

## THE BEST WRITING ANYWHERE, EVERYWHERE



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### THE DEATH TREATMENT

*When should people with a non-terminal illness be helped to die?*

By Rachel Aviv

*Belgian law allows euthanasia for patients who suffer from severe and incurable distress, including psychological disorders.*

In her diary, Godelieva De Troyer classified her moods by color. She felt “dark gray” when she made a mistake while sewing or cooking. When her boyfriend talked too much, she moved between “very black” and “black!” She was afflicted with the worst kind of “black spot” when she visited her parents at their farm in northern Belgium. In their presence, she felt aggressive and dangerous. She worried that she had two selves, one “empathetic, charming, sensible” and the other cruel.

She felt “light gray” when she went to the hairdresser or rode her bicycle through the woods in Hasselt, a small city in the Flemish region of Belgium, where she lived. At these moments, she wrote, she tried to remind herself of all the things she could do to feel happy: “demand respect from others”; “be physically attractive”; “take a reserved stance”; “live in harmony with nature.” She imagined a life in which she was intellectually appreciated, socially engaged, fluent in English (she was taking a class), and had a “cleaning lady with whom I get along very well.”

Godelieva, who taught anatomy to nurses, had been in therapy since she was nineteen. With each new doctor, she embraced the therapeutic process anew, adopting her doctor’s philosophy and rewriting her life story so that it fit his theory of the mind. She continually dissected the source of her distress. “I am confronted almost daily with the

consequences of my childhood,” she wrote to her mother. She’d wanted to be a historian, but her father, domineering and cold, had pressured her to be a doctor. Her mother, who was unhappy in her marriage, reminded her of a “slave.” “New insight,” she wrote in her diary. “Do not want to always nod yes like her and be self-effacing.”

Godelieva was preoccupied with the idea that she would replicate her parents’ mistakes with her own children. She married when she was twenty-three, and had two children. But the marriage was tumultuous and ended in divorce, in 1979, when her son was three and her daughter was seven. Two years later, their father, Hendrik Mortier, a radiologist, committed suicide. As a single parent, Godelieva was overwhelmed. In a diary entry from 1990, when her children were teen-agers, she instructed herself to “let my children be themselves, respect them in their individuality.” But she found herself fighting with her daughter, who was independent and emotionally distant, and depending on her son, Tom, a “victim of my instability,” she wrote. She worried, she told her psychologist, that her children were “now paying for all that has happened generations earlier.”

The happiest time in Godelieva’s life began when she was in her early fifties and had a new boyfriend. She felt as if she had finally moved beyond the dramas of her childhood, an achievement for which she credited her new psychiatrist. “He opens the wound completely, cleans it thoroughly and closes it so it can heal,” she wrote to a friend. Godelieva, who had blond hair and a wistful smile, made many friends during these years. “She was the most beautiful woman,” Tom told me. “People would say to me, ‘Oh, I could fall in love with your mother.’” Christiane Geuens, a close friend, said, “People always wanted to know her. When she walked into a room, everyone knew.”

Godelieva was delighted when Tom and his wife had a child, in 2005. She promised that she would make up for her failures as a mother by being an attentive grandmother. In photographs, she is physically affectionate with Tom’s daughter, holding her as she brushes her teeth, or sitting on the bed with her, braiding her hair.

Then, in 2010, her boyfriend broke up with her, and she felt black again. She stopped wearing makeup and doing her hair, and she cancelled dates with friends, she said, because she felt ugly and old. She felt that she had lost her *levensperspectief*, a Dutch

word that refers to the sense that there is something to live for. Tom was only thirty minutes away, but she no longer had the energy to drive to his house. She accused Tom of being insufficiently sympathetic, and Tom, who had just had a second child, blamed her for abandoning him and his family. After several months of fights, they stopped speaking. In her diary, she wrote, “I don’t think there can be fruitful contact with the children with all his aggression toward me.” Tom’s sister, a lawyer who does human-rights work in Africa, also avoided her; she found it too painful to be sucked back into her mother’s depression, which had dominated her childhood. (She has asked not to be named.)

Godelieva felt as if her emotional progress had been an illusion. She had seen the same psychiatrist for more than ten years and had consulted him on every decision, even those involving financial investments and home renovations, but she had now lost faith in his judgment. She complained to friends, “I give him ninety euros, he gives me a prescription, and after ten minutes it’s over.” Her psychiatrist acknowledged that there was no cure for her condition; the best he could do, he said, was listen to her and prescribe antidepressants, as he had been doing for years.

In the summer of 2011, when she was sixty-three, Godelieva met a new doctor. She attended a lecture by Wim Distelmans, an oncologist and a professor of palliative medicine at the Free University of Brussels. Distelmans was one of the leading proponents of a 2002 law in Belgium that permits euthanasia for patients who have an incurable illness that causes them unbearable physical or mental suffering. Since then, he has euthanized more than a hundred patients. Distelmans, who wears leather coats and boots and artfully tossed scarves, has become a celebrity in Belgium for promoting a dignified death as a human right, a “tremendous liberation,” and he gives talks at cultural centers, hospitals, and schools around the country.

In September, 2011, Godelieva saw Distelmans at his clinic. Four months later, she sent an e-mail to her children: “I have filed a euthanasia request with Prof. Distelmans based on psychological distress. I have gone through the entire procedure and am now waiting for the result.”

*“Hey—you can actually bear the ocean better if you put the shell down.”*

Tom and his wife had just had their third child. They both taught chemistry at Leuven University College, part of the oldest university in Belgium. When Tom received his mother's e-mail, he showed it to his supervisor, Lies Verdonck, a doctor who was familiar with Distelmans's work, and asked her what to do. She said there was no way that Distelmans would approve the euthanasia request without first speaking with the patient's family. "Stay focussed on your job and your children," she urged Tom.

At the time, Tom was in the process of searching for a nursing home for Godelieva's mother, from whom Godelieva was estranged. He was angry that the task had fallen to him, and felt that his mother was being manipulative. She had expressed suicidal thoughts before, and they'd passed, so he decided not to respond to the e-mail. His sister, who was in Africa, replied that she would respect her mother's decision, but that it hurt her.

On April 20, 2012, three months after Godelieva sent the e-mail, Tom received a short letter from his mother that was written in the past tense. She reported that her euthanasia had been carried out on April 19th, at the university hospital of the Free University of Brussels. "I donated my body to science," she wrote. On the back of the letter, she'd left the phone number of a friend who had the keys to her house.

Tom immediately drove to the house of the friend, who offered him a drink and then explained that she and her husband had driven Godelieva to the hospital. Tom accused the couple of coöperating with a suicide. They were defensive: they said that it was Godelieva's choice, and they didn't want her to have to take a taxi to the hospital alone. Later, they admitted to Tom that in the car Godelieva was chatting and laughing, and they had begun to wonder if they knew her as well as they'd thought.

Tom felt his mind shutting down. He drove to his mother's house, which he hadn't visited in more than a year. She had just completed an addition to the first floor: before they separated, she and her ex-boyfriend had wanted to grow old in the house without worrying about stairs. The interior of the house was decorated with framed photographs of her grandchildren. Large drawings of Tom and his sister hung on the living-room wall.

In the drawer of Godelieva's bedroom desk, Tom found drafts of several farewell letters that she had written to friends, her neighborhood association, and a chorus that she sang in, as well as a master list with an "X" by each name, as if she were composing thank-you notes after a party. She thanked her friends for their companionship, apologized for causing them pain, and explained that "the loneliness, no chance of a cure after forty years of therapy, nothing to look forward to—all this has led me to see that the only thing remaining is a dignified end of life."

There was also a draft of a long letter to her children, which was far more emotional than the one she had sent. "I have not been able to handle the rift with you, Tom," she wrote. "I have loved you very much but you have not seen it as such." She then addressed her three grandchildren: "I have missed you very much." She also wrote, before crossing it out, "I will not see my grandchildren grow up and that causes me pain."

In his mother's living room, Tom found an article about Distelmans in *De Morgen*, a leading Flemish newspaper, which featured a large photograph of him sitting on a bed, wearing jeans, a patterned shirt, and a silver bangle bracelet. The reporter described Distelmans as a doctor who "cannot stand injustice." Distelmans spoke about his disdain for doctors who assume that they know what their patients need, and told the reporter that the "euthanasia law has such a symbolic value. People have a voice."

Tom also discovered a booklet, produced by LEIF (Life End Information Forum), an organization founded by Distelmans, that outlined the medical and legal options available to people who are dying or want to die. On the final page, the authors introduced an excerpt from "Utopia," by Thomas More, who describes a world in which "officially sanctioned euthanasia is regarded as an honorable death." In More's ideal society, government officials and priests visit suffering invalids and say, "Why don't you break out and escape to a better world?"

**I**n Belgium, euthanasia is embraced as an emblem of enlightenment and progress, a sign that the country has extricated itself from its Catholic, patriarchal roots. Distelmans, who was brought up as a Catholic and then rejected the Church, told me

that his work is inspired by an aversion to all forms of paternalism. “Who am I to convince patients that they have to suffer longer than they want?” he said.

Belgium was the second country in the world, after the Netherlands, to decriminalize euthanasia; it was followed by Luxembourg, in 2009, and, this year, by Canada and Colombia. Switzerland has allowed assisted suicide since 1942. The United States Supreme Court has recognized that citizens have legitimate concerns about prolonged deaths in institutional settings, but in 1997 it ruled that death is not a constitutionally protected right, leaving questions about assisted suicide to be resolved by each state. Within months of the ruling, Oregon passed a law that allows doctors to prescribe lethal drugs for patients who have less than six months to live. In 2008, Washington adopted a similar law; Montana decriminalized assisted suicide the year after; and Vermont legalized it in 2013.

*“You boys who have to take your medications with food, now’s the time.”*

The right-to-die movement has gained momentum at a time of anxiety about the graying of the population; people who are older than sixty-five represent the fastest-growing demographic in the United States, Canada, and much of Europe. But the laws seem to be motivated less by the desires of the elderly than by the concerns of a younger generation, whose members derive comfort from the knowledge that they can control the end of their lives. Diane Meier, a professor of geriatrics at Mount Sinai School of Medicine, in New York, and one of the leading palliative-care physicians in the country, told me that “the movement to legalize assisted suicide is driven by the ‘worried well,’ by people who are terrified of the unknown and want to take back control.” She added, “That is not to say that the medical profession doesn’t do a horrible job of protecting people from preventable suffering.” Like most doctors who specialize in palliative care, a field focussed on quality of life for patients with severe and terminal illnesses, she thinks legalizing assisted suicide is unnecessary. “The notion that if people don’t kill themselves they’re going to die on a ventilator in the hospital would be humorous if it weren’t so serious,” she said. She believes that the angst propelling the movement would be diminished if patients had greater access to palliative care and if doctors were more attentive to their patients’ psychological suffering.

In Oregon and Switzerland, studies have shown that people who request death are less motivated by physical pain than by the desire to remain autonomous. This pattern of reasoning was exemplified by Brittany Maynard, a twenty-nine-year-old newlywed who moved to Oregon last year so that she could die on her own terms rather than allowing her brain cancer to take its course. Her story appeared on the cover of *People*, which described her as having the “soul of an adventurer and the heart of a warrior.” She became the poster child for assisted death—a far more palatable one than Jack Kevorkian, who had previously filled that role. Unlike the patients whom Kevorkian attended to with his makeshift “suicide machine,” Maynard appeared neither passive nor vulnerable. Since her death, seven months ago, lawmakers in twenty-three U.S. states have introduced bills that would make it legal for doctors to help people die.

Opponents have warned for years that legalization will lead to a “slippery slope,” but in Oregon fewer than nine hundred people have used lethal prescriptions since the law was passed, and they represent the demographic that is least likely to be coerced: they are overwhelmingly white, educated, and well-off. In Belgium and in the Netherlands, where patients can be euthanized even if they do not have a terminal illness, the laws seem to have permeated the medical establishment more deeply than elsewhere, perhaps because of the central role granted to doctors: in the majority of cases, it is the doctor, not the patient, who commits the final act. In the past five years, the number of euthanasia and assisted-suicide deaths in the Netherlands has doubled, and in Belgium it has increased by more than a hundred and fifty per cent. Although most of the Belgian patients had cancer, people have also been euthanized because they had autism, anorexia, borderline personality disorder, chronic-fatigue syndrome, partial paralysis, blindness coupled with deafness, and manic depression. In 2013, Wim Distelmans euthanized a forty-four-year-old transgender man, Nathan Verhelst, because Verhelst was devastated by the failure of his sex-change surgeries; he said that he felt like a monster when he looked in the mirror. “Farewell, everybody,” Verhelst said from his hospital bed, seconds before receiving a lethal injection.

The laws seem to have created a new conception of suicide as a medical treatment, stripped of its tragic dimensions. Patrick Wyffels, a Belgian family doctor, told me that the process of performing euthanasia, which he does eight to ten times a year, is “very magical.” But he sometimes worries about how his own values might influence a

patient's decision to die or to live. "Depending on communication techniques, I might lead a patient one way or the other," he said. In the days before and after the procedure, he finds it difficult to sleep. "You spend seven years studying to be a doctor, and all they do is teach you how to get people well—and then you do the opposite," he told me. "I am afraid of the power that I have in that moment."

**A**lthough doctors in Belgium had been covertly performing euthanasia before it was legalized, the majority of them opposed the euthanasia law, according to a survey conducted at the time. The chairman of Belgium's largest medical association cautioned against making "the exception the rule." But the political composition of the Belgian government had recently shifted; for the first time since the Second World War, secular politicians (liberals, socialists, and the Green Party) had more power than Christian Democrats, who resisted legalization. Peter Backx, the former editor of Belgium's largest medical journal, said that the law seemed like a "bit of political revenge." At the Senate hearings on the law, the phrase "self-determination" was repeated ninety-seven times.

The right to a dignified death is viewed as an accomplishment of secular humanism, one of seven belief systems that are officially recognized by the government. Belgian humanism, which was deeply influenced by the nineteenth-century Freemasonry movement, offered an outlet for those who felt oppressed by the Church, but it has increasingly come to resemble the kind of institution that it once defined itself against. Since 1981, the Belgian government has paid for "humanist counsellors," the secular equivalent of clergy, to provide moral guidance in hospitals, prisons, and the armed forces. Humanist values are also taught in state schools, in a course called non-confessional ethics, which is taken by secular children from first through twelfth grade, while religious students pursue theological studies. The course emphasizes autonomy, free inquiry, democracy, and an ethics based on reason and science, not on revelation. Jan Bernheim, an emeritus professor of medicine at the Free University of Brussels, who studies ethics and quality of life, told me that euthanasia is "part of a philosophy of taking control of one's own existence and improving the objective conditions for happiness. There is an arrow of evolution that goes toward ever more reducing of suffering and maximizing of enjoyment."



The Belgian Council of Ministers appointed Wim Distelmans to serve as the chairman of the Federal Control and Evaluation Commission, which reviews euthanasia deaths to insure that doctors have complied with the law. In terminal cases, two doctors need to confirm that the patient's suffering stems from an incurable illness. For non-terminal cases, three doctors must agree. But doctors have adopted increasingly loose interpretations of disease. Distelmans told me, "We at the commission are confronted more and more with patients who are tired of dealing with a sum of small ailments—they are what we call 'tired of life.'" Although their suffering derives from social concerns as well as from medical ones, Distelmans said that he still considers their pain to be incurable. "If you ask for euthanasia because you are alone, and you are alone because you don't have family to take care of you, we cannot create family," he said.

*"Now what?"*

Last year, thirteen per cent of the Belgians who were euthanized did not have a terminal condition, and roughly three per cent suffered from psychiatric disorders. In Flanders, where the dominant language is Dutch, euthanasia accounts for nearly five per cent of all deaths. (The percentage is lower in the southern, French-speaking parts of Belgium.) The Flemish media have adopted a mostly uncritical approach to euthanasia, running numerous articles about the courage of people who have chosen to die. Last year, *De Standaard*, a prominent Flemish newspaper, published a long tribute to a depressed mother who was euthanized after being abandoned by her boyfriend and becoming disillusioned by her psychiatric care. "I am forever grateful to her that she handled this so well," her twenty-four-year-old son told the paper. "I am so glad we were able to say goodbye in a beautiful way."

The suicide rate in Belgium (excluding cases of euthanasia) is the second-highest in Western Europe, a phenomenon often attributed to the Flemish personality type known as "*binnenvetter*," a person who holds emotions inside. Joris Vandenberghe, a professor of psychiatry at the University of Leuven and a member of the Belgian Advisory Committee on Bioethics, said that he finds euthanasia requests therapeutically useful, because they prompt patients who would not otherwise seek medical help to consult with doctors about their feelings of hopelessness. He said that most of his patients, even those who are approved for euthanasia, end up deciding that they want to live. But he rejects the idea that suicide is always an indication of

pathology. “There’s a whole philosophical history of looking at suicide as a rational choice,” he said. “We, as humans, have the possibility to weigh our own life and decide to end it.”

**T**om believes that everyone is suicidal in at least some small way. In his early twenties, the impulse was strong. “There was a red light constantly flickering above me,” he said. He undertook what he called “aggressive reading”: Dostoyevsky, Antonin Artaud, Freud, Sándor Ferenczi, Tolstoy, Carl Jung. He found himself drawn to theories of suffering. He wanted to know what it was that made one person survive and another give up.

When Tom was twenty-two, he enrolled in graduate school, for chemistry, but instead of studying he researched his father’s suicide. He often took the train to Ghent, where his father had worked, and interviewed his colleagues and friends. Godelieva, following the advice of her psychiatrist at the time, hadn’t told her children how their father died; she said only that he suffered from headaches. Tom and his sister quickly figured it out. Tom began to see his father as a kind of Dorian Gray figure: he had lived extravagantly, seeking pleasure, success, and distraction. He drove a new Mercedes while he owed millions of Belgian francs and was under the threat of legal action. “He could not see himself as he really was,” Tom recalled. He left a suicide note on his bathroom mirror that said, “I am a victim of the shit that exists in the world today.”

In her diary, Godelieva wrote that she couldn’t comprehend why her husband would kill himself. But at other times she felt that she understood perfectly—“I am just like him,” she wrote—but she said that, for the sake of the children, she could never do the same. Neither Tom nor his sister thought that she would have killed herself on her own. She was passive, dependent, and averse to risk. She didn’t like to make a mess. Most of all, she trusted her doctors’ authority. Distelmans was the last in a series of charismatic and accomplished doctors whose theories she had revered. After finding strength in their guidance, she eventually became disillusioned by each treatment. “I can still hardly believe how many amateurs are walking around in this medical field,” she wrote to a friend in the late nineties, after giving up on another therapist.

When Tom read his mother's daily planner, he saw that she had met with Distelmans at least six times in the past eight months. Seven weeks before her death, she donated twenty-five hundred euros to LEIF, the organization that Distelmans had founded. On the bank-transfer form she had written, "Thanks to the staff at LEIF."

Until Godelieva's death, Tom had never given much thought to euthanasia, though he was vaguely in favor of it. "Distelmans was just a voice I heard on the radio from time to time," he told me. Tom was brought up as an atheist, and in school he had studied non-confessional ethics. When the euthanasia law was passed, he and his wife, who were in the same graduate program, had recently fallen in love. They assumed that the law was for old people who were already dying.

Now it seemed to Tom that there were few people reflecting critically on the law. Three days after his mother's death, the leading Belgian humanist association named Distelmans one of ten "heroes of self-determination" in the past fifty years, at a celebration for Flemish Heritage Day. When Tom complained to the ombudsman at the hospital of the Free University of Brussels, the ombudsman replied that everything had proceeded according to his mother's "free will." Even Godelieva's friends reserved judgment; few had realized that she suffered from clinical depression. At her memorial service, people skirted the issue. They told one another that you never know how someone is feeling inside, and that "every house has its own cross," an attitude that Tom described as typically Flemish. Tom likes to joke that he must have some secret French roots, because he finds it nearly impossible to contain his feelings.

Godelieva's friend Christiane Geuens told me that she knew that Godelieva was upset about her breakup, but she never imagined that she was considering euthanasia. Less than two weeks before she died, Godelieva had spent all day at Geuens's home. Godelieva lit a fire and then sat on the couch, wrapped in a blanket, and told stories. The only indication that something was off was the movie she decided to watch. She wanted to see "Sophie's Choice." She had already seen the movie and read the book, and afterward she went on about her identification with Sophie, who was so burdened by her past that she committed suicide. Geuens didn't see how their situations were comparable, but Godelieva said that they were the same.

A week after his mother's death, Tom e-mailed a psychiatrist named Lieve Thienpont, whose name he had seen several times in his mother's daily planner. "May I ask why you approved active euthanasia for my mother and why I was never involved in that decision?" he wrote. Thienpont invited him to meet with her and Distelmans, both of whom are founding members of Ulteam, a clinic for patients who have questions about ending their lives. In the past three years, nine hundred patients have come to Ulteam, half of whom complained that they were suffering psychologically, not physically.

On May 15, 2012, Tom went to Distelmans's clinic, a small brick modernist building in a residential suburb on the outskirts of Brussels. He brought his colleague Steven Bieseeman along for moral support. "I was there to help Tom control his emotions, because he can be quite hot-tempered," Bieseeman, a doctor, told me.

*"Keep your eyes peeled for a place to charge our phones, men."*

They sat at a conference table, and Distelmans explained that he never rushes his decisions. He said that he had urged Godelieva to contact her children, but that she had not wanted to inform them. He asked Tom why he had scheduled the meeting.

"Because you killed my mother," Tom replied.

Distelmans responded calmly that it was Godelieva's "absolute wish" to die.

Tom said that his mother's "absolute wish" was also to be a good grandmother. He had brought some of her papers and letters, and he began reading from the draft of her suicide letter to him and his sister. "I feel frustration and sadness because I have not been able to build a connection," he read. Then he showed them an apology letter that he had written to his mother when he was twenty, after one of many fights. "Forgive me," he read. "You have dealt with the worst. . . . You care about me. I am not living up to your expectations. That hurts. I don't know how to deal with that."

Distelmans was silent. "He was very cool, very distant," Bieseeman said. "He didn't seem to be touched."

When Tom saw that his reading had elicited no response, he pushed his chair back from the table and stood up. Bieseman recalled, “He was screaming, ‘You went along with the madness of my mother! You went along with her tunnel vision, her defeatism. You’ve just taken away the suffering of one person and transposed it to another!’ ”

Distelmans repeated that he was certain that Godelieva had wanted to die, and that this was her right. Then he said that it seemed there was nothing left to discuss. They all stood up and shook hands, and Tom and Bieseman left the clinic.

**D**istelmans told me that he had no doubts about the way he handled Godelieva’s case. He explained that she was “a very nice person, a very warm person,” and that she had “wanted to do one decent thing in her life, and that is to die in a decent way, because the rest of her life was such a horrible mess.” When I asked if he worried about transference—perhaps she had idolized him or depended too much on his opinion—he laughed and said, “I’ve never met a patient who is willing to die to please someone else.”

Thienpont, whose practice is mostly devoted to issues surrounding euthanasia, was similarly confident about the decision to end Godelieva’s life. Since Ulteam opened, in 2011, Thienpont said it has been “overrun by psychiatric patients”—a phenomenon that she attributes to the poor quality of psychiatric care in the country. In Belgium, it is not uncommon for patients to live in psychiatric institutions for years. Outpatient care is minimal, poorly funded, and fragmented, as it is in most countries. In a new book, called “Libera Me,” Thienpont urges doctors to accept the limits of psychiatry, and argues that some patients live with so much pain, their thoughts unceasingly directed toward death, that their mental illnesses should be considered “terminal.” Before approving a euthanasia request, she does not require patients to try procedures that they think are invasive. Godelieva had never had electroconvulsive therapy, though it is effective for about half of patients with depression. “Sometimes it really is too late,” Thienpont told me. “If the patient’s energy is gone, then it is not humane to say, ‘Well, maybe if you go to a hospital that specializes in your problem for two more years it will help.’ I think we have to respect when people say, ‘No—that is enough.’ ”

Euthanasia for psychiatric patients was rare in the early years of the law, but patients complained that they were being unfairly stigmatized: psychic suffering, they argued, was just as unbearable as physical pain. Like cancer patients, they were subjected to futile treatments that diminished their quality of life. Dirk De Wachter, a professor of psychiatry at the University of Leuven and the president of the ethics commission for the university's psychiatric center, said that he reconsidered his opposition to euthanasia after a patient whose request he had rejected committed suicide. In 2004, she set up a camera in front of a newspaper office in Antwerp and set herself on fire.

De Wachter believes that the country's approach to suicide reflects a crisis of nihilism created by the rapid secularization of Flemish culture in the past thirty years.

Euthanasia became a humanist solution to a humanist dilemma. "What is life worth when there is no God?" he said. "What is life worth when I am not successful?" He said that he has repeatedly been confronted by patients who tell him, "I am an autonomous decision-maker. I can decide how long I live. When I think my life is not worth living anymore, I must decide." He recently approved the euthanasia of a twenty-five-year-old woman with borderline personality disorder who did not "suffer from depression in the psychiatric sense of the word," he said. "It was more existential; it was impossible for her to have a goal in this life." He said that her parents "came to my office, got on their knees, and begged me, 'Please, help our daughter to die.' "

De Wachter told me, "I don't want to kill people—I don't think psychiatrists should kill people—but when the suffering is so extreme we cannot look the other way." When he gives lectures, he tries to appeal to Christian audiences by saying, "If Jesus were here, I think he would help these people."

René Stockman, the director of a Catholic organization, Brothers of Charity, which says that it runs a third of the psychiatric institutions in Belgium, told me, "They are using our Christian vocabulary in a new context. They say they are 'saving' people from their bad lives, through 'mercy' and 'compassion.' I cannot accept that." He sees euthanasia as a failure of both psychiatry and medical education. "Any questions about ethics—they say, 'Oh, we need a specialist for that.' They are not learning to reflect morally on what they are doing."

*"That was Swanson, sir. He wasn't on the list, but I'll add him."*

**JUNE 2, 2003**

**I**n the months after his mother's death, Tom searched online for criticism of the Belgian approach to euthanasia, but it seemed to take only two forms: objections from Catholics, who argued that life is sacred and only God should end it, and from Holocaust survivors and their descendants, who were disturbed to see doctors delving into the business of judging whether certain lives were worth living. Although the latter concern blurs a fundamental distinction—under the Nazis, the sick and the disabled never asked to die—it was exacerbated by the fact that Distelmans led seventy medical professionals and scholars on a “study trip” to Auschwitz last year. A brochure for the trip explained that for those who are “constantly confronted with existential pain and questions about the meaning of life” Auschwitz is an “inspiring place to contemplate these issues.”

In October, 2012, Tom compiled a list of thirty Belgian physicians and academics who had publicly questioned the law and sent them a long e-mail about his mother's death. “The fact that W. Distelmans has euthanized my mother without contacting me or my sister keeps festering,” he wrote. “It is difficult for me to grasp that right now there is no public basis and political support to combat these absurd practices.”

Herman De Dijn, a Spinoza scholar, responded. He cautioned Tom that the Belgian media would not be receptive to his opinion. De Dijn, an emeritus professor of philosophy at the University of Leuven, said that Godelieva's story sounded like “utopia realized: everything is neat and clean and terrible.” He was troubled by the way that his colleagues' theories about autonomy seemed to have stiffened into ideology, a mentality that the euthanasia law both reflected and encouraged. “Once the law is there, you have people asking themselves new questions,” he told me. “Do I really have quality of life? Am I not a burden on others?” He believed that “human dignity should include not only respect for personal choices but also for connectedness to loved ones and society.” He worried that the concept had been “reduced to the ability to have certain experiences.”

Emboldened by De Dijn's response, Tom wrote an essay that built on his theories. The seed for the essay was a notice for a lecture, called “On the Sofa with Wim

Distelmans,” that he saw on the Web site of a youth organization. Over pastries and coffee, Distelmans would discuss euthanasia with teen-agers. Tom sent a version of the essay, originally titled “Euthanasia on the Sofa,” to Flanders’s leading newspaper and magazine, both of which rejected it. Eventually, it was published in *Artsenkrant*, a magazine for physicians. “I am afraid that the notion of ‘free will’ has become dogma, behind which it is easy to hide,” he wrote. “Wouldn’t it be better to invest in mental health and palliative care?”

The Flemish newspaper *De Morgen* picked up the story and ran an article summarizing Tom’s complaints. Two days later, Jacinta De Roeck, one of three senators who sponsored the euthanasia law and the director of Belgium’s Liberal-Humanist Association, published an op-ed in the paper, asserting that there had been no abuses of the law since it was passed, ten years earlier. “Fortunately our society has started to understand that there can be mental suffering that is unbearable, and cannot in any way be lessened,” she wrote. “Sometimes a patient sees only one possible solution: euthanasia, within the perfectly drawn lines of the law. No one has the right to disapprove of this choice.”

The next week, Tony Van Loon, a professor of moral sciences at the Free University of Brussels, who is Thienpont’s longtime partner, wrote an article in *De Morgen* titled “The Right to Self-Determination Is the Ultimate Answer.” Van Loon, who works with Ulteam, alluded to Godelieva’s case by describing her as “a mother who says her suffering is unbearable, in part because of the troubled relationship with her son.” He said that the patients at Ulteam had been ignored and silenced by other doctors. “May they be allowed to die like human beings?” he wrote. “Or must they wait until they are nothing more than a corpse so that their next of kin can comfort themselves with their remains?”

**I**n the summer of 2013, Tom asked a doctor named Georges Casteur to inspect his mother’s medical records. Casteur, the former president of the provincial council of the doctors of West Flanders, had performed euthanasia several times in his career, but he believed that it should be used only for patients who are close to death. “There’s a great difference between helping people who are already dying and helping people to die,” he told me. He didn’t understand why physicians were framing the latter as a



patient's right. "My colleagues are so against paternalism that they say, 'You want to die? O.K., I'll kill you.'"

Casteur reviewed Godelieva's medical file at Distelmans's clinic, with Distelmans sitting beside him. Casteur says that he learned that Godelieva had struggled to find three doctors who would say that she had an incurable illness, as the law required. One psychiatrist wrote that her desire for euthanasia was "not mature," because she had "ups and downs." According to Casteur, a second concluded that she could still be helped; the psychiatrist observed that when Godelieva discussed her grandchildren she became emotional and expressed doubts about her decision to die. In addition to Thienpont, Distelmans consulted Godelieva's former therapist, who wrote that, "after recent rejection by her latest partner and by her children, her psychiatric issues will not improve." Two weeks before Godelieva's death, Distelmans asked if he could call her children, but she refused. "It would not change her decision anyway," Distelmans wrote. She died with three photographs in her pocket: a picture of her holding Tom on her lap when he was a baby, a picture of her feeding one of Tom's young daughters ice cream, and a photograph of her and her daughter walking together through a field.

Based on Casteur's notes, Tom submitted a complaint with the Belgian Order of Physicians and the public prosecutor of Brussels, alleging that Godelieva's condition had not been incurable. A reunion with her children and her grandchildren, he argued, might have alleviated the loneliness that was at the core of her suffering.

When a Dutch news service reported on Tom's complaint, Tom found himself reading all the comments online. People accused him of using Distelmans as a scapegoat, of placing his own needs before his mother's, of not understanding the law, of being secretly Catholic. Then he saw a comment by a woman named Margot Vandevenne. "To those who reacted in such a way: you have no idea how it is to experience something like that!" she wrote. "This is an unbearable pain that you can only know when you have experienced this YOURSELF." In a second comment, she wrote that Distelmans "euthanized my mother half a year ago because of depression, and I wasn't told until a day after her death, and not even by the doctor."

*"It's not a possibility now, but when the kids are grown Sam and I figure we'll have time for a divorce."*

**DECEMBER 6, 2004**

Vandevenne, who was nineteen and had a young son, had filed a criminal complaint against Distelmans, but she worried that nothing would come of it. The investigative process is confidential, and, in the past thirteen years, no case has been referred for prosecution. Tom encouraged Vandevenne to file a complaint with the Order of Physicians and offered to help her write it. Her mother, who was fifty-four when she died, had been mourning the recent deaths of both of her parents and suffered from depression, unexplained pain, and an inability to “find a meaningful purpose in her life,” as one doctor wrote. On March 8, 2014, Margot sent the Order of Physicians a letter protesting the circumstances of her mother’s death. “My son and I have not even had the chance to say goodbye to my mother,” she wrote. “I wonder every day whether I would have been able to change her mind if I had been informed.”

Less than a week later, the philosopher Etienne Vermeersch, the former president of the Belgian Advisory Committee on Bioethics, wrote an editorial in *De Morgen* accusing Tom and others of conducting a “smear campaign.” “They are filing complaints with the Order of Physicians and with the court in order to frighten generous doctors with the spectre of prosecution,” he wrote. “If this disastrous strategy succeeded, hundreds of people in extreme need would once again no longer be helped.” He wrote that Belgium “stands, ethically, at the top of the world.” He republished the editorial on a Web site and urged anyone who objected to the recent criticism to sign a petition. More than seven thousand people did, including senators and representatives, the country’s minister of social affairs and health, the former mayor of Antwerp, academics, artists, actors, journalists, novelists, sports figures, and doctors from Ulteam.

Vermeersch, who is eighty-one and was recently voted the most influential intellectual in Flanders, was one of the country’s earliest proponents of euthanasia, and he sees the law as his progeny. Last year, he successfully campaigned for legislation that made children with incurable illnesses eligible for euthanasia, and he, along with several politicians, is now working to expand the law so that people with dementia can be euthanized, provided they articulate their wishes in advance. When I met him at his home, a spectacularly messy house, with piles of boxes blocking the view out his windows, he told me that he did not think Godelieva’s case was particularly complex; he said that he’d seen cases that were more “delicate.” He described a couple who came

to him for guidance after their bipolar daughter had been euthanized. They were sure that if she had waited a few months her pessimism would have lifted. Of this case, Vermeersch said, “I see that there is a problem, but you also have to look at the two sides.”

Vermeersch seemed to refer to death as an option that had upsides and downsides, like any other choice, and I mentioned that it appeared that a lot of people in Belgium were less afraid of death than I was.

Vermeersch looked at me as if he were recalculating my age downward. “How can you be afraid of nothing?” he said. “Nothing can do you no harm.”

I said, “I’m afraid of not existing.”

“Millions and billions of years you did not exist—what was the problem?”

“But now I’ve formed relationships,” I said.

“After death, your relationships are finished,” he said brightly. “You are in the state you were before conception.”

**T**om likes to joke that he has “seven thousand enemies,” the people who signed Vermeersch’s petition. He refers to his insecurity complex so often that it seems to have taken on a concrete existence of its own. He alternates between denouncing the leading philosophers in Belgium and feeling ashamed of the idea that he would judge anyone. “I don’t want to get trapped in a situation where I feel that I am worth something,” he told me.

Vermeersch’s petition gained Tom some notoriety, and people began introducing him to others who had become disenchanted by aspects of the law. Recently, he began corresponding with the daughter of Lily Boeykens, the country’s most prominent feminist, who asked for euthanasia because she showed preliminary signs of Alzheimer’s. After two doctors rejected her request—she was still living on her own,

giving interviews, and throwing dinner parties—Boeykens, who was seventy-four, found a neurologist at the University of Antwerp, Peter De Deyn, who agreed to euthanize her. She told the doctor, who studied Alzheimer's, that she would give him her brain for his research. In an audiotaped conversation, she explained to her daughter that “De Deyn will keep the part of my body that he needs.”

On the morning on which the euthanasia was scheduled, Boeykens's daughter, Kerstin, said that she called De Deyn, crying, and begged him to move her mother's 9 A.M. appointment a few hours later, so that she would have time to drop her children off at school and then drive to the clinic. But De Deyn said that he was booked for the rest of the day. (De Deyn denies that this happened.) Records show that Boeykens died at 9:20 A.M., at which point De Deyn removed her brain and performed an autopsy. Kerstin filed a complaint with the Belgian Order of Physicians, writing that “my mother and Dr. P. P. De Deyn made a deal: brains in exchange for assistance with suicide.”

De Deyn, who has euthanized thirty patients suffering from dementia, maintained that the euthanasia date had been determined before they discussed the donation of Boeykens's brain. He dismissed Kerstin's account, telling me that she was a psychiatric patient—the same thing that Distelmans said about Tom when discounting his complaints. (Kerstin said that she has no history of psychiatric treatment, a fact that her primary-care doctor confirmed.) The chairman of the Belgian Order of Physicians told Kerstin that she would not be informed of the consequences of her complaint because the process was secret. “I am pro-euthanasia—I don't want to get rid of it,” she told me. “I just want to shut down these cowboys. They're a clique; they protect each other.”

Last fall, Tom filed a complaint with the European Court of Human Rights, arguing that the law in Belgium lacked safeguards to prevent abuse. His complaint referred to a recent study in the *British Medical Journal*, which found that only half of euthanasia cases in Flanders had been reported to the Federal Control and Evaluation Commission. There were no repercussions for failing to report euthanasia deaths to the commission, a situation likely aided by the fact that nearly half of the sixteen members on the commission are affiliated with right-to-die associations.

**OCTOBER 28, 2013**

Tom felt so aggrieved by Distelmans's prominence that he tried not to talk about him while driving. Each time Distelmans received a prize or a grant—and there have been many—Tom took it as a personal insult. His anger at his mother was channelled toward her doctor, who seemed to be everywhere. Last spring, Tom was reviewing his eight-year-old daughter's journal for school, as he does every night, when he saw in the pages a flyer with Distelmans's face on it. "Euthanasia lecture: With Wim Distelmans," it said. It had been put there by his daughter's non-confessional-ethics teacher, who is also the chair of the local humanist chapter. Tom and his wife e-mailed the school's principal to complain that the ethics teacher was promoting a lecture by the doctor who had euthanized the grandmother of one of her pupils. The principal apologized for causing discomfort but explained that the "flyer has only an informative character which gives parents the opportunity to get informed about this contemporary humanist subject." She wrote that the subject of euthanasia was in keeping with the curriculum, but she said that she would advise teachers not to discuss it until after the second grade.

Tom thought about pulling his daughter out of non-confessional ethics but decided not to, because it wouldn't make sense for her to study Catholicism—the other class offered during that period—and he didn't want her to have to sit alone for two hours every week. She was popular, and he didn't want her to feel like an outsider. His wife, who has an aura of quiet competence, had managed to keep their domestic life remarkably regular in the years since Godelieva's death. They live in a suburb of Leuven, in a clean, bright, square house that they designed themselves; when they were shopping for architectural models, the word they kept repeating was "practical." Tom's tone of voice shifts when he talks about his children. He seems suddenly light.

At times, Tom appeared almost bewildered by his stability—a fulfilling job, a loving marriage, three healthy children. He assumed that at some point he must have decided to live, a choice that still surprises him. He attributed it to some sort of primitive drive to know how things would turn out. "I wanted to see if I was capable of becoming someone," he said, before adding that he still doesn't know. When he becomes depressed or dramatic, his wife tells him to think of their children, and says, "You have no choice but to continue," a phrase that Tom repeats often.

O n one of my last days in Belgium, Tom took me to meet his grandmother, whose flaw Godelieva had described so relentlessly that Tom had trouble seeing her as a person in her own right. Tom had always felt a little wary of her, but his grandmother had been a steady presence in his life, and he had come to appreciate that. Tom visits her about once a month, for half an hour, until they run out of things to say.

As soon as we arrived, Tom spotted her walking down the hallway toward the cafeteria. She was dressed like a schoolgirl, in a long skirt, a maroon cardigan, and a starched white shirt buttoned to the base of her neck. Her excitement at seeing her grandson was mild. She nodded, smiled timidly, and led us upstairs to her room.

She sat on a cushioned chair, her ankles crossed, while Tom opened her cabinet and took out an antique box of photographs, most of which had been taken at the farm where she had grown up and spent most of her life. “Good pictures, Oma,” he said as he shuffled through several piles, searching for older photographs. He finally found what he wanted: photographs of British soldiers who had recuperated at the farm after the Second World War. His grandmother had fallen in love with one of the soldiers, and they had planned to marry. But, at the last minute, to please her parents, she married Tom’s grandfather instead.

Years later, his grandmother searched for the soldier, and, when they were in their seventies, after the deaths of their spouses, they reunited. “They had one romantic summer before he died,” Tom told me. He showed me a picture of his grandmother and the veteran standing in front of the farm, holding hands and beaming.

I said that it was a very nice picture.

“Yeah, but it destroyed everything,” Tom said, explaining that his grandmother had spent fifty years married to a man she didn’t love. He repeated a phrase that his mother had written several times in her diary: “You can feel whatever you want on the inside, but never let it show on the outside.”

After we left, Tom explained that his mother had always said that she wasn’t “conceived out of love.” At the thought, he seemed to soften toward her. “She really had a tough

time,” he said. “She was in pain—I’m not going to say anything different.”

He began speaking about how traumas are passed from one generation to the next, and how suicides, perhaps more than any other death, reverberate through a family. It was an idea that we’d discussed many times, and, when I didn’t immediately respond, he seemed to tire of it. “Well, it is what it is,” he said. “We have to continue. People will always start over.” ♦

*Rachel Aviv is a staff writer. She won the 2016 Scripps Howard Award for “Your Son Is Deceased,” her story on police shootings, which appeared in the magazine last year.*

**MORE: MEDICINE BELGIUM**

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