



By Stephanie Nolen

Stephanie Nolen is examining medically assisted death around the world. She reported this article from Amsterdam, Groningen and Castricum, the Netherlands.

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Soon, Irene Mekel will need to pick the day she dies.

She's not in any hurry: She quite likes her life, in a trim, airy house in Castricum, a Dutch village by the sea. She has flowers growing in her back garden, and there is a street market nearby where vendors greet villagers by name. But if her life is going to end the way she wants, she will have to pick a date, sooner than she might like.

"It's a tragedy," she said.

Ms. Mekel, 82, has Alzheimer's disease. It was diagnosed a year ago. She knows her cognitive function is slowly declining, and she knows what is coming. She spent years working as a nurse, and she cared for her sister, who had vascular dementia. For now, she is managing, with help from her three children and a big screen in the corner of the living room that they update remotely to remind her of the date and any appointments.

In the not-so-distant future, it will no longer be safe for her to stay at home alone. She had a bad fall and broke her elbow in August. She does not feel she can live with her children, who are busy with careers and children of their own. She is determined that she will never move to a nursing home, which she considers an intolerable loss of dignity. As a Dutch citizen, she is entitled by law to request that a doctor help her end her life when she reaches a point of unbearable suffering. And so she has applied for a medically assisted death.

In 2023, shortly before her diagnosis, Ms. Mekel joined a workshop organized by the Dutch Association for Voluntary End of Life. There, she learned how to draft an advance request document that would lay out her wishes, including the conditions under which she would request what is called euthanasia in the Netherlands. She decided it would be when she could not recognize her children and grandchildren, hold a conversation or live in her own home.

But when Ms. Mekel's family doctor read the advance directive, she said that while she supported euthanasia, she could not provide it. She will not do it for someone who has by definition lost the capacity to consent.





Flowers on Ms. Mekel's sill. Ms. Mekel's diary, which she writes in every day, on her writing desk. Credit...Melissa Schriek for The New York Times

A rapidly growing number of countries around the world, from Ecuador to Germany, are legalizing medical assistance in dying. But in most of those countries, the procedure is available only to people with terminal illness.

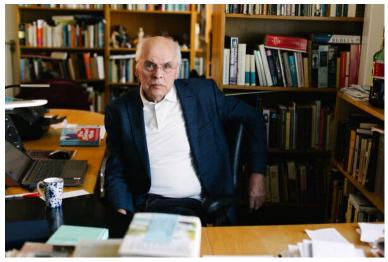
The Netherlands is one of just four countries (plus the Canadian province of Quebec) that permit medically assisted death by advance request for people with dementia. But the idea is gaining support in other countries, as populations age and medical interventions mean more people live long enough to experience cognitive decline.

The Dutch public strongly supports the right to an assisted death for people with dementia. Yet most Dutch doctors refuse to provide it. They find that the moral burden of ending the life of someone who no longer has the cognitive capacity to confirm their wishes is too weighty to bear.

Ms. Mekel's doctor referred her to the Euthanasia Expertise Center, in The Hague, an organization that trains doctors and nurses to provide euthanasia within the parameters of Dutch law and connects patients with a medical team that will investigate a request and provide assisted death to eligible patients in cases where their own doctors won't. But even these doctors are reluctant to act after a person has lost mental capacity.

Last year, a doctor and a nurse from the center came every three months to meet with Ms. Mekel over tea. Ostensibly, they came to discuss her wishes for the end of her life. But Ms. Mekel knew they were really monitoring how quickly her mental faculties had declined. It might seem like a tea party, she said, "but I see them watching me."

Dr. Bert Keizer is alert for a very particular moment: It is known as "five to 12" — five minutes to midnight. Doctors, patients and their caregivers engage in a delicate negotiation to time death for the last moment before a person loses that capacity to clearly state a rational wish to die. He will fulfill Ms. Mekel's request to end her life only while she still is fully aware of what she is asking. They must act before dementia has tricked her, as it has so many of his other patients, into thinking her mind is just fine.



Dr. Bert Keizer, who will fulfill Ms. Mekel's request to end her life only if she still is fully aware of what she is asking. Credit...Melissa Schriek for The New York Times

"This balance is something so hard to discover," he said, "because you as a doctor and she as your patient, neither of you quite knows what the prognosis is, how things will develop — and so the harrowing aspect of this whole thing is looking for the right time for the horrible thing."

Ms. Mekel finds this negotiation deeply frustrating: The process does not allow for the idea that simply having to accept care can be considered a form of suffering, that worrying about what lies ahead is suffering, that loss of dignity is suffering. Whose assessment should carry more weight, she asks: current Irene Mekel, who sees loss of autonomy as unbearable, or future Irene, with advanced dementia, who is no longer unhappy, or can no longer convey that she's unhappy, if someone must feed and dress her.

More than 500,000 of the 18 million people in the Netherlands have advance request documents like hers on file with their family doctors, explicitly laying out their wishes for physician-assisted death should they decline cognitively to a point they identify as intolerable. Most assume that an advance request will allow them to progress into dementia and have their spouses, children or caregivers choose the moment when their lives should end.

Yet of the 9,000 physician-assisted deaths in the Netherlands each year, just six or seven are for people who have lost mental capacity. The overwhelming majority are for people with terminal illnesses, mostly cancer, with a smaller number for people who have other nonterminal conditions that cause acute suffering — such as neurodegenerative disease or intractable depression.

Physicians, who were the primary drivers of the creation of the Dutch assisted dying law — not Parliament, or a constitutional court case, as in most other countries where the procedure is legal — have strong views about what they will and will not do. "Five to 12" is the pragmatic compromise that has emerged in the 23 years since the criminal code was amended to permit physicians to end lives in situations of "unbearable and irremediable suffering."



Ms. Mekel with her son Melchior. Credit...Melissa Schriek for The New York Times

## A Shock

Ms. Mekel, petite and brisk, had suspected for some time before she received a diagnosis that she had Alzheimer's. There were small, disquieting signs, and then one big one, when she took a taxi home one day and could not recognize a single house on the street where she had lived for 45 years, could not identify her own front door.

At that point, she knew it was time to start making plans.

She and her best friend, Jean, talked often about how they dreaded the idea of a nursing home, of needing someone to dress them, get them out of bed in the morning, of having their worlds shrink to a sunroom at the end of a ward.

"When you lose your own will, and you are no longer independent — for me, that's my nightmare," she said. "I would kill myself, I think."

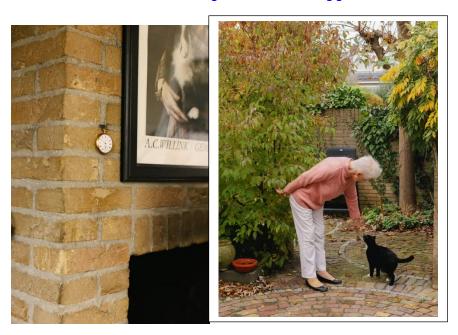
She knows how cognition can slip away almost imperceptibly, like mist over a garden on a spring morning. But the news that she would need to ask Dr. Keizer to end her life before such losses happened came as a shock.



Stephanie Nolen

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Learn more about how Stephanie Nolen approaches her work.



A clock on Ms. Mekel's living room wall. A neighbor's cat in her garden. Credit...Melissa Schriek for The New York Times

Dr. Pieter Stigter, a geriatric specialist who works in nursing homes and also as a consultant for the Expertise Center, must frequently explain to startled patients that their carefully drawn-up advance directives are basically meaningless.

"The first thing I tell them is, I'm sorry, that's not going to happen," he said. "Assisted dying while mentally incompetent, it's not going to happen. So now we're going to talk about how we're going to avoid getting there."

Patients who have cared for their own parents with dementia may specify in their advance directive that they do not wish to reach the point of being bedridden, incontinent or unable to feed themselves. "But still then, if someone is accepting it, patiently smiling, it's going to be very hard to be convinced in that moment that even though someone described it in an earlier stage, that in that moment it is unbearable suffering," Dr. Stigter said.

The first line people write in a directive is always, "If I get to the point I do not recognize my children," he said. "But what is recognition? Is it knowing someone's name, or is it having a big smile when someone enters your room?"

Five-to-12 makes the burden being placed on physicians morally tolerable.

"As a doctor, you are the one who has to do it," said Dr. Stigter, a warm and wiry 44-year-old. "I'm the one doing it. It has to feel good for me."

Conversations about advance requests for assisted death in the Netherlands are shadowed by what many people who work in this field refer to, with a wince, as "the coffee case."

In 2016, a doctor who provided an assisted death to a 74-year-old woman with dementia was charged with violating the euthanasia law. The woman had written an advance directive four years earlier, saying she wished to die before she needed to enter a care home. On the day her family chose, her doctor gave her a sedative in coffee, and then injected a stronger dose. But during the administration of the medication that would stop her heart, the woman awoke and resisted. Her husband and children had to hold her down so the doctor could complete the procedure.

The doctor was acquitted in 2019. The judge said the patient's advance request was sufficient basis for the doctor to act. But the public recoil at the idea of the woman's family holding her down while she died redoubled the determination of Dutch doctors to avoid such a situation.



Dr. Pieter Stigter in the garden of the Euthanasia Expertise Center in The Hague. Credit...Melissa Schriek for The New York Times

## A Day Too Late

Dr. Stigter never takes on a case assuming he will provide an assisted death. Cognitive decline is a fluid thing, he said, and so is a person's sense of what is tolerable.

"The goal is an outcome that reflects what the patient wants — that can evolve all the time," he said. "Someone can say, 'I want euthanasia in the future', but actually when the moment is there, it's different."

Dr. Stigter found himself explaining this to Henk Zuidema a few years ago. Mr. Zuidema, a tile setter, had early-onset Alzheimer's at 57. He was told he would no longer be permitted to drive, and so he would have to stop working and give up his main hobby, driving a vintage motocross bike with friends.

A gruff, stoic family man, Mr. Zuidema was appalled at the idea of no longer providing for his wife or caring for his family, and he told them he would seek a medically assisted death before the disease left him totally dependent.

His own family doctor was not willing to help him die, nor was anyone in her practice, and so his daughter Froukje Zuidema found the Expertise Center. Dr. Stigter was assigned to his case and began driving 30 minutes from his office in the city of Groningen every month to visit Mr. Zuidema at his home in the farming village of Boelenslaan.

"Pieter was very clear: You have to tell me when," Ms. Zuidema said. "And that was very hard, because Dad had to make the decision."

When he grasped that the disease might impair his judgment, and thus cause him to overestimate his mental competence, Mr. Zuidema quickly settled on a plan to die within months. His family was shocked, but for him the trade-off was clear: "Better a year too early than a day too late," he would say.

Dr. Stigter pushed Mr. Zuidema to define what, exactly, his suffering would be. "He would say, 'Why is it so bad to get old like that?" Ms. Zuidema recalled. "'Why is it so bad to go to a nursing home?" She said the doctor would tell her father, "'Your idea of suffering is not the same as mine, so help me understand why this is suffering, for you.'"

Her reticent father struggled to explain, and finally put it in a letter: "I don't want to lose my role as a husband and a father, I do not want to be unable to help people any longer ... Suffering would be if I could no longer be alone with my grandchildren because people did not trust me any longer: even this thought makes me crazy ... Do not be misled by a moment in which I look happy but instead look back at this moment when I am with my wife and children."

The progress of dementia is unpredictable, and Mr. Zuidema did not experience a rapid decline. In the end, Dr. Stigter visited each month for a year and a half, and the two men developed a relationship of trust, Ms. Zuidema said.

Dr. Stigter provided a medically assisted death in September 2022. Mr. Zuidema, then 59, was in a camp bed near the living room window, his wife and children at his side. His daughter said she sees Dr. Stigter "as a real hero." She has no doubt her father would have died by suicide even sooner, had he not been confident he could receive an assisted death from his doctor.





Henk Zuidema's chair. Froukje and Grietje Zuidema, Henk's daughter and mother, in their garden. Credit...Melissa Schriek for The New York Times

Still, she is wistful about the time they didn't have. If the advance directive had worked as defined in the law — if there had been no fear of missing the moment — her father might have had more months, more time sitting on the vast green lawn between their houses and watching his grandchildren kick a soccer ball, more time with his dog at his feet, more time sitting on a riverbank with his grandson and a lazy fishing line in the water.

"He would have stayed longer," Ms. Zuidema said.

Her sense that her father's death was rushed does not outweigh her gratitude that he had the death he wanted. And her feeling is widely shared among families, according to research by Dr. Agnes van der Heide, a professor of end-of-life care and decision making at Erasmus Medical College, University Medical Center Rotterdam.

"The large majority of the Dutch population feel safe in the hands of the doctor, with regards to euthanasia, and they very much appreciate that the doctor has a significant role there and independently judges whether or not they think that ending of life is justifiable," she said.

For five to 12 to work, doctors should know their patients well and have time to track changes in their cognition. As the public health system in the Netherlands is increasingly strained, and short of family practitioners, that model of care is becoming less common.

Ms. Mekel's physician, Dr. Keizer, said his lengthy visits to patients were possible only because he is mostly retired and not in a hurry. (In addition to his half-time practice, he writes regular op-eds for Dutch newspapers and comments on high-profile cases. He is a bit of an assisted-dying celebrity, and, Ms. Mekel confided, the other older women at the right-to-die workshops were envious when they learned that he had been assigned as her physician.)

Now that he is clear on her wishes, the tea parties are paused; he will resume the visits when her children tell him there has been a significant change in her awareness or ability to function — when they feel that five to 12 is close.



Ms. Mekel in her living room. Credit...Melissa Schriek for The New York Times

## An Intolerable Price

Ms. Mekel is haunted by what happened to her best friend, Jean, who, she said, "missed the moment" for an assisted death.

Although Jean was determined to avoid moving to a nursing home, she lived in one for eight years. Ms. Mekel visited her there until Jean became unable to carry on a conversation. Ms. Mekel continued to call her and sent emails that Jean's children read to her. Jean died in the nursing home in July, at 87.

Jean is the reason Ms. Mekel is willing to plan her death for sooner than she might like.

Yet Jean's son, Jos Van Ommeren, is not sure that Ms. Mekel understands her friend's fate correctly. He agrees that his mother dreaded the nursing home, but once she got there, she had some good years, he said. She was a voracious reader and devoured a book from the residence library each day. She had loved sunbathing all her life, and the staff made sure she could sit in the sun and read for hours.

Most of the last years were good years, Mr. Van Ommeren said, and to have those, it was worth the price of giving up the assisted death she had requested.

For Ms. Mekel, that price is intolerable.

Her youngest son, Melchior, asked her gently, not long ago, if a nursing home might be OK, if by the time she got there she wasn't so aware of her lost independence.

Ms. Mekel shot him a look of affectionate disgust.

"No," she said. "No. It wouldn't."

Veerle Schyns contributed reporting from Amsterdam.

## Read by **Stephanie Nolen**

Audio produced by Tally Abecassis.

https://www.nytimes.com/2025/02/16/health/assisted-death-alzheimers-netherlands.html?smid=nytcore-ios-share&referringSource=articleShare

Good to read Stephanie again. I first encountered her as the exceptional Africa correspondent for *The Globe and Mail*. Stephanie has the capacities to give proper treatment to this MAiD/ assisted dying imbroglio we are trapped in. TJB