

## **The Elie Wiesel Prize in Ethics**

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*An Inculpable Love*

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## **An Inculpable Love**

*Now you've departed and gone to the  
Unseen—  
On what strange ways you've gone from our  
world!  
You shook your feathers and you broke the  
cage;  
You flew away, far, to the soul's own  
world....  
Be silent—there is no more pain of  
speaking:  
You are protected by a loving friend!*

—Rumi

This is a story about love. This is a story about compassion and courage. This is a story about a vivid and determined life. This is a story about beauty and happiness and agreement and fulfillment and promise. This is a story about pain and wonder and exhaustion and depression. This is a story about humor and acceptance and support; and this is a story about God. This is a story about separation and about peace. But don't be overwhelmed, because this is really just a story about love.

This is also a story about physician-aided dying, which is more commonly, but less correctly, known as physician-assisted suicide. This rather ugly conception of an often-welcome event is one of the reasons terminally ill patients face rejection by their doctors and even their families when they request what is known euphemistically as an “early exit.”

When I was young, I knew a woman whose determination astounded me. It is generally difficult for a personality trait as subtle as this to be noticeable to a child, but it always surprised little me that a woman of such petite build and gentle demeanor could harbor such a strong will. In her life, this woman had three goals: to marry a Methodist minister, to have four children, and to build a house in a suburb. In her last months, she derived much satisfaction from having achieved all three. It strikes me that these are not lofty goals, but that they are oddly attainable—appropriate for a woman

who could not risk living a life unfulfilled. She pursued these and other goals with unflinching determination. And, when it was time, she pursued the death she had chosen with the same unassuming conviction.

In her life, she had been a traveler, a reader, a dark chocolate lover, and a great collector of maps and memories. She loved jigsaw puzzles. In an essay I wrote in fifth grade about a special person, I commented—in the way that only a child can—that she didn't "like to put on makeup," and that although "she was sort of sad because she wasn't feeling very well, she still managed to keep a great sense of humor." In her youth, she was uncommonly beautiful, with dark, full hair and an elegant and genuine smile. People say her eyes used to dance. Hers was an organic, resilient beauty that persisted, even in the face of debilitating illnesses and depression.

Of course, she had never been one to shy away from challenge. She and her Methodist minister husband relocated to South America, where three of their children were born, so that he could take a five-year post as pastor of the American Church there. Back in the States she pursued her vocation as a librarian, which had always been one of her passions. For a woman of her time, she was unusually brave and accomplished, making the symptoms of her illness even more disturbing.

Disease knocked at her door subtly at first, beginning with a contaminated over-the-counter sleeping pill that began the cascade of debilitating health problems. Nothing could cure the Eosinophilia Myalgia caused by the factory blunder, and its effects were complicated by the Parkinson's Disease and osteoporosis that followed. These diseases exist in popular consciousness as blind and faceless executioners, overtaking their victims slowly and deliberately in their helpless old age.

For ten years, she struggled bravely against these diseases and their symptomatic manifestations, including pain, difficulties in walking, speech, concentration, and the periodic arrival of depression. In the last year of her illnesses, she fell at least three times, first severing her knee tendon, next breaking her shoulder and then her leg. Her internist summed it up best when he told

her, “I don’t know of anyone who has gone through more in the last few years than you have.” Finally, knowing that recovery was not a possibility and that she would instead continue to deteriorate, her focus changed, and she decided to stop fighting the losing battle against her body. And so she put her mind to it.

Yet, her desire to speed the process along by taking a lethal dose of pills was highly disparaged socially and legally. Even in Oregon today, after the passing of the Death with Dignity Act, her wish to control her own dying would likely not be legally granted because, devastating as her diseases were, they would not have been deemed directly fatal within six months. Thus, her case presents the ethicist with an unusually vexing ethical dilemma and the family with an excruciating decision.

### **The story**

*Dear Mom,*

*5 December 1998*

*Let’s think of all the possible circumstances that could lead to a change of heart:*

- 1) We move out to be with you.*
- 2) One of my sisters gets pregnant.*
- 3) Okay, as a last resort I get pregnant.*
- 4) I write a great mystery, which I send you in installments. Okay, it never ends.*
- 5) We come for a visit and don’t leave, thus making it very inconvenient for you.*
- 6) I confess to the world that I did indeed have an affair with Bill Clinton and that’s why I left Arkansas. Would you stick around to support me?*
- 7) World War III breaks out. Would you stick around to see how it ends?*
- 8) One of us gets dreadfully ill. The timing is terrible.*
- 9) You win the lottery.*
- 10) I get my hair cut.*

*Well, none of these would seem to offer much hope, except if you won a million dollars maybe you could buy your way into a clinical trial for some new depression medicine. If I’ve overlooked anything do-able, just let me know.*

*Your daughter, always thinking—*

With the support of her husband, she consulted her primary care physician about the possibility of his prescribing a lethal dose of barbiturates. He agreed to prescribe medication that she could stockpile, but not without significant ethical reflection. Though he knew he agreed with her

decision on a moral level, risking his job gave him pause. Despite the legal danger, he wrote the prescription.

As the plan began to take shape, the rest of the family needed to be consulted, and a holiday family reunion provided the occasion. In the high-ceilinged living room of the house they had built, she shared the news with her family, and reflected on the beautiful life she had known. Three daughters, one son, and their spouses listened somewhat uncomfortably, but no one outright objected.

Over the next months, family opinions vacillated. The two eldest daughters seemed to come to terms with their mother's decision after doing their own research, and were therefore able to share the emotional burden with their mother and father. The progression of this acceptance can be seen through one of the daughter's letters over the three months. After her mother's announcement that she had set the date for the first week in March, the daughter began to write desperate letters to her—each one giving new reasons why she shouldn't cut her life short. She questioned her mother's decision and wanted to make sure she exhausted every tactic to get her to change her mind. She realized in the end, however, that her mother was as determined as ever and that what she needed was support from her family.

*Dear Mom,*

*31 December 1998*

*Happy New Year. There's a little black humor for you. I'm dreading this year, as you can imagine.*

*I have a question for you. At the end of your little speech, you welcomed us to ask questions, disagree, or try to talk you out of it. Do you think you really, deep down, want to be talked out of it? If you feel really ambivalent, I think we could do a pretty good job of making you reconsider. Unfortunately, we can't offer you a cure or even a good shot at feeling better. I guess we'd just want you around for ourselves.*

*Wishing every day for more time—*

*Dear Mom,*

*6 January 1999*

*I have realized that when I wrote you that long letter I really supported your decision—but in an abstract, theoretical kind of way. In coming face to face with the reality at Christmas time, I was taken aback at my resistance, at my need to hope, at my search for reasons to keep you from following through by believing that this isn't what you really want.*

*Well of course you don't. What you really want is to get better. If we accept that that isn't going to happen, then this is next best for you, as you see it.  
Now I see it again, too. I see that what you need is our support, not more articles and suggestions and questions.  
I love you, Mom. Thanks for being so strong.*

*Dear Mom and Dad,*

*18 February 1999*

*What a visit that was! I don't even know what to say or where to begin. I admire the methodical way that you are approaching this. As we made clear, we will be there to support you in whatever way you need.*

*I've learned a lot from both of you during this long and difficult process. Thank you for being such good teachers. I'll call you soon—*

*P.S. If you change your mind, we'll have a party!*

In the end, she was inspired by her mother's courage and conviction, and when the time came, she was the most prepared of anyone in the family to carry out her mother's wishes. Having read the Hemlock Society's *Final Exit*, she knew that the prescription given to her mother was not among the most lethal of the recommended barbiturates, but that it should still be effective. She knew how to crush up the pills and stir them into the applesauce. She knew to give her mother enough vodka to enhance the drug's lethality but not so much that she vomited. She knew, but prayed she would not have to use, the procedures by which to manually end her mother's life if the medication did not appear to be working. She and her older sister were prepared to enact these necessary, unpleasant steps out of love for their mother, and she made them promise to "do whatever it took" to carry the plan to fruition.

On the appointed morning, the sun rose peacefully over a dusting of freshly fallen snow. Inside the family had gathered, and emotions—though unspoken—were running high. This was not a family that fainted or screamed or became overly emotional. This was a family that was stoic and stable and Swedish and sure. Having come to terms with everything beforehand, all that remained was to go through the motions, it seemed.

So the two eldest daughters now directed their attention to the tasks at hand. Together, they crushed the pills into the applesauce, and poured the vodka. Together, they brought it upstairs, and together now with the rest of the family, they sat on the bed while their mother—still as determined as ever— ate the applesauce and drank the vodka slowly, and deliberately, without flinching. What was in their minds then can only be imagined, but it was quiet in the room. The father recited a prayer and they held hands and exchanged emotional goodbyes with their mother. In these moments of anticipated death, the dominant, almost palpable, shared sensation was not one of fear or panic, but one of rest and peace and love. And she closed her eyes, and her breathing slowed, and some say God was there with her and with them.

And so they waited.

And waited.

And snow began to quietly fall outside, which made everything beautiful and calm and right in the way that only quiet, falling snow can.

And the hours passed, and the snow kept falling, and it was sticking now so that there were a few beautiful inches on the ground and things still seemed right. Only their mother's slow breathing had not ceased, and she was still alive and somehow that determined body of hers had resisted the barbiturate assault and had refused to die. The daughters knew that this was not what their mother wanted, and they worried that if she did resist death at this point, the damage to her brain would be irreversible. They knew they couldn't go to the hospital, and they couldn't call her doctor or a nurse to ask what to do because what they had already done, regardless of the motivation, was illegal. And

on that beautiful, snowy afternoon, they were alone. And they felt it. But they kept waiting and hoping, and the snow kept falling.

After 8 hours, she was still breathing, and the eldest two daughters knew it was up to them to do something. Asking their father and younger sister to leave the room, they reviewed their options. The older daughter was unable to stomach the *Final Exit* recommendation to tie a plastic bag around her head. So they gathered all of their courage and used a pillow to stop her breathing.

### **The Caregiver**

*“You are protected by a loving friend”*

She and her husband had given new meaning to the wedding vow, “I take thee in sickness and in health, to love and to cherish, till death do us part.” It had been obvious throughout their courtship, their marriage, their child-rearing, and her ten years of debilitating illness, during which he had been constantly at her bedside, attending with unfailing patience to her every need. This was the picture of the truest love; which, it turned out, was *not* weddings or raising children, or whispered I love yous. The truest love was in cleaning her catheter, in seeing every anti-depressant on the market fail to return her to her former, vibrant self, and in holding her as her own body betrayed her, overcome by ten years of ravaging illness. The truest love was helping to bring her release when it was time, though it was at great cost to him.

So did he ever feel guilt at having helped her put an end to her suffering? He says, “never” with sobering assurance. Nor did he ever feel that it was remotely selfish of her; calling it selfish, as critics of physician aided dying often claim it is, “would be to say something more about our wish for her to continue in this state than of her wish to escape it.” She had given all she could to life, to her children and grandchildren, and she was no longer herself. She knew, with certainty, that it was time, and his support then became a mere continuation of the role he had mastered over the past ten years

as her number one advocate, primary caregiver, closest friend, and husband. Any potential guilt was mitigated by his strong belief in situation ethics and, most important, his love for her.

And this love was necessarily a love that transcended death. As a minister, he had performed countless funerals, and was no stranger to death or grieving. He had attempted, in his “feeble human way, to help bring about the most loving thing,” by incorporating her suffering into his own. In his eulogy, he hinted at the depth of his own suffering: “Your death has struck at the center of my being. This farewell to you, therefore, is more painful than anything I have ever known.” And it was this depth of love that allowed him to reconcile this ethically and theologically complicated action.

## **The Ethics**

When her doctor agreed to prescribe the pills, he told her she should do it alone. He told her she shouldn't tell anyone, including her children, and that her husband should be downstairs. Ethicists, theologians, and medical professionals have argued both sides of this issue with equal ferocity, but most of us are hard pressed to come down unequivocally on either side. Until we imagine our parent or our spouse, in whose suffering we have intimately shared, taking a lethal dose of pills without warning and completely alone. For her daughters, imagining their mother committing a sad, lonely suicide was “unacceptable on a human level.”

The legalization of physician aided dying should be a decision approached with extreme caution. There are many foreseeable circumstances in which the right to die could be abused, such as an elderly person's seeking an “early exit” in order to minimize the emotional or financial strain on the family. That the recent Oregon Death with Dignity Act requires that the patient meet strict criteria—such as two oral and one written request and two doctors' approvals—is a testament to the seriousness with which such a law is and should be considered.

I said before that this case was particularly ethically vexing because it fell outside the Oregon parameters for legal physician aided death, but this is not entirely true. The family members faced a complicated social, ethical, theological and legal dilemma in carrying out their mother's wishes, and some would judge them harshly for it. But to deem the action ethically complicated or wrong would be to ignore the beautiful simplicity of the whole story, which is really, again, just a story about love. In the end, she died as she had lived: with beautiful, calm conviction, surrounded by people who loved and admired her strength to carry on in the face of struggle and to die when she felt it was her time. There is nothing easy about dying, just as there is nothing easy about loving. And what of the love that transcends normative legal and ethical judgments? What of the lovers who, in defying separation, bear witness to the very love of God? Consider the love that enabled this family, against societal pressures, to give their tired mother peace when she asked for it, now absorbing her suffering as their own.