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 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

⁵ Kahler'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 ADMMD... 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 revaluation 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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