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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