

Life and death in *Alzheimer's disease*

What happens when a family doesn't know a loved one's wishes.

BY JESS PRISCHMANN, MD

Eleven years ago, my grandmother began the slow, cruel decline of Alzheimer's dementia. During the early stages of her disease, I felt searing pain watching her try to live independently.

Little did I know that the early pain would pale in comparison with the agony of watching her body attempt to die.

Alzheimer's is not just a disease of lost memory. It is a terminal condition with no hope of recovery or cure. It not only robs individuals of their ability to remember the past, it also pillages virtually every other bodily function.

Unlike with other terminal diseases—cancer, for example—a person with dementia is often unable to participate in his or her own end-of-life care.

Eight months ago, my grandmother suffered a devastating stroke, which, among other things, impaired her sight and ability to swallow. She had to rely on nursing care for all activities of daily living. It seemed clear that this was the time to place her in hospice so she could maintain her dignity during her last few months of life. What I never anticipated was the difference of opinion among family members who felt that withdrawing care was a cruel way to prematurely terminate life.



The author as a child with her grandmother.

My grandmother had never vocalized her end-of-life wishes, and elders in the family argued that I had no way of knowing what she would have wanted. Withholding food and fluids, they said, was not an ethical way to allow someone to die. I, on the other hand, strongly disagreed with the assumption that death from dehydration was unduly painful.

I recalled a poignant, well-written supplement by the Alzheimer's Association that states: "Lack of hydration is a normal part of the dying process and allows a more comfortable death over a period of days. Using IV hydration can draw out

dying for weeks and physically burden the person."

Two weeks ago, my grandmother was found obtunded and rushed to the emergency department, where she was intubated and transferred to the intensive care unit. She was diagnosed with pneumonia and severe dehydration and, despite my strong objections, was started on life-saving measures. I was told that her doctors advised that the pneumonia and dehydration were potentially reversible.

Again, the family was given the atrocious challenge of deciding her fate. Why wouldn't they treat a revers-

ible medical condition?

In an article titled "Ethical Issues Near the End of Life," Dr. Muriel Gillick, director of the program on aging at Harvard Medical School writes, "Some have cautioned that excessive deference to patient autonomy has the potential to place unwanted and unreasonable responsibility for technical medical decisions on patients or their surrogate decision-makers. Given the array of treatments now available for advanced and chronic illness, it is difficult, and at times nearly impossible, for patients or their surrogates to fully comprehend the burdens and benefits of the available options."

PHOTO COURTESY OF JESS PRISCHMANN

Last week, I rushed to my grandmother's bedside. I held her cold, swollen, mottled hand and thanked her for everything. I told her to take care of my mother from heaven and provide the family *ashirwad*, a Hindi word for blessing.

I have stopped my efforts to end her suffering. I have no idea how or when she will die. I have peace in knowing that she is surrounded by those who love her deeply. They feel as strongly about her will to live as I do about her right to die. I will never know what she would have wanted, but I do know that my continued attempts to influence her care have fractured relationships in ways that will exist long after she is gone.

More than 5 million Americans have Alzheimer's disease. For their families, this chronic, terminal condition creates an ocean of swirling feelings: sadness, anger, frustration, exhaustion and, hopefully, peace.

I am left to wonder if this situation could have been avoided. Should we have discussed end-of-life care 11 years ago? Should an advance directive have been a mandatory part of the treatment course? Did her physicians take an active role in advising the family, or did they present all options as equal?

My grandmother was the family caregiver. She raised her own children and most of her grandchildren and never asked for anything in return. She had no enemies. Her ability to remain impartial was her greatest quality—in life and in death. MM



Jess Prischmann is the owner of Prischmann Facial Plastic Surgery in Edina. She writes:

"My grandmother died in March of last year, shortly after I wrote this essay. For a long time, I felt so much anger. In Indian

families, the oldest son is often given the responsibility of making decisions on behalf of the family. Therefore, the power of attorney was assigned to my uncle, who felt very strongly that withdrawing care was not a good option. I was angry at him for keeping my grandmother as a full code until the very end. I was angry at my relatives, who I felt did not stand up to him.

"And then, someone told me that love is the force that keeps us all on Earth. My uncle loved her so much that he couldn't let her go. My grandmother's soul felt so loved that she couldn't depart her physical form. It no longer grieves me to think about the way she died.

"I think there needs to be a change in the way the medical community handles end-of-life care in Alzheimer's disease. We need to discuss patients' wishes before dementia impairs their ability to do so. As doctors, we must also realize the power and responsibility we have to help advise surrogate medical decision-makers when a loved one is dying. Until we have a cure for Alzheimer's disease, we need to see death as a natural end point, not an unfortunate outcome."

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