The Personal Toll of Photographing a Story About Euthanasia

I spent nearly three years photographing the Paralympic athlete Marieke Vervoort as she prepared to die by choice. It became one of the most emotional assignments — and friendships — of my life.



By Lynsey Addario

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<u>Times Insider</u> explains who we are and what we do, and delivers behind-the-scenes insights into how our journalism comes together.

In April 2017, The New York Times sent me to Japan to meet and photograph the decorated Paralympic athlete Marieke Vervoort while she carried out the last wish on her bucket list: dying.

Marieke was fresh off the Paralympic circuit, having just won bronze and silver medals in wheelchair racing in Rio de Janeiro in 2016. She had previously won gold in the 2015 world championships, as well as gold and silver in the 2012 London Paralympics. She was a celebrity in Belgium and in athletic circles for her athletic accomplishments and her public announcement that she had completed the paperwork to end her life by euthanasia.

Belgium, where Marieke lived, was one of just a handful of countries where euthanasia was legal for non-terminally ill patients. Marieke's degenerative muscular disease was not terminal, but as it worked its way up her body over two decades, it left behind a trail of paralysis.

I met and photographed Marieke in Japan, seven months after the Rio Games. She invited the Times sportswriter Andrew Keh and me to <u>document her life</u>, her suffering and her struggle with deciding when to die. She was savvy enough to understand that a poignant story and series of images could bring attention to her decade-long campaign for the global right to euthanasia. I ended up shuttling between my home in London and hers in Diest, Belgium, for two and a half years.

Marieke planned every detail of her death. She wanted to be surrounded by a handful of close friends and her parents in her bedroom in Diest when she was administered the lethal injection; she wanted to lie in a Coca-Cola red coffin surrounded by white roses; she carefully selected the speakers (including a comedian, whom she instructed to tell a dirty joke) and musicians for her private funeral. She would be cremated, and most of her ashes would be partitioned into little lockets for all her loved ones. A portion would be reserved and spread by her parents among the fields of lava by the dark blue sea in Los Hervideros, on the Spanish coast: her beloved second home, where she trained for the Paralympics.

She had no regrets. In fact, she had done more than most people do in 10 lifetimes.

But there never really seemed to be a right time to die. While Marieke first did the paperwork for euthanasia in 2008, she admitted she wasn't ready to end her life then. She just wanted the option of knowing she had the power and the permission to do so when the pain became unbearable. In the years I photographed Marieke, her condition deteriorated, and she selected three dates for euthanasia. All came and went, for different reasons, and the story — and our friendship — continued.

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During her a March 2019 visit to Lanzarote, in the Canary Islands, Marieke Vervoort spent some time in Los Hervideros, a spot that had become special to her. She had trained for the Paralympics there and asked for some of her ashes to be spread there after her death. Lynsey Addario for The New York Times

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I have spent my entire career photographing people whose lives were stolen from them by measles or malaria in the Democratic Republic of Congo or South Sudan, malnutrition in Somalia or Yemen, a car bomb in Iraq or an airstrike in Syria. I've photographed families torn apart by war and extreme poverty. Until Marieke, I had never met someone who had elected to die. I had never met someone so full of life — so emotionally determined that she could complete a triathlon in a wheelchair while deeply sick and heavily medicated — but who couldn't muster that determination to plow through the daily pain and loneliness of a degenerative muscular disease, year after year.

I've never photographed someone so consistently over the span of two and a half years; inevitably, she became a friend. Most of the time I was with Marieke, I watched her sleep. I didn't photograph much. I learned how to hold her when she choked, to pat her back and comfort her, hoping she regained consciousness. Sometimes I took a photograph right away, and then tried to help — because I was the only one in the room, and though I had been taught as a young photographer never to intervene, I am a human being.

I grew close to her parents, too — especially her mother, who spoke little English. We messaged often in Dutch, assisted by Google Translate. Even though I'm not sure my messages ever really said what I intended, they enabled us to have a close relationship. As a mother, I couldn't fathom what she was going through as she ushered her daughter through moments of joy and darkness, only to know how and when it would all end. I admired the strength and support of Marieke's parents, to be able to let her go.



Marieke's parents embrace outside the bedroom door while Marieke is prepared for euthanasia. Lynsey Addario for The New York Times

On Oct. 22, Marieke was scheduled to die at home in Diest — this time, she hoped, for real.

A few weeks earlier, when Marieke and I discussed how she wanted me to photograph her death, she was more lucid than I had seen her in almost all the time I had known her. She vacillated between excited and strangely calm. The doubt was gone; she no longer booked dates into her schedule for months — or weeks — in the future. She asked me to be one of a handful of people in the room with her during her euthanasia.

Marieke's parents, Jos and Odette, sat at the foot of the bed, and everyone reluctantly took their places around her, forming a human cocoon. Her doctors alternated trips to her bedside, emptying fat syringes full of the barbiturate Thiobarbital into an IV line into her neck. Her parents sat before her. Every few minutes, her father looked away. Her longtime psychologist held her wrist.

By the end of her life, I knew most of Marieke's friends, and her dogs no longer barked when I arrived at her home to find her half-conscious on the couch. When I was back in London, or in Los Angeles over Christmas, she sent me long voice messages on WhatsApp — during which she sometimes fell asleep, woke up again and picked up where she left off. She called me sweetheart and told me she loved me. I eventually reciprocated.



Odette said goodbye to Marieke before the coffin was closed. Her funeral took place the next day. Lynsey Addario for The New York Times

I don't know whether I crossed the lines of journalism by becoming close to my subject or who decides when it is O.K. for a "subject" to become a friend. I don't think my ability to tell Marieke's story has been compromised by our closeness, and I wouldn't know any other way to tell the story of someone's death by choice. I needed to get to know Marieke and her family to understand how painful and difficult life could be, to decide to end it.

The people in her bedroom that evening began to whimper and eventually sob, as the color drained from Marieke's face and her lips turned blue. She looked as she had so often throughout my time with her — medicated, sleeping, mouth slightly agape — but this time, for the first time, she looked at peace, without pain.



Pallbearers carried Marieke's red coffin to the hearse waiting to take her to a crematorium in Schaffen, Belgium, where she was raised. Lynsey Addario for The New York Times