But where can we find the necessary resources to respond to psychological and existential suffering? The theories of Viktor Frankl seem to be a good starting point since this psychiatrist devoted his entire career to empirical research on the meaning of life.

¹Palliative sedation lowers the state of consciousness of the dying with the help of medication, in order to relieve their pain, their (feeling of) choking, and/or their anguish. If it may be necessary to maintain sedation until the patient's death, in no way does sedation seek to hasten death. According to a study conducted in Leuven University Hospitals and published in the *Journal of Pain and Symptom Management* in January 2011, under the title '*Palliative sedation, not slow euthanasia: a prospective longitudinal study of sedation in Flemish palliative care units*,' 8% of the patients admitted to the palliative care unit needed palliative sedation at the end of life.

7.1 Viktor Frankl: The Question of Meaning at the Heart of Medicine

Viktor Frankl was born in 1905 in Vienna. Doctor in Medicine and in Philosophy, he is the founder of logotherapy, the third Viennese school of psychotherapy, along with Freud and Adler. Deported to Auschwitz in 1942, his psychiatric career was brutally interrupted by 3 years in the concentration camps. Furthermore, a manuscript which contained the essence of the thinking he had been developing since the 30s was lost. But this painful episode did not turn Frankl's life into a failure. On the contrary, it became the bedrock of his work, validating his theories that life can have meaning even in the most degrading of circumstances.

We owe it to the work of Viktor Frankl that the question of meaning, a fundamental philosophical theme, *entered the world of Medicine* and became the basis of a new school of psychotherapy: logotherapy. In a survey involving thousands of students, Frankl established that for most participants finding meaning in life was their highest priority. Being human always points, and is directed, to something, or someone, other than oneself—be it meaning to fulfil, dedication to a cause or another human being to encounter. Humans are not pure instinct, neither is their behaviour entirely determined. They need purpose, direction and motivation, without which they risk experiencing 'existential frustration' with widespread consequences such as alcoholism, substance abuse, suicide, depression, and fear of ageing.

Existential frustration leads to 'noögenic neurosis' which has its roots in the 'noös' or the spirit of the person, and arises from meaninglessness. Sometimes, man's search for meaning can induce tension instead of inner balance, but this tension is vital to mental health. People with a purpose in life are more likely to withstand adversity. Frankl quotes Nietzsche: '*He who has a why to live can bear almost any how*' [1] and points out that missing accomplishment can bring about minor psychological disorders in the young unemployed.

During therapy, Frankl's primary focus with patients is to awaken transcendence, i.e. the capacity to rise above adversity using their inner resources of mind and spirit. In order to do so, he conducts an existential analysis of what gives purpose and meaning but, unlike other European existentialists, Frankl is neither pessimistic nor anti-religious. He endeavours to draw together the fragile threads of a broken life and to reveal the pattern of meaning and responsibility they are displaying.

During consultation Frankl often asked patients with symptoms of depression why, all things considered, they would not commit suicide. The range of answers he gathered in conversations with thousands of people allowed him to 'empirically' ascertain a collection of motivations in life which can be grouped into three categories: finding meaning in accomplishment, in love, and in suffering. Accomplishment is achieved through creating a work or doing a good deed; love is about experiencing something in-depth such as goodness, truth, and beauty which can be found in nature or culture, or—better still—getting to know the uniqueness of another human being through love. Thus, Frankl recounts how, despite the dullness of the camp barracks, some prisoners stood in awe of the beauty of a sunset. As to the meaning of suffering, Frankl was struck by how many people in the camp were able to find

meaning in spite of suffering and, for a number of them, even because of their suffering. Suffering, of course, is to be avoided as much as possible, but faced with unavoidable suffering, one needs to develop a way of bearing it. Frankl believes that this is possible. In Auschwitz, he has seen people 'shoulder' their situation like heroes. He liked to quote Dostoyevsky '*There is only one thing I dread: not to be worthy of my sufferings.*' One needs to uplift suffering, make the most of each situation, adapt, and learn. If suffering cannot be avoided, one needs to learn how to suffer.

Let me give an example of existential analysis into what gives purpose and meaning to life. A man suffering from depression came to see Frankl because he could not overcome the loss of his wife with whom he had shared 50 years of marriage. Frankl confronted him with the question 'What would have happened, if you had died first, and your wife would have had to survive without you?' 'Oh,' the man said, 'for my wife this would have been terrible; she would have died of grief!' and felt much better after Frankl told him that he had spared his wife this suffering by surviving and mourning her.

In the camps, amidst indescribable suffering, Frankl encountered many opportunities that gave his life meaning. To name but one example, he chose to care for people with infectious disease rather than working on the night shift, thinking: '*if I die, I'd rather it be caring for the sick than doing useless work.*' Another drive for him was to carry on developing his theories. Frankl knew that that desire kept him going. In any case, he was one of the few survivors, even though on his arrival at the camp, the SS officer hesitated a long while before considering him suitable for work instead of sending him straight to the gas chamber.

According to Frankl, we need to look outside ourselves to find meaning. Through self-actualisation and transcendence, we can turn our talents into achievements. Reaching out, we can find meaning in self-effacing love, or in service to relieve another's suffering. '*For success, like happiness, cannot be pursued; it must ensue, and it only does so as the unintended side effect of one's personal dedication to a cause greater than oneself or as the by-product of one's surrender to a person other than oneself.*'

Similarly, when 'one expects nothing more of life' is not the time to put an end to it, Frankl says. Instead, it is the time to ask oneself 'what does life expect from me?' This is particularly true for people with a life-threatening illness. He remembers a patient who had been paralysed from his neck down since an accident which rendered him a quadriplegic, aged 17. This young man learned to live with his condition and even managed to take courses at College via a special telephone. In a letter to Frankl he wrote: '*I view my life as being abundant with meaning and purpose. The attitude that I adopted on that fateful day has become my personal credo for life: I broke my neck, it didn't break me. I believe that my handicap will only enhance my ability to help others. I know that without the suffering, the growth that I have achieved would have been impossible.*' [2].

A suffering person can find great solace in knowing that they are a unique person. Each one of us is unique and irreplaceable and nobody can suffer in a patient's place. They alone can face up to their situation and accept it with courage and

strength. With dignity too. And crying can be dignifying. There is no need to be ashamed of tears, for tears bear witness to the greatest of courage, to suffer and accept the struggle ‘in spite of the despites’. Suffering makes us stronger. Nietzsche said it even more clearly: ‘*Was mich nicht umbringt, macht mich starker*’ (‘What doesn’t kill me, makes me stronger’) [3].

No one knows what the future holds. Even though prisoners in the camp had little chance of surviving, they could not exclude the hope that they might find happiness again be it in a family, a job, or in freedom. Also, the past could be a comfort for a prisoner, without making him nostalgic, because that which we have experienced or done well, cannot be taken away from us. Our experiences, the deeds we have done, our positive thoughts, all our suffering—no one can take them away. Even committed to the past, they are not lost because we have experienced them. In times of trial, the past is as contemporary as the present day, if not more so.

Death, which is inevitable, must spur us to live in a responsible way. In life there are many opportunities for self-actualisation, and bringing to fruition the talents we have. If we seize these opportunities, we will be able at the end of life to look back with contentment on all we have been able to experience and achieve.

Such an attitude towards suffering can be achieved thanks to an inner freedom we can maintain, whatever the circumstances. Our capacity to choose our attitude and stick to it, whatever the circumstances, is the ultimate—and probably the only real—human freedom. Human beings can uphold this ultimate freedom in adversity, although Freud claimed the opposite. Frankl holds that, within certain limits, human beings can choose their destiny and pleads for allowing more space and importance to human freedom and responsibility in the practice of psychiatry. ‘*A human being is not one thing among others; things determine each other, but man is ultimately self-determining. What he becomes—within the limits of endowment and environment—he has made out of himself. In the concentration camps, for example, in this living laboratory and on this testing ground, we watched and witnessed some of our comrades behave like swines while others behaved like saints. Man has both potentialities within himself; which one is actualised depends on decisions but not on conditions.*’ [4] For Frankl, freedom without responsibility was an oxymoron. That is why he suggested that the Statue of Liberty in New York Harbor be supplemented by a ‘Statue of Responsibility’ somewhere along the West Coast.

7.2 How Can We Apply Viktor Frankl’s Theories to Helping Patients?

Now that we know something about Frankl’s theories, we can try and apply them to the situation ill people find themselves in. How do patients find meaning despite suffering and illness? Why do some experience meaningfulness and are keen to keep alive despite the hardship? Why are others disheartened and feel their life is not worth living?

7.2.1 First Pathway: Accomplishment Through Love

A number of patients hang on, hoping to be at a family event such as the wedding of a child or the birth of a grandchild. Others want to stick around as long as possible so as not to leave their partner behind or in order to watch their children grow.

A 72-year old patient with prostate cancer had already received many treatments, including chemotherapy, when he suffered a relapse in October. By that time, he had become frailer due to his advancing disease and prior treatments. We discussed the possibility of another course of chemotherapy. The patient was undecided because of his overall condition but, as his daughter was getting married the next year on July 26th, he wondered about his chances to be around for the wedding. We told him that life-expectancy can be difficult to gauge, but a new line of chemotherapy might help him make it, which seemed unlikely without any more treatment. He decided to have the treatment, knowing that he could stop it at any time if he wanted. He had four courses of chemotherapy until February, when he asked for a pause due to fatigue. In April he had two more courses before asking for another pause. He was at his daughter's wedding and the following day was admitted to hospital, where he died on July 28th. This man's motivation to live was undoubtedly boosted by the will to be at his daughter's wedding.

Illness can be *an opportunity to deepen a relationship*. We have seen couples who, having had a difficult relationship, found peace and a revived love when one fell ill and the other could—finally—start looking after them. A patient wondered whether his wife could still love him in the circumstances, to which she replied ‘now it is getting interesting!’

Many patients fear becoming a burden, although being cared for by someone can be very beneficial, both for the patient and for the carer. Here follows a conversation with a patient in the presence of her daughter:

‘Doctor, I don’t want to be a burden to my children.’—‘Have you ever cared for someone who was ill?’—‘Oh, yes, I looked after my mother for three years and my father for six months before they died.’—‘Did that worry you?’—‘Not at all, I did it with great pleasure.’ Before I could tell her that maybe it was her turn now, her daughter took her mother’s feet and, in tears, asked if she would let her care for her.

Thus, it will not be surprising that patients who are isolated, with few family members around, may find it more difficult to find meaning than others who are well connected. Studies show that the survival rate in cancer patients is higher for people who enjoy personal bonds [5] and in our practice we note that euthanasia requests are more often made by people who are lonely. Long lasting family conflicts can also trigger psychological suffering. Unfortunately, these are often difficult to solve and it is not uncommon that patients request euthanasia ‘because they no longer see their children.’

7.2.2 Second Pathway: Accomplishment Through a Meaningful Life

Many people want to go on living, despite illness or treatment, because they feel they have a reasonable quality of life and they can still enjoy good times. They plan weekends and trips in between chemotherapy courses, are happy as long as they can have a cigarette or enjoy cycling in good weather. Such an attitude requires the patient to adjust and adapt. They need to avoid focussing on what they can no longer do, in favour of finding new pursuits or resuming old ones they had let go of for lack of time. Sorting pictures, for instance, can be very meaningful. In youth one looks forward, in older age or illness, there is not much to look forward to anymore, but one can enjoy looking back on a life full of wonderful moments. Memories can be cherished with thanksgiving. Some patients say *'it is not so hard to leave, because I've had a full and meaningful life'*. Nobody can take our memories away!²

Even so, not everybody can achieve this, and particularly people who suffer from depression can find this very difficult. This is where the doctor and professional carers have an important input: they can help the patient and their family find meaning. That is, if they do not shy away from the question of meaning for themselves. In order not to cause an erroneous understanding of the notion of Christian Salvation through suffering, I do not say that patients find meaning in suffering, preferring to use the expression: *patients can find meaning in life despite suffering*.

7.2.3 Third Pathway: Knowing How to Deal with Suffering

Challenging patients' fears of physical pain, decline, and the burden of treatment are important. I can think of a number of reasons why these fears seem to have increased in recent years. First, we are less confronted with death in everyday life, so we no longer see it as a natural process. Another source of fear is the practice of therapeutic obstinacy which proves ineffective and leaves the patient exhausted. Finally, there are the media who repeat again and again that *'now that we have euthanasia, we no longer have to endure horrible suffering'*, by which they generate a very negative image of suffering.

In our daily clinical practice, we notice that dispelling patients' fears bring peace. We assure them that we will not undertake therapeutic obstinacy. We explain that they may die from kidney or liver failure or a cerebral herniation,³ for instance, which usually induces coma and a peaceful death after a few days. We tell them that, if necessary, we can use palliative sedation to lower their consciousness during the last hours of life. Eight percent of the patients in our university hospital have

²Some palliative care units allow patients to meet with a biographer who can help them write their memoirs.

³A cerebral herniation is the shift of a part of the brain structures through a reduced opening, for instance the connection between the skull and the cervical spine. This leads to compression of the brain structures and loss of function, which will lead to coma and death.

palliative sedation at the time of death; in New Delhi, India, community palliative care teams can help up to 20% of patients dying at home with palliative sedation. Being clear about these helps drive out patients' fears of not being helped in the terminal stage.

A patient suffering renal cancer with bone metastases that paralysed her was still in treatment. Yet, she needed to remind us regularly that she was determined to request euthanasia at some point in the future. When we asked why, she said that she did not want to end up 'attached to a ventilator in ICU in a vegetative state.' We told her that was unlikely because admission to ICU is not easy for patients with advanced metastatic cancer, as intensive care makes no sense when the underlying condition can no longer be treated. We also said that we would make a note in her file stating her request not to be transferred to ICU and we reminded her that we did not practise therapeutic obstinacy. On hearing this, the patient's face lit up immediately, and she told me that if this was the case, she would no longer request euthanasia. After a few months her cancer treatment, which had become ineffective, was stopped. She was transferred to a nursing home near her daughter and lived there happily for two months, enjoying several outings. She organised a party for her 70th birthday, surrounded by about a hundred friends. When her condition deteriorated again six weeks later, she was nearing the end of life. She then asked for euthanasia again, but died naturally a few days later, before her request could be fulfilled. She was in fact already dying, after having filled her last weeks of life with meaning, despite being paraplegic.

Being open with the patient, describing their situation clearly and precisely brings peace. Good communication with patients about their diagnosis and prognosis is a real challenge for doctors, which we have to face up to. For many patients, not knowing is often worse than clear information, even when it is bad news. With so much to research online, patients and families will soon find out if they were not given accurate information, and they will lose trust in their doctor, while good communication based on facts can help them appraise what they might still try to achieve in life.

Illness can teach us how to live with uncertainty, in a way that is habitual for less stressful cultures. Living with uncertainty is particularly difficult in a society which keeps projecting itself into the future and seeks insurances to keep it safe from each and every hazard. When one suffers a chronic disease with an uncertain outcome, one is bound to experience living more in the moment. If patients have been given bad news of a cancer diagnosis, it does not necessarily mean that good surprises can no longer come their way. They may respond well to treatment, even better than expected, or their illness can plateau for a while, and it would be sad to throw that lease of life away with negative thinking.

Recently an ambulance was seen in front of a patient's house. She had been suffering from cancer for many years and her condition was deteriorating. Neighbours came out, worried about her, only to discover that she was fine, but that her husband, who had been in very good health, had suffered a pulmonary embolism and died...

Finally, doctors too must learn to accept death as the natural outcome of illness and of every human life. For some, death can be a relief after a long and difficult illness. Theresa of Lisieux's autobiography [6] is interesting on the subject: 'Oh!

What is agony? It feels like I am in it all the time... how will I manage to die? I will never know how to! Could it be today? If I were to die right now, how wonderful it would be! When will I choke completely? I can't stand any more...' Thus, we notice that even a Doctor of the Church like little Theresa can at the same time both long to die and fear death, but it must be said that she experienced 'agony' (during the last hours of life) in a time when palliative care was not as advanced as it is today... Although people without any religious perspective can find ways to live with suffering, we are aware that religion can mitigate patients' psychological and existential suffering. Someone who stands tall in the faith that God loves them personally, that their name is written in the palm of His hand, and that He gave His life for them may have a different outlook on death and dying. But some atheists also speak about their 'spirit', or the 'soul of the world' and discuss their 'desire for eternity'. We each hold a seed of eternity in us which drives our longing for total and sustainable happiness, and leaves us horrified at the thought that death might lead to nothingness. For those of us who have faith, death becomes a passage... to another mysterious way of life.⁴ From experience, I would say that people with faith often die more peacefully, but they too can suffer terminal anxiety, which can be something physiological.

7.3 What Happens in a Country Where Euthanasia Has Been Decriminalised?

The most important reasons why patients request euthanasia are: fear of deterioration, of becoming dependent, of being a burden, of terminal suffering and of no longer being able to do what one was used to. Very rarely do patients request euthanasia because of severe and unappeasable physical pain; it is more often about existential suffering underlying the physical pain. Let us think for instance of an elderly lady in a nursing home who suffers urinary incontinence and is becoming blind. When she asks for euthanasia, it is not because of intolerable physical pain, but because of underlying psychological suffering such as loneliness. Another person with a similar physical condition, who is well supported by family and friends, may not even think about euthanasia!

Cases of euthanasia that hit the media in Belgium are a perfect example. A transsexual man who was not satisfied with his bodily transformation is but one example of someone suffering psychologically, not physically. The writer who requests euthanasia as soon as he notices the first symptoms of Alzheimer's disease does so because he fears foreseeable deterioration, more than because of what he is currently experiencing. Twins who requested euthanasia out of fear of becoming blind still had good eyesight at the time of their euthanasia, and the Nobel prize winner with bowel cancer spoke of his loneliness in the face of illness.

⁴Thus, some compare death to a new birth. In his mother's womb, a baby does not know either what to expect after birth. Why should he leave this warm and comfortable place where he has his needs met?

Euthanasia requests are more frequent among people who are isolated or depressed. It is important to make them understand that, if we can no longer add days to their life, we can still add life to their days! The last phase of their life can still be full of meaning, for instance when they feel supported by carers, or a long-standing family conflict can be resolved. Because of this, carers and family members need to dig deep into their creative resources, day after day, to make patients' lives satisfying. The purpose of palliative care can be summed up in two Latin words: '*consolare et sedare*' to bring comfort and peace—a peace which is physical as well as psychological, spiritual, and social. Furthermore, the question of meaning which is a feature of human beings all through their lives needs to be taken seriously in their final moments. Palliative care respects the course of an illness which leads the patient to natural death, neither precipitating nor delaying it unnecessarily. Family and carers will draw on everything they can, with love and ingenuity, to make those final moments meaningful: a last opportunity for self-actualisation and growth; a final moment of humanity and love.

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Resisting

8

Julie Blanchard

To accept the concept of 'unappeasable suffering' as a legal condition of euthanasia is to disguise a wolf in sheep's clothing.

Nicole B. (volunteer in bioethics)

Trained in France, I have been practising in Belgium since 2015. As general practitioner, I also hold a diploma in palliative care, a degree requiring 2 years of training and placements. Before coming to Belgium, I practised in France in a mobile hospital and community palliative care team, and in a palliative care unit.¹

When in Belgium, I elected to work in a setting where I would be spared quandaries of conscience. As early as the employment interview, I made clear that I would not perform euthanasia and wished to work with people who shared my views; even my head of unit does not perform euthanasia. When the question is raised by a patient, it is a matter for discussion and I can express my opinion. That is why the workplace suits me. Besides, we never admit patients specifically for euthanasia.

My rule of thumb is not to take part in it in any way. When a patient expresses a wish to be euthanised, I report it in the staff meeting, making very clear that

¹Palliative Care Units (PCU) in France are comparable to British hospice wards. Patients stay for a limited time in beds set aside for specialist palliative care and support. Priority is given to more complex and difficult situations. PCUs, like hospices, engage in a triple mission of caring, education and research. (www.sfap.org/rubrique/definition-et-organisation-des-soins-palliatifs-en-france).

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the information I share can in no way be considered medical advice on my part about the euthanasia request. I simply report that I have heard the patient's question. Luckily, I am not ostracised because of my convictions and can see all patients. On the other hand, some members of staff who are in favour of euthanasia will help patients fill in their request form if they cannot do it themselves. But even they accept my refusal to be involved in euthanasia and I experience genuine respect; when a euthanasia is planned on the ward, the team makes sure that those of us who are against it are not present at the time of the lethal injection.

8.1 The Request for Euthanasia

Organisations that advocate the right to euthanasia campaign to incite people to write down Advance Directives requesting euthanasia. This mainly serves to belittle the act in people's minds, who see it more and more as a merely civil act. But the Advance Directives form—which needs to be updated every 5 years—only applies to situations where the patient is unconscious, which represents a very small percentage of the actual cases of euthanasia... at least so far. Furthermore, a number of patients who have registered Advance Directives with the local authority wrongly believe that this covers all possible end of life situations, which can lead to painful misunderstandings.

Another issue worth mentioning is that of the 'trusted person'² whose role is not very clear, and the chosen person is not always aware of what their designation entails. Some organisations have started to provide 'trusted persons' for people who do not know who to ask in their immediate circle of family and friends. Thus, a 'trusted person' is reduced to paperwork, devoid of emotional connection.

According to the law, the euthanasia request needs to be handwritten by the patient, or, if they cannot do it, by a third person in the presence of two witnesses. What bewilders me is that as soon as a patient says 'I want to die!' certain health workers take this literally. What we consider a cry for help and an expression of suffering in palliative care, becomes for some an outright request for euthanasia! Some carers will not even take the time to reformulate the patient's request and verify that they have understood what the patient is really saying. Does the patient actually mean: 'I want you to make sure I die'? So often, a lot depends on the carer's attitude towards the patient. In palliative care, we are used to hear patients speak along those lines. That is normal! We know that death is part of life, that it is natural to die, that it is a challenging time one has to go through, and that we can talk about it without it being understood that the patient wants to be euthanised!

²In Belgium, unlike in France, naming a 'trusted person', i.e. a person who can speak or decide on the patient's behalf, is not included in the hospital admission form.

8.2 Family Pressure

It happened to me once or twice, in Belgium and in France,³ that a family asked for euthanasia for their loved one. The main challenge for the people around a patient is time: the time illness takes to bring life to a close, and the duration of the final phase. Patrick Baudry says it very well: ‘Terminal restlessness is not only a sequence of physiological reactions leading to death; it is a psychological and spiritual process which eludes us to a large extent. Speaking only about symptoms would mean reducing it to a last illness. Yet, we stand facing a mystery’. [1].

Human nature is better at tolerating an ordeal when one knows how long it will last. But End of Life essentially changes our perception of time. This is not easy. There can be a huge disparity between what people imagine and what is really happening. Often too, family members who notice physical decline, immediately think ahead about the end of life.

I remember a patient who had written Advance Directives for euthanasia ‘in the event’. Day by day, he was becoming frailer but, fully accepting his physical condition, he took it in his stride and enjoyed all the ‘good’ that he was offered. As days went by, it was his family who raised the question of his euthanasia request...

Patients can be very frail in these moments. They walk a tightrope and it does not take much to sway them to one side or the other.

Working in a mobile palliative care team within a hospital,⁴ one can find oneself at odds with a ward team. Thus, I remember advising against prescribing around-the-clock morphine to a 90-year-old patient. His daughter pleaded: ‘But Doctor, he is nearing the end of life, you cannot leave him like this!’ I replied: ‘I understand that it is hard for you to watch your dad dying. We do all we can to relieve his pain during his care, but there is no medical reason to increase morphine in between those times’. As it happened, the ward doctor had prescribed around-the-clock morphine to hasten the patient’s death; there were conflicting medical opinions. Such moments of tension are difficult; they happen a lot with mobile teams.

8.3 Explaining Euthanasia

I once heard a colleague say lightly: ‘There’s no problem with killing someone who is dying!’ This gruesome pun tragically points towards a reality where many illegal requests for euthanasia are thus conceded: when a patient says they long to die, morphine doses are progressively increased until death ensues. This reflects a tendency to impatience in the society which puts pressure on everyone: carers, family and patient; people are no longer permitted to take time to die.

³In Belgium, euthanasia will not be penalised under certain conditions, in France it is still totally illegal.

⁴Mobile palliative care teams within a hospital can be called to any of the hospital wards to advise the ward team on end of life care of a terminal patient on the ward.

The purpose of the law, however, is to help the patient who is nearing the end of life and to inform them about alternative options. Unfortunately, not all professionals have a sound knowledge neither of the law nor of the framework regulating a euthanasia request. So, in practise, procedures can be rather messy, and medical reports are not always registered according to the law.

When a patient asks me about euthanasia, I explain clearly what it is about: a request for death by appointment. I remind them that the euthanasia request is not irrevocable and that they can change their mind at any time. I try to comprehend the reasoning behind their request and reassure them that, nowadays, nearly all physical pain can be controlled, and that we will support them all along. It is extremely important that the doctor is available to discuss their concerns with a patient.

I remember an elderly woman with all her children around her. They wanted ‘something that happened gradually and peacefully’. (The gradual process of euthanasia is a contradiction in terms!). We met with the children who told us about their idea of ‘gradual peaceful death’, and we explained that euthanasia, consisting of a lethal injection after which the person dies very quickly, is all but gradual and peaceful. Appalled at such horror, the children changed their mind but, in any case, the request could not have been endorsed because the patient had not written her request down; she had only talked about it. The request came from the children who wanted to speed up the process. It is likely that, had we not been able to explain so clearly what euthanasia was, the ambiguous situation would have rendered their mother’s end of life very distressing for all involved.

Sometimes it does not take much... I am reminded of a patient who could not stand any more pain nor being a burden to everyone. I said to her: ‘I am convinced that you can think of at least three sunbeams in your day and when I come back tonight, I will expect you to tell me what has been beautiful in your life today’. She replied that I was her sunshine... And when adequate pain relief had set in, she did not ask for euthanasia again.

8.4 The Trap of ‘Integrated’ Palliative Care

Euthanasia brings an end to all support.

In France, I looked after a patient who had a deep impact on me. He was a self-made businessman, brilliant and handsome with a gorgeous wife... and had been living with cancer for 6 months. He was exceedingly angry. But feeling listened to and respected, he gradually settled down and even thanked me. This man needed to feel heard in his suffering as he experienced it. I had told him from the start that I was against euthanasia, and that boundary was very clear between us. He taught me a lesson which was very obvious with him and helps me to this day: that boundaries facilitate support.

There is an increasing pressure to integrate euthanasia within palliative care. There is a trend in hospitals to transfer patients to palliative care units when nothing more can be done to cure them, in the understanding that euthanasia is part of palliative care.... To me, euthanasia and palliative care are each other’s opposite!

The hospital's Communication Department once sent me an invitation to a palliative care training course in which euthanasia was considered to be the ultimate care. I declined, stressing how important it was not to confuse palliative care with euthanasia.

Pressure comes from the medical staff too. In an insidious way, staff in favour of euthanasia can portray those who are against it as unkind; insinuating that leaving a patient like this without agreeing to their request for euthanasia lacks humanity. One sometimes wonders whether doctors who refuse to practise euthanasia are deemed cowards, by colleagues who have 'the courage to perform it!' In my book, it is not a matter of courage but of my conviction that we can support the patient in other ways, without having to kill them. The tragedy is the speed with which people become upset in these discussions. If one is looking for proof that something is unhealthy about euthanasia, the fact that people cannot discuss it calmly fits the bill!

There is a difference between causing death and letting someone die naturally. After euthanasia, there is a chilling silence in the ward, nothing like the reflective silence following a natural death, even when it has been difficult, like the death of a young person whom we have looked after for a while. The atmosphere following a natural death is different from that following euthanasia. People are upset too, but it is not the same. There is not a deliberate act to cause death.

Often carers hide behind the 'patient's choice' which they consider their duty to carry out. Saying so is a way to protect themselves: 'I am only the executor, I have no part in the decision making'.

Once I overheard: 'Has Mrs. So and So's treatment arrived?' Can one consider euthanasia to be a treatment...? Worse, on the death certificate, euthanasia is recorded by ticking 'natural death'. Is it impossible to declare euthanasia?... What a confession!

8.5 Sedation: Misunderstandings and Confusion

The Foundation against Cancer explains '*palliative sedation is a deliberately chosen medical treatment. It consists in administering medication to reduce consciousness. If pain and discomfort in the palliative phase can no longer be controlled, it is possible—after discussion with patient and family, and only with the patient's informed consent—to resort to palliative sedation. Palliative sedation is in no way a means to "hasten death", its sole purpose is to relieve pain*'.⁵

However, a number of patients ask for terminal sedation because they see it as a gentler and more compassionate form of euthanasia! The fact that some colleagues speak about euthanasia and palliative sedation within one and the same conversation with a patient—something I choose not to do—may add to the confusion. Sedation is a way of relieving uncontrollable symptoms such as respiratory or psychological distress which do not respond to any medication. Sedation can also offer temporary respite and allow a patient to review their situation when waking up. It is imperative to use the minimal effective dose.

⁵ www.cancer.be/aide-aux-patients/soins-palliatifs-et-fin-de-vie/la-s-dation-palliative.

I have prescribed temporary sedation for a patient whose wound care was excruciating despite appropriate pain and anxiety medication.

Sedation can eventually become permanent, but only in the patient's very last days, when all else has indeed been tried.

8.6 Palliative Care: A Hospital Paradigm

Palliative care can serve as an example. On the oncology ward, for instance, the doctor would call upon our mobile specialist palliative care team for an interdisciplinary meeting about a patient's care: how to alleviate their pain, nausea and vomiting, etc. Even when a family asks for our advice, the ward doctor's approval is required, which is logical.

The mobile specialist palliative care team has an advisory role: the doctor who is in charge of the patient has the last word regarding their treatment. This way of working is very encouraging as it allows us onto the wards where we can promote palliative care. The advice we give may or may not be followed, but our visit will have enabled a discussion with the doctors on the ward; a dialogue has begun. I may still be young, but whatever the ward doctor's experience, when asked what to put in the syringe driver I say 'It is your decision doctor, and depends on what you are aiming for. I don't believe increasing the doses is warranted unless the patient's condition requires it'.

Palliative care is not a new medical speciality. It is a way of thinking about patient care and it would probably be more appropriate to speak about 'palliative culture'. Some oncologists gladly admit to an increasing need to resort to palliative care because of the advances in cancer treatment which lead to unheard-of developmental stages.

I remember a doctor who frequently called upon us to talk about a patient, aware of the need to start with palliative care as early as possible in the course of treatment. Starting in the curative phase of treatment helps with building a therapeutic alliance, and eases the transition into palliative care when curative care is no longer an option.

Another interesting aspect of working in the mobile palliative care team is that we often deal with registrars whom we can support with complex treatments. When something mentioned on a prescription surprises me, I take it upon me to challenge the registrar about their aim: 'Why did you prescribe this? What is your goal?' Sometimes, they reply: 'My boss told me to do so'. This is when I remind them that it is their prerogative to take responsibility for what they write on the prescription. Often, they will comment: 'You are right, I cannot do that...' and change the prescription. I think this is a tremendous awakening of their conscience! Some registrars even told their boss to write their own prescription... they would not do it, and I fully endorse them! Of course, there are the others too who say it happens everywhere... I then advise to do what feels right to them. I believe it is easier for them not to think and simply do as they are told. And sometimes, I need to dot the 'i's and cross the 't's': 'Are you aware that we are a palliative care team, not a euthanasia team?'

8.7 Contradiction and Ambiguity

Sometimes disguised forms of euthanasia take place which bring us to a halt as powerless witnesses. There are situations which do not fall under the legal framework when morphine doses are increased until death ensues. When one looks through a patient's medical prescriptions, their history is revealing. In situations like that, when treatments are given that are not in accordance with the principles of palliative care, I may decide to withdraw from a patient's care.

One of the weirdest situations we can be confronted with is when a doctor asks for the palliative care team to intervene, while, at the same time, increasing the doses and inducing disguised euthanasia...

Patients' self-determination and fear of medical paternalism are the two pillars of euthanasia, which have justified lifting the essential ban on killing. But what are we to make of a doctor who increases morphine doses without anyone asking them? Is that not an even greater form of paternalism? And why are not even the legal prescriptions applied? Some blame the long-drawn-out paperwork, but I believe it is more an unease of doing something which does not really feel right. A shifty expression I have heard a number of times to name euthanasia echoes this: 'On to morphine-champagne!'

Thus, my advice to registrars is to look for training schools and placements where they can be taught real palliative care, where euthanasia is not on offer.

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Behind the Scenes of Euthanasia

9

François Trufin

Caregivers in palliative care must fight to continue providing the care that ensures a peaceful end of life ... in an atmosphere that favors death.

Dr. Jacques T. (doctor in palliative care)

*Our conscience is an infallible judge,
when we have not already killed it.
Honoré de Balzac.¹*

Euthanasia is on everybody's lips, the media, politicians, public services, and various organisations.... However, the debate is often biased or ill-informed, and it is my wish to contribute to this volume by describing the (harsh) reality surrounding the practise of euthanasia as accurately as possible.

Life in our hospitals no longer runs smoothly and gently; it is exceedingly busy and often near breaking point. As a member of the healthcare staff, I notice how difficult it can be for us nurses, doctors, psychologists, and social workers, to keep our heads above water when it comes to 'ethics'.

¹*La peau de chagrin* (1831).

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9.1 Distress of the Healthcare Worker

It may be easy to proclaim oneself for or against euthanasia from afar, but when one is faced with a patient's end of life and their request for euthanasia, boundaries can get blurred when one is overcome by reason, feelings, and a sense of duty. One cannot imagine what happens behind closed doors in a patient's room, a hospital corridor, a doctor's office, or a meeting room, but more often than not I have been a direct or indirect witness to the deep distress doctors experience when they perform euthanasia. They may work in different hospitals or come from varied backgrounds: they all seem to experience certain inner conflict between their sense of duty and deeply held beliefs.

Such was the experience of a qualified doctor who 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. Can there be anything harder to bear? Who could guess that behind the confident and experienced doctor, an honest and sincere man endures such suffering?

In public, professionals stress their 'sense of duty' and the responsibility to conform with patients' requests to justify their performing euthanasia, but in the depths of their hearts, conscience rebels...

In another hospital, another doctor cried his heart out to the ethics committee: 'I will do it once more for this patient; but this is the last time. I have already performed euthanasia twice this year, and that is as much as I can bear'.

Many practitioners are compelled by what they consider to be their duty to perform euthanasia, but they can sometimes overlook that by putting an end to a human's life, they are also putting an end to their own peace of mind. One can understand that their 'blemished' conscience is tempted to bury the experience of euthanasia as deep as possible in order to survive, while the performer tries to persuade themselves of their 'good' deed. It is a matter of psychological survival. And this could be one of the reasons why partisans of euthanasia are so persistent.

When a GP in the audience expressed disagreement during a lecture aimed at promoting euthanasia, the only answer the speaker could come up with was: 'But can't you open your eyes? Euthanasia is good!' It sounded like downright autosuggestion according to the 'Coué method'²...

That is why I feel that maintaining the conscientious objection clause in the law is of the utmost importance. We have only one conscience and we owe it to ourselves to hold it dear. It is what makes us into who we are as a spouse, a friend, a

²Popular method based on optimistic autosuggestion developed by French psychologist Emile Coué (1857–1926).

relative, a healthcare worker.... By not respecting or by ducking it, we alter our deepest self.

9.2 Euthanasia: A 'De-Humanising' Act

It is well known that the workload in health services is increasingly heavy. Continually understaffed, the numerous administrative tasks on top of the daily schedule of nurses render patient care more complex and difficult. Euthanasia happens in this turmoil.

At a handover meeting, there was a heated discussion about a patient who had requested euthanasia. The euthanasia was planned to happen this very day, and was to be performed by a highly respected doctor in high demand, whose timetable is continually overbooked. The euthanasia was scheduled for 2:30 pm but when the clock struck 2.30, the doctor was still in consultation and running very late. The patient became impatient and so was the family who had come in specially to escort their loved one on this final journey. The patient paced up and down the room, waiting for death. Tension mounted in the ward as family members came and went from the patient's room which happened to be in the middle of the ward corridor, while nurses continued to provide care to other patients. General unease was at its peak; a real nightmare. When, finally, the doctor arrived several hours late, another problem surfaced: he had not fitted a catheter nor an intravenous drip for years... The nursing staff on duty did not want to be involved in euthanasia and claimed their right to conscientious objection. Eventually, barely following the protocol and showing little respect for the staff, the doctor called in a nurse from another ward who accepted to assist him. With an ironic comment to the ward team 'You have to live with the times!', she helped the doctor and euthanasia was performed with more than three hours deferral...

But I do not want to dwell on such a gruesome note. The deep unease that euthanasia has brought to our services has also—and probably in the first instance—to do with the fact that our doctors are fine people. Most of them are gems, competent and dedicated to the work they are doing.

When I made that point, a psychologist who is in favour of euthanasia, commented: 'One has to acknowledge that euthanasia requires a doctor to de-humanise themselves momentarily'. I was struck by the word 'de-humanise' used by this experienced psychologist. Did he mean that one needs to 'de-humanise oneself' in order to be able to perform euthanasia? That otherwise it is untenable? That is perplexing! How could we de-humanise? We are born human and I do not believe that we can withdraw that humanity at any time until death. We do not have that capacity. From our first breath, our first heartbeat, I dare even say from conception we are and remain a human being, all the way until death. We cannot change our human condition. To say that one might 'de-humanise oneself' is an oxymoron.

What is more, official records reveal healthcare worker's unease with euthanasia. There is no mention of 'euthanasia' on the death certificate; one has to tick 'natural death' to record it. Officially having to declare that dying after a lethal injection is a natural death, reveals a general unease regarding euthanasia. This is outright a State lie. All the more so when we consider that the doctor's identity on the form is

concealed³ in the case of euthanasia, while it is explicitly documented in any other significant medical act. If euthanasia is beneficial for the patient and should be considered progress for society, why can one not mention explicitly that a patient died following euthanasia? And why should the name of the doctor who performed a 'valuable' act be concealed?

There is an obvious gap between the reality on the ground and what is being discussed in high circles.

During a debate at the Ministry of Health, I was struck by the intervention of a professor of Medicine. The discussion was getting out of hand, each putting forward their arguments for or against euthanasia—some about the patient's rights, others about respect for the individual—when this doctor stood up, slammed his fist on the table, and asked: 'Do you really believe it is easy for us, doctors, to perform this lethal act?'

This man who was generally considered a great supporter of euthanasia dared to assert the muted distress of the practitioner in the midst of this high circles debate.

9.3 When Conscience Competes Against Law and Bureaucracy

Lately, a great debate hit the media questioning the freedom of healthcare institutions to choose whether or not to allow euthanasia on their premises. The law is unclear about this and the void this causes can lead to fierce lawsuits by patients or families against institutions that have refused to consider euthanasia for patients in their care. But this debate is misguided. To understand this better, let us look at both the viewpoints of health professional and patient.

Each professional signing an employment contract is expected to stand by the values of the institution he signs with. And so, before signing, they will have examined whether these values are compatible with their own and with their conscience. In the matter at hand, let us take the example of a healthcare institution which chooses not to allow euthanasia on their premises. When signing an employment contract with them, the new staff member agrees to this. They may even be particularly sensitive to this very principle which concurs with their personal values, and therefore look forward to joining this particular end of life care team. They might not even have considered accepting the job had it not been for this determining factor...

³After performing euthanasia, the doctor has to complete two sections of a form which serves to verify whether the act happened in accordance with the law. The Federal Control Commission corroborates 'a posteriori' whether the prescribed conditions and procedures have been complied with. They do so, examining the anonymous section of the form. If the Commission considers that not all the stipulations were followed, the second section, with the doctor's name, is opened and in the event of a two-third majority endorsing the decision, the case will be sent for further investigation to the Crown Prosecutor in the locality where the patient died. This happened only once in 15 years since the introduction of the law.

Now, let us look at the patient... They too may have chosen a specific institution because they know euthanasia does not happen there. A patient or family considering euthanasia might be well advised to enquire about the institution's policy before applying, and if the charter stipulates that no euthanasia is performed on the premises, look elsewhere where their need can be met.

Sadly, we have to note that freedom of expression and respect for the other are equivocal in this debate, as they seem to work in one direction only. Little or no room is left for institutions that stand for life.

During a hospital inspection, an institution was blamed for not having any euthanasia protocol. The director objected they did not need one since internal regulations stipulated that euthanasia would not be performed on their premises. The inspectors summoned the hospital to update the document and lay down a euthanasia protocol...

Considering the law is unclear, it seems to me that such an attitude denotes abuse of power.

Having considered the healthcare workers' conscience issues and experience of euthanasia in the first section, let us now turn to the patients. Undeniably, situations are equally complex and difficult for patients and their families, who are suffering. Faced with their request for euthanasia, what does palliative care have to offer? Can they come up with an answer or even a valuable alternative?

9.4 Euthanasia, a Stage in Accepting One's Illness

A number of specialists have explored different stages patients can go through when they are given bad news: denial, anger, bargaining, depression, and acceptance can be experienced to a greater or lesser extent. I would want to add a further stage: requesting euthanasia.

This new stage came about in the social context in which we live, marked by a legislation decriminalising euthanasia under certain conditions; by media, sometimes encouraged by biased activists, publicising difficult and exceptional situations; and, finally, by the testimony of healthcare workers who have performed euthanasia and become cheerleaders of the practise so as not to be overwhelmed by second thoughts. These contextual factors have rendered a euthanasia request very nearly systematic for the seriously ill. Continual brainwashing has secured in people's minds—without the slightest shadow of guilt—the option that an end can be put to their life *'as and when they would like it'* and a euthanasia request has become a societal claim which we all have to contend with, avid defenders of life included. Requesting euthanasia has become the norm. Hence, I see a parallel between the request for euthanasia and the anger stage of grief. We need to integrate it in the process, but most of all see it as a temporary stage, not an endpoint. Nothing forces us to kill!

But what happens precisely in practise? A patient will arrive at the hospital with a note from their GP saying: *'Thank you for taking care of Mr(s) X for euthanasia'*,

clear and to the point! This often happens with GPs who are not against euthanasia but do not wish to perform it themselves. They tell the patient ‘*They will do it at the hospital*’ and the patient is convinced that they will be euthanised within days of being admitted to the hospital, not realising it is not that simple. According to the law,⁴ patients can be referred to the hospital either at a family’s request, who do not want to live where their loved one has died or at the GP’s request who asserts: ‘I’ve reached my limit!’ Euthanasia referrals rarely happen from one GP to another, rather, it is suggested that the patient goes to hospital.⁵ But most hospital doctors refuse to perform euthanasia ‘on request’, and the patient ends up in a palliative care bed.

In order to rise above the ideological feud ‘*for or against euthanasia*’, one needs to remember that patients who are referred are people, first and foremost. We cannot shut them out of our care simply because they requested euthanasia. But this does not mean that we should accept putting people to death either. Admitting them to the palliative care ward requires us to accept the people as they are, with their understandable anger and unbearable anguish, and help them face up to their death, and working through anger and fear towards acceptance. When we support patients competently and with empathy, we may help them consider their demise differently than how it looks through a euthanasia-tinted lens, and help them to live life fully till the end.

A request for euthanasia is not the end of the road. We need to look at it as a new phase, among the other stages of grief, on the way to acceptance. At the end of this process, we hope that the person, with the help of the palliative care team, will be able to die a natural death, having lived their life to the full till the end. A patient who requests euthanasia is usually in the thralls of dread: fear of suffering, of dying, of being a burden... Euthanising them in that distress deprives them of the time to ease their worries and find answers to their questions. Furthermore, it confirms a failure and denies them the hope to overcome it.

The health professional who is aware of this possible care pathway will no longer feel apprehensive around a patient requesting euthanasia; they will take them by the hand and walk alongside them to the end of the road.

A patient arrived in our department accompanied by her husband. She was about 50 and had so far been living at home, taking 32 medications a day. Convinced that she was a burden to her husband and her two children, she repeated day in day out: ‘Let me go, I want to die, please don’t give me any more medication’. She attempted suicide four times. On the fourth attempt, she pushed herself down the staircase in her wheelchair. Her husband, who loved her deeply, was totally overcome. He was devastated at the thought that he could not prevent her throwing herself down the staircase. To the GP it was clear that she wanted to die and he referred her to the hospital for euthanasia.

⁴The 2002 law on euthanasia, section 14, makes referral to a doctor of the patient’s choice obligatory: ‘The physician who refuses to take a euthanasia request into consideration is deemed to refer the patient to a doctor of their choice when requested by the patient or their “trusted person”’.

⁵This can happen both ways. The hospital team which refuses to perform euthanasia for a patient who fulfils the criteria and has the necessary forms, can discharge them home where a consenting physician can do so.

When she came in her husband shouted: 'Don't let anyone get in our way, she is to be euthanised'. The team started to panic. I went to see the patient and we had a 4-hour conversation with husband and wife. We argued and as I was not agreeing to go ahead with euthanasia, he wanted to take his wife back home and have her referred elsewhere. I told him: 'The choice is up to you, but right now, your wife cannot be transported; any movement is extremely painful and we need to take care of her pain first. I guarantee you we will do all we can to make her comfortable. When she is, you can still decide whether you want her to be transferred in order to be euthanised'. Thus, the situation calmed down, the husband decided to leave his wife in our department and we worked together. Seeing how, with the combined use of painkillers and controlled sedation, his wife rested peacefully in bed, he became convinced that palliative care was effective. A very tactile man, he appreciated the massages with essential oils we gave his wife. We encouraged him to bring the CDs they listened to together. The two children, both young adults, followed suit, even though they were ill at ease at the start. They feared they might betray their mother's resolve who had been adamant from the start that she wanted euthanasia. We reassured them saying that she was receiving no more medical treatment and we did nothing to prolong her life, only to make her comfortable.

This lady died peacefully in her husband's arms, listening to the music they had played at their wedding. After a week, her husband came back, asking to see me. He thanked me with a box of chocolates... and asked whether I could keep a place for him in our palliative care ward when his time came!

The sad thing is that it took 32 medications and four suicide attempts for this woman to be heard and cared for, rather than be the object of therapeutic obstinacy.

Too often, unreasonable and coercive therapies are maintained. Because health-care professionals perceive death as a failure, they go ahead with heavy treatments and invalidating surgeries which take away patients' quality of life and cause appalling suffering. Exhausted and desperate, euthanasia seems the only way out for the patient: they cannot go on like this! The doctor can no longer witness the suffering he brought on the patient either, and tends to go along with their euthanasia request. If only the patient's wishes about having another course of chemotherapy or undergoing more debilitating surgery could be better assessed, they would have the choice, with the help of palliative care, to end their life with dignity.

9.5 Euthanasia as a Wake-Up Call from Indifference

The above example puts the finger on the drama that lies hidden beneath a number of euthanasia requests. Another, even more striking, situation has deeply transformed my professional practise.

During the Christmas holiday, a 75-year-old lady, whose convalescence after hip surgery was difficult, suffered several falls at home. Feeling relatively well but no longer able to live alone, she was placed in a nursing home—which happened to be cruelly understaffed—by her overworked children. In the home for a whole month, she witnessed people being left in bed—even for meals—three or four days running during long weekends, for instance, when the staff was reduced. Sometimes residents' cry for help to go to the bathroom would go unnoticed, and the like. Fearing she might end up in a similar situation, she preferred to end her life right away. She stated her wish to the GP, completed the documents in due form, and was given the all clear to be euthanised. The nursing home sent her to the hospital. Since

she was not imminently dying, there needed to be, by law, a month's delay between acceptance of the request and the actual euthanasia. During this time, she was cared for by our palliative care team, even though her condition did not warrant it. The psychologist saw her regularly. When I overheard the following sentence, it rang like thunder to my ears: 'Did you notice? I had to request euthanasia for people to start taking an interest in me'. Indeed, she had several visits a day, received proper care, saw the psychologist, some people would bring chocolates... Even people from the nursing home came to visit the star she had become. And this all came about after she had volunteered for 'death's corridor'. It was a very unhealthy situation where it appeared that requesting euthanasia became an 'open sesame' to receiving proper care and support.

That patient caused a professional electroshock for me! She made me realise how important those moments at a patient's bedside are, when we give them our time to talk or even play cards, and simply to be human. Her experience spurred me to call together a group of volunteers who give of their time to go and sit at a patient's bedside. It also taught me that, whether a euthanasia request comes from the patient or a family member, it is worth checking whether they want to test the medical world. I have been positively surprised to realise that when we say calmly: 'No, we do not practise euthanasia, but we have something better to offer you', people are willing to listen. And when we explain that pain will be relieved and that their quality of life is our main concern, the euthanasia request quickly fades away. Relief from pain and being treated as a human being is what most patients and families long for.

There is still another dimension worth considering. Families, like doctors, are often upset when euthanasia is mentioned. Family members do not always agree for or against euthanasia, and this can lead to painful conflicts in the very ward corridor.

I remember a family that was torn apart over the question of euthanasia and I spent a long time in the patient's room, talking to each of the family members. I do not remember what I said, but the crisis calmed down and palliative care was quietly put into action.

Often, a request for euthanasia comes from caring people who cannot fathom the idea of being a burden to their loved ones. Our art as healthcare staff consists in helping the patient find ways of expressing their love.

Thus, a volunteer suggested a quadriplegic grandmother could tell stories to her grandchildren. This helped her come out of the shell she felt locked in.

9.6 Sedation: Palliative Practise or Hypocrisy?

Defenders of euthanasia can sometimes point the finger at sedation, which they deem to be hypocritical. Nevertheless, sedation has a place in palliative care, when the doses are controlled and it is used with the intention to relieve a patient's suffering.

While morphine derivatives can take care of physical symptoms (difficulty breathing, unappeasable pain, etc.), sedation can relieve psychological distress

which also needs to be taken care of. The principle of sedation is to give a patient respite for a longer or shorter while, at regular intervals, in between which the patient can be peacefully awake when their suffering is more bearable.

A lady who used to be the tenant of a small pub was admitted to the palliative care ward. Despite many courses of chemotherapy, her illness had progressed and reached terminal stage. A very active lady, the patient suffered huge physical and psychological pain. She missed terribly standing behind the bar and having contact with the clients. Her treatment had two objectives: relieve her physical pain with morphine and, with an eye on her psychological comfort, allow moments of rest when she asked for them with controlled sedation. She would always be awake during visiting hours when family or clients came in and they would have a beer and a chat, as they were used to in the pub.

About to become a grandmother for the first time, her ultimate goal in life was to make it to the birth of the child. Sedation helped her to hold on and she was happy and relaxed. However, on the eve of the expected birth, her condition took a turn for the worse and it became unlikely that she would make it. Sedation was stopped around midday the following day when the grandchild came in. Full of joy and strength, the patient could get up, hold the baby, and contemplate it with wonder. That evening, she took to bed never to get up again. She died peacefully two days later, happy for having achieved her goal and held her grandchild.

When it is used properly, there is nothing hypocritical about sedation! It is a palliative tool geared at the patient's and their family's well-being. While morphine is a painkiller for the body, sedation can relieve psychological distress.

This being said, it does happen that high doses of morphine or other substances are administered despite the risk that such doses might hasten death. We constantly adapt to a patient's pain and suffering in palliative care, so as to make sure they are comfortable. When pain and suffering are very resistant, we may sooner or later have to prescribe such high doses of medication that they may induce the patient's death. Even so, the professionals will have fulfilled their contract with the patient to keep them comfortable until the very end. It needs mentioning that, at no time are the care or medication given intended to end a patient's life; the intention is only to relieve their pain and make them comfortable. Although, pharmaceutically, there may seem to be only a very thin line between palliative care and euthanasia, in effect the difference is huge. In palliative care we administer the lowest dose possible by which the patient's suffering can be relieved; in euthanasia a large dose is administered to make sure the patient dies. Healthcare workers who administer sedation are very aware of their intention either to relieve or to kill thus ensuring their peace of mind.

One day a colleague asked me: *'What difference do you see between euthanasia and palliative care? The patient dies anyway. The aim is to respect their wish to die'*. Having recently visited the Opal Coast (Northern France), a metaphor came to mind. I said:

A person at the end of life is like someone standing on the edge of a very high cliff. They can see the sea lapping the rocks down below. They know they may soon have to leave solid ground to enter the sea. The person who asks for euthanasia does not dare to jump on their own. It is too high and they do not know how to get down below. So, they ask the doctor to

give them a push to help them plunge. In palliative care, rather than pushing the patient off the cliff, we take them by the hand and lead them down to the shore along a coastal path. Palliative care means taking the time to find the path which suits the patient, to go down with them all the way, and allow their nearest and dearest the time they need to walk along that path with them. Of course, the path can be very steep and tricky at times, but carefully and cautiously, both patient and family can reach this beach from where the patient can travel peacefully.

We all get to the bottom of the cliff, but the way to get there is very different.

9.7 When Trust Meets Professional Integrity⁶

One of our professors quoted Dr. Portes: *‘The career you have chosen is about an encounter between trust and professional integrity’*; it is about the professional integrity of the healthcare professional meeting the patient’s trust. Unfortunately, too often patients’ trust is fading away or even turned into suspicion when they are dealing with professionals whose integrity has dwindled to a perverted sense of duty. The medical world is annoyed when patients look for information on the Internet, ask for a second opinion, and express distrust. But what is at stake is more than the globalisation of information online: in failing to provide proper answers to ethical dilemmas, medicine has broken the delicate balance of trust and professional integrity. And I greatly enjoy the trust patients grant me, thanks to my refusal of euthanasia.

But what about training and the ideas that are conveyed nowadays?

Some lecturers are pretty good at convincing an audience of hundreds of people that, under certain circumstances, euthanasia is an act of love. Knowing how to play on emotions and feelings of guilt, they use it to convey how beautiful a response to suffering euthanasia can be. Many of us have sat in lectures of this kind. But when they are geared to young professionals in training, they may cause huge damage, anaesthetising their capacity to be with someone’s pain and suffering. Here too, one could speak of a betrayal of trust in the young, through a changed nature of the tutor’s professional integrity.

But I do not despair. Even if today many are trained for euthanasia, believing it to be a part of patient care, I am convinced that there will always be enough people to look reality in the eye and not run away from life’s tragedy. And I hope that they may discover by themselves what I was brought to understand.

One day I was travelling home after having dealt with a particularly difficult situation. I was in total turmoil, at the end of my tether. Driving home from the hospital takes me about half an hour, across beautiful scenery. That evening, the sun was highlighting the autumnal colours, and suddenly it dawned on me: ‘Fortunately nature does not react like us humans... What if the leaves said at the end of the summer: “I want to die. Soon, there will be no more

⁶Dr. Louis Portes (1891–1950), ‘Du consentement à l’acte médical’ (communication à l’Académie des Sciences Morales et Politiques, 30 janvier 1950), in *A la recherche d’une éthique médicale*, Paris, Masson et PUF, 1955.

tree sap, so better end my life right away". If this were the case, we would miss out on the autumnal beauty. As early as July many still green leaves would litter the ground and there would be none left to display their colours in fall. The richness of autumn lies in the time leaves take to let the vital juice dry out and die. In spring and even more in summer, all the leaves are green, but in fall an extraordinary variety of colours is displayed. Similarly, a human being in the twilight of life lets go of their masks and reveals their true self. In everyday life, running after time, we all have green leaves and, sometimes, it is not until the end of our lives that we realise that, beneath the green, there is a wide array of warm and exquisite colours. Palliative care is the autumn of our life; it is the time the leaf takes to gradually detach from the tree. Even though the sun is not always shining and there are difficult times of heavy showers and wind storms, the leaf holds on to the tree with all the colours it has left. Could we imagine a year with three seasons only? Could we go from 35 °C in summer to -10 °C winter without any period of transition? No!... However, that is what happens with euthanasia'.

I have met all sorts of people during my career, from the humblest to those who are used to being in the limelight. For each and all of them, masks come down at the end of life. No doubt this is very difficult for the person, but it is also very beautiful to watch. They reveal their deep inner self and remind us that they are unique and irreplaceable. We see a person readying themselves to leave this life. For sure, their body is often falling to pieces, and their mind is slowed down, but what is being said, what is being experienced, is of a beauty and intensity that remind me of the autumn leaves...

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Postface

Timothy Devos

I would like to conclude this work with some important points to remember that shed light on our daily life.

The authors of “*Euthanasia: searching for the full story*” give us a very positive message. Doctors and nurses need to believe in their patients’ resilience, the inner force that allows a person to adapt to new and difficult situations, to redefine his life goals and to recognize that he is capable of what seems impossible. Every day I see magnificent examples of this in hospital. But this resilience is sometimes undermined and needs to be reinforced by family members, friends, and health-care staff, especially in palliative care. Negative signals, be they direct or indirect, can snuff out this inner flame. Thus, doctors and nurses help their patients, not only through their medical and scientific knowledge but also by being bearers of hope, without however resorting to extraordinary measures to prolong life. To bring hope is not necessarily to tell a sick person that she will heal. It is listening to her suffering. It is seeking with her the meaning of her life in spite of her suffering. It is making her feel, in spite of all she is living through, that her life is worth living, that she still can love.

Accepting a request for euthanasia sends the patient a signal. It confirms that her life in effect is no longer worth living. The law however stipulates precisely that euthanasia must never be proposed. But the examples given in this book show that this border is often crossed. Here is another example that was related to me by a young intern in psychiatry. It speaks volumes about the shift that is taking place in our society. His middle-aged patient was suffering from alcoholism and spoke to him about the thoughts of suicide that oppressed him when he had had too much to drink. To deal with this, he was in the habit of calling the helpline of the suicide prevention center. Then this patient, very upset, told him that the last two times he had called the center, the person at the other end of the line had suggested to him that he ought to discuss euthanasia with his family doctor. At the time the patient told this to the young intern, he was sober and stated that he had no intention of discussing the option of suicide with his doctor and even less of requesting it. The patient was distraught because at the time of his call for help he was told that his life was perhaps no longer worth living and even that he was a nuisance.

Most requests for euthanasia are rooted in mental suffering, even if there is an underlying physical pathology. Several references are in agreement on this point [1].

Everything depends on the way the health-care staff approach this mental suffering. This is precisely the reason why the health-care staff's message of hope and interest in listening is so important. Is not there a risk that requests for euthanasia caused by a feeling of loneliness and uselessness will multiply exponentially if the bonds of solidarity continue to unravel in the name of the total autonomy of the individual person?

"*Euthanasia: searching for the full story*" also shows us how family members and the health-care staff who carry out or assist in euthanasia are distraught. Yet there is very little scientific literature about this matter. Numerous testimonies show a malaise, even a sense of guilt, among health-care workers. An elderly person in a rest home requests euthanasia and the staff members blame themselves in the belief that they probably did not give this person the best care. This is the reality. For doctors who induce death, the emotional burden is not negligible and can lead to emotional exhaustion and a feeling of loneliness [2]. There is an urgent need to acknowledge this phenomenon, to document it, and then, if necessary, to conduct a deeper inquiry into the matter.

In Belgium it is clear that the promise and the numerous expectations of the law on euthanasia of 2002 have not been fulfilled. The law was supposed to bring transparency to and control over euthanasia, which at that time was carried out in secret. Today, we know that many euthanasia cases are not reported and that the system of control after the fact [*a posteriori*] is largely insufficient. The paternalism of the doctor was to be brought to an end, but this book shows us that a new form of paternalism has appeared today. It is no longer the paternalism from the past over whether or not to start a treatment, but a paternalism concerned with life or death. Furthermore, an insightful analysis demonstrates that there is a link between unreasonable persistence in treatment and euthanasia, namely the doctor's rejection of powerlessness. Doctors and nurses must accept their powerlessness when faced with certain situations, as this book shows.

It has been for me a very great honor to work with the authors of this collective work. They have taught me a great deal. All of them, from the perspective of their particular expertise and experience, have analyzed the evolution in end-of-life care in an honest and open way. In this book there is neither negativism nor fatalism. The authors wish neither to judge nor to blame. On the contrary—they are all looking to the future and the book leaves us with this message: "We can do better in caring for the sick at the end of their lives. We must aim higher!"

References

1. Federal Commission for the Control and Evaluation of Euthanasia, 7th Report to the Legislative Chambers, 2014–2015, W. Distelmans. Palliatieve sedatie: trage euthanasie of sociale dood?, 51.
2. Stevens KR Jr. Emotional and psychological effects of physician-assisted suicide and euthanasia on participating physicians. *Issues Law Med* 2006;XXI(187).

Brief List of Health-Care Terms for the Non-specialist

Acute geriatric medicine:	an acute geriatrics department admits as inpatients elderly patients who present several disorders and a significant state of physical, mental, and/or social dependence.
Anoxia:	a deficiency of oxygen the blood distributes to the tissues.
Antalgia:	the attenuation of pain.
Cerebral (brain) herniation:	the protrusion of brain tissue, blood, or cerebral fluid through a natural orifice, for example, through the connection between the skull and the spinal canal.
Declarations/ Directives on Euthanasia:	<p><i>Advance declaration/directive of euthanasia:</i> the form by which a person “requests that, in the event he/she is no longer able to express his/her will, a doctor perform euthanasia if all the conditions stipulated by the law are met.” It will be implemented only in cases where the person is unconscious.</p> <p><i>Obligatory declaration of euthanasia:</i> the form for verifying the legality of the completed act. The Federal Commission for the Control and Evaluation of Euthanasia certifies a posteriori [after the fact] that the conditions and procedures stipulated by the law have been adhered to. In order to accomplish this, the Commission examines the anonymous section of the forms completed by the practitioners who carried out euthanasia. If the Commission deems that the legal conditions were not met, it opens the second section, which names the doctor. If the case does not appear to conform to the law, the Commission, by a vote of two-thirds majority, sends the record to the royal procurator at the place of the patient’s death. This has happened only once in 15 years in the 13,000 cases of euthanasia officially declared (as of the end of 2017).</p>
Decriminalization of euthanasia:	the assurance given to doctors who induce the death of their patient at the patient’s request that they will not be criminally prosecuted, <i>provided that</i> they operate within the boundaries of and meet the criteria of the law. It is inexact to say that euthanasia has been legalized or that it has become a right.
Deontology and teleology:	the deontological perspective is concerned above all with obligations and duties (in a broader sense than a strictly legal interpretation) of the profession. The teleological perspective is more interested in results.

Euthanasia:	the act performed by a third party (a doctor) who intentionally puts an end to the life of a sick person at the person's request. It involves administering orally or intravenously a substance or combination of substances with the intention of inducing death. Although certain authors use the term "lethal sedation" for a slower euthanasia, it is nonetheless clear that it is a form of euthanasia whose aim is contrary to that of "palliative sedation" (see "Sedation" in the following).
Extraordinary measures or unreasonable persistence in treatment:	the implementation of disproportionate means with a view to prolonging a patient's life. Since a cure is no longer possible, the burden of treatment is incommensurate with the expected beneficial effects.
Federal Commission for the Control and Evaluation of Euthanasia (CFCEE):	the organization charged with verifying whether a doctor's act of euthanasia met the conditions and followed the procedure stipulated by the law.
Gastrostomy:	a procedure implemented when oral feeding is no longer possible, involving the surgical opening of an orifice that communicates directly with the stomach, in order to supply the patient with suitably prepared nutrition. With the aid of the light of the gastroscope (a tube with a camera), the doctor makes an incision in the proper place in order to create an orifice that allows the feeding tube to be introduced. The orifice created in this way is known as a "percutaneous gastrostomy."
Grief:	the process undergone by everyone who experiences a loss. The classic stages of grief are denial, anger, bargaining, depression, and then ideally acceptance. Grief is experienced not only in the case of a deceased loved one. One may go through all the stages upon receiving various kinds of bad news: loss of employment, separation, chronic illness, loss of autonomy, or incurable illness. These stages are very upsetting for the person and those around him and can make support necessary.
Human dignity: There are two conflicting concepts:	<ol style="list-style-type: none"> <li data-bbox="389 1056 1018 1160">1. Ontological dignity: a person has dignity by the very fact of his nature as a human being. Nothing can take away this dignity. It is the responsibility of health-care workers to provide the care and attention worthy of his quality of being human, to the very end. <li data-bbox="389 1166 1018 1293">2. Existential dignity: a concept that has to do with the image that a person has of himself. Accordingly, a person has dignity inasmuch as they are autonomous and have the capacity to function. For example, once one becomes dependent on another, one will have lost one's dignity.

Lethal injection without the patient's request:	according to the law of 2002, this act cannot be called euthanasia and must be labeled as murder.
Medical restraint:	the restriction of a patient's mobility through physical or chemical means. Employed for various reasons, it can be criticized on ethical grounds when it reduces the freedom of the patient.
Morphine:	a substance extracted from opium capable of relieving intense pain—by working on the central nervous system—and inducing sleep. When used in the proper dosage, it has no effect on the duration of a patient's life.
Multiple myeloma or Kahler's disease:	cancer of the bone marrow induced by the uncontrolled proliferation of a specific type of white blood cell, the plasmocytes. Normally, these cells specialize in making antibodies.
Pain management:	the study of the physiology of pain in order to better treat and manage pain.
Palliative care:	the monitoring and management of patients with an active, progressive disease, the stage of which is very advanced and the prognosis (expectation of recovery) is very poor. This form of care aims to maintain the quality of life by treating pain and other physical, psychological, and spiritual problems that are linked to it. The treatment is not intended to accelerate or delay death (see below "Palliative care units").
Palliative care units:	institutional health-care units that take patients into palliative care for a limited time. They consist of beds exclusively for the practice of palliative care and support. Admission is restricted to the patients whose situations are the most complex and/or most difficult, thus assuring a triple mission of care, teaching, and research. There exist also mobile palliative care teams and palliative care hubs that send health-care workers to the bedside of patients in other hospital services, to rest homes, or to patients' homes. They are available to support and counsel the primary caregivers, that is, family doctors, nurses, and the families of the patients at the end of life.
Passive euthanasia:	the withholding of commensurate treatment or care normally due, with the intention of putting an end to a person's life. Strictly speaking, the expression "passive euthanasia" has no meaning, since it contradicts the sole legal definition of euthanasia (see "Euthanasia" above). What is called "passive euthanasia" is nothing other than the refusal to use extraordinary measures to prolong life (see "Therapeutic de-escalation" below). That being said, there are nonetheless criminal abstentions that are disguised cases of euthanasia.

Psychiatric disorders:	<p><i>Anorexia</i>: the mental disorder of nutritional behavior, characterized by a refusal to maintain normal weight. The fear of becoming obese, or indeed simply fat, incites people who suffer from anorexia to follow very restrictive diets. They sometimes have episodes of bulimia or purging. In keeping with their distorted perception of reality, the anorexic person continually sees herself as fat in spite of her low weight.</p> <p><i>Bipolar disorder</i>: variations of mood out of proportion with events. They attain such an intensity that the individual no longer perceives that their exuberant mood or their anger is out of bounds, or alternatively, that their depression is so deep that they are paralyzed by it and haunted by suicidal thoughts.</p> <p><i>Borderline</i> (“borderline personality disorder”): a mode of generally unstable interpersonal relations, self-esteem, and feelings, with a marked impulsiveness that appears at the beginning of adulthood and is present in a variety of contexts. Borderline individuals make frenzied efforts to avoid real or imagined abandonment.</p> <p><i>Obsessive compulsive disorder</i>: OCD is an anxiety disorder characterized by obsessions, compulsions, or both. In an attempt to repress their obsessions, the afflicted person feels obliged to engage in repeated gestures and compulsions; these are genuine rituals that can take up to several hours a day and that interfere in a significant way with the activities and relationships of the affected person.</p> <p><i>Schizophrenia</i>: a disease of the brain defined as a loss of contact with reality, manifested by disturbances of certain mental functions. It is not an illness of the soul, nor a lack of will, nor a double personality (dissociative identity disorder), but rather a defect of certain nervous circuits of the brain.</p>
Reformulation:	ascertaining that what the patient has said has been properly understood, by restating what they have said and asking them if that is indeed what they meant. It is one of the key concepts of palliative care.
Sedation:	palliative sedation reduces the awareness of the dying person by using medication to relieve their pain, their sensation of asphyxia, and/or their anguish. It is commensurate with the patient’s condition, is regularly reassessed, and is most often temporary. Although it is sometimes necessary to continue sedation until the patient’s death, it is in no way intended to accelerate their death.
Stroke (CVA):	a stroke, or cerebrovascular accident (CVA), occurs when the flow of blood encounters an obstacle (either a blood clot, in the case of thrombosis, or the rupture of a blood vessel, in the case of a cerebral hemorrhage) that blocks its passage to the different parts of the brain, thus depriving the cerebral cells of their vital supply of oxygen, causing their dysfunction and then death within a few minutes. A stroke often entails the paralysis of a part of the body and/or a speech disorder.
Therapeutic de-escalation:	intentionally sparing patients burdensome treatments that they do not necessarily need in order to heal, with the intent of preserving their maximum quality of life; or intentionally offering patients the least burdensome effective treatments, with the intent of preserving their maximum quality of life. One also speaks of “commensurate care,” that is, care that is suited to meeting these new objectives. When healing is no longer possible, one prefers to stop invasive or painful treatments in order to make patients as comfortable as possible.