

The Dignity of Human Life
Professor Elizabeth Schiltz
World Day of the Sick, February 11, 2017

It is really an honor to spend some time with all of you, and it was such a pleasure to participate in the beautiful Mass with His Excellency, Archbishop Hebda, and those dedicated chaplains of Curatio and of the Order of Malta, Fr. Johnson and Fr. Eilen. I thank you. I was humbled by the invitation to address the members of Curatio and the Order of Malta, because those are organizations of people who dedicate their lives and their livelihoods and so much of their attention to caring for the sick and the vulnerable. I'm sure that I can't teach you anything, so I'm going to spend my time thanking you.

I've always had a very special affinity to St. Bernadette and Our Lady of Lourdes as well. I was born and raised in Europe - in Germany - and I spent two years of my childhood, from ages 4 to 6, in Orleans, France. My father was a civilian working with the U.S. military in Europe, and my 5 brothers and sisters and I spent most of our childhood in Germany, but those 2 years in France had a really deep impact on us. Our parishes, when we were growing up, were the local parishes at the army bases where my father worked. They were part of what was called the Military Vicariate. It was under the leadership of the Archbishop of New York City, and confirmations would take place every couple of years, whenever a local bishop happened to be coming through to one of our parishes. So my 4-year-old sister and I were both confirmed at the same time, and we had a massive fight over who could get St. Bernadette as their confirmation saint. Those of you who have kids and those of you who have siblings, you know we couldn't share it, right? So, she was older and she got Bernadette, but I actually didn't feel too bad about my second-place saint, because I got St. Joan of Arc. Not too bad ... not too bad.

Another one of my favorite associations with St. Bernadette and Lourdes is a memory I have of my two oldest kids, who when they were about 4 and 6 years old developed an obsession for about a year over this video we had - a cartoon of the life of St. Bernadette - and they spent an entire year just out of the blue, every once in a while, dropping to their knees, clasping their hands, and looking up to the heavens, saying, "Oh, the Lovely Lady!" That's a really strong memory of mine. But I only visited Lourdes once, and it was in March of 1995 and I was pregnant with my third child then. My husband and I took a pilgrimage, and we spent a couple of days entranced by that stunningly beautiful valley and those incredible rosary processions, and the intensity of the experience of hope and healing that was all around us. We had a special reason for making this pilgrimage at that time, because we had just gotten the results of an amniocentesis that told us that my son, who was then about 4 months old in my womb, was going to be born with Down's Syndrome. So, I took the plunge into the waters at the spring at Lourdes in prayer, but I really wasn't too sure what to pray for. I didn't pray that he wouldn't have Down's Syndrome, because I knew that

he did, but I prayed that he'd be healthy and that I would know how to take care of him.

I suppose those prayers really did work, because our son Peter was born with none of the physical health problems that are commonly associated with Down's Syndrome, and I did manage to take care of him, with a lot of help, but most especially from my mother. My mother knew what she was talking about when it came to raising a son with special needs. My older brother, Jim, had been born mentally retarded in 1955, and she raised him despite the advice of medical professionals and military officials, quite in line with the standards of the time, that she and he and our family would be better off if he were raised in an institution. My parents refused, and we siblings had the blessing of growing up with Jim.

I know that witnessing the way that my parents cared for Jim, and growing up in a family in which it was taken for granted that Jim would be part of everything we did, profoundly influenced my rather matter-of-fact reaction to Peter's diagnosis. But one of the most striking things that I learned from my mother was what she said to me when I called her right after receiving my son's diagnosis. Her reaction was so surprising to me. Her first words were, "Oh, Lisa! You're going to meet such wonderful people!" And she was right! And those wonderful people are people like you, people who have dedicated their lives to caring for the sick and the vulnerable. One of the greatest blessings in my life is the people I have met, who have helped me care for my son, Peter.

Think of what my mother said to me! Her very first words of comfort for her daughter, knowing exactly - better than almost anybody else could - what difficulties lie in front of me, as I raised this particularly vulnerable son. She didn't tell me, "Oh, Lisa, it will be alright," or "Lisa, you know, God never gives us more than we can handle," or "Oh, Lisa! You are going to experience such wonderful joys in raising this little angel. It's going to expand your soul." No, she didn't tell me any of those things. She said, "Oh, Lisa! You're going to meet such wonderful people."

My mother, Bernice, passed away this past October, just a few months short of her 90th birthday. Her death certificate listed as the cause of death complications from Parkinson's disease and geriatric failure to thrive. Now, those of you who are medical professionals, you probably know much more about this than I do, but that last seemed, and still seems to me, like a very cold, judgmental way of saying she died of old age. The years leading up to her death, with the progression of her Parkinson's disease, were really rough. I wish I could tell you all that wonderful people sprang out of the woodwork to take care of her, but the fact was that the brunt of the care was borne by my older brother, Bill, and his wife, Daina, who were the two of our siblings who still lived closest to her, and by my older brother, Jim, the mentally retarded son, who lived with her still and really served as her primary caregiver, enabling her to live in her own home until the last few months before her death. Now Bill, Daina and Jim were indeed among the wonderful people that I feel so blessed to

know, but those last couple of years were really hard on them and those of us living far away from Mom and all of our relationships with each other.

Parkinson's is not a disease with a very graceful progression, if there is such a thing as a terminal or chronic disease with a graceful progression. What I think was the hardest on all of us was watching how the disease robbed my mother of so much of what we commonly consider as her dignity. My mother was an elegant, clever woman, with a mischievous sense of humor ... a voracious reader. She was interested in everything. She was a superb cook; she specialized in schnitzel, stuffed cabbages, and potato pancakes. She loved going out to eat. She was an adventurer. She traveled all over Europe with my father when they were young, with us kids while we were growing up, and then after my father retired and they moved back to the States, she traveled all over the States visiting all of us. She went back to Europe; she went to Ireland; and she went to the Holy Land with my brother Jim, after my father passed away. She was one of those women who insisted on driving, until she totaled her car at the age of 88.

Parkinson's took away her ability to engage in the world of ideas, when she lost her ability to concentrate on movies and books. Parkinson's took away her ability to communicate with us, as it robbed her of her speech. Parkinson's took away her ability to cook for herself and even enjoy a good restaurant meal, as she grew increasingly embarrassed by how hard it was for her to get her food into her mouth and to chew and swallow. She lost the ability to walk; she lost control of her bladder and her bowels; and she even lost, towards the last few months of her life, her connection with reality. It was probably a result of the medication. She even sometimes lost her ability to express what we all know was her love for us, launching into angry tirades about being placed in a really wonderful assisted living situation, as we reached the end of our ability to care for her in her own home. But in the weeks before she died, she managed to spend time with each of her children, and each of us had some special experiences with her. I consider myself so especially blessed by the last few days I spent with her, just days before her death.

At that time, she was in a rehab facility after a stay in a hospital due to a fall, and we were working on arrangements for some sort of hospice care. I flew into Pittsburgh and spent two days in the rehab facility with her. The first day confirmed what my siblings had been telling everybody and why they were urging us to come and visit her. She was barely conscious, she had no interest in eating or engaging in any interactions really, but still I offered to pray the rosary with her and she wanted me to do that, and I was able to do that. I was mostly, though, during that first day, concentrating on the lack of wonderful people in those caring for her. The food that they were serving at this place was absolutely unappetizing and inedible. I spoke to the dietician, who told me that she had been given orders to have her fed in a group setting so that she could be given assistance in eating, but I watched as indifferent, inattentive aides would just drop trays of food in front of her in her room and then leave. I spent a large part of that day, as she slept, calling skilled nursing facilities

desperately and futilely, looking for places with good reputations and capacity. It was a rough day.

But the next day, when I came back to her room, she wasn't there. I eventually found her with an occupational therapist, as lively and alert as she had been in months, talking about what she was planning on doing to regain the strength to push herself up out of her wheelchair. Her next appointment for the day was a physical therapist. She pushed herself straight up out of her wheelchair, she walked towards me on two parallel bars with strength she hadn't displayed in months, and the whole time she was sharing stories with the PT about how she used to take us kids on long "Volksmarches" in Germany. These were organized walks through the countryside that ended up with glasses of wine and sausages and medals for everybody who participated in them. But the highlight of my day with her was the hour-and-a-half that we spent with the woman who came in twice a week to do the hair of the residents in that facility. I managed to talk my way into her appointment book, at the urging of my sister-in-law, since my mother's hair was really getting out of control. This lovely woman stayed late to give my mother a haircut and a permanent. She had an assistant, a middle-aged woman with cognitive impairments, who helped wheel customers in and out of the salon, and who helped with the physical challenges of washing and setting the hair of the frail, elderly women. While these wonderful women tenderly washed, cut and set my mother's hair for her permanent, my mother talked. She talked about how her mother, a widow raising 11 kids on the coal miner's pension of my father and her salary as a cleaning woman in downtown office buildings, would take in foster children during the Depression whose parents couldn't afford to take care of them. And she told me this story that I'd never heard about how once her older brother convinced her mom that they could take a set of three foster kids - three siblings - so that they didn't have to split that sibling group apart.

That afternoon, freshly permed and still as chatty as a jaybird, my mom wolfed down some soup and a tuna salad that I smuggled in from a nearby store, and she asked her to wheel her around the facility for a while just to get out a bit and see some things. As I left her that night she was watching the TV news and reading a newspaper, something she had not expressed interest in doing in months. When I left her that evening, I thought she was bouncing back, but the very next day she slid back again and a few days later she was dead. I later learned that it's not uncommon for those about to die to experience a surge like this. I am so blessed to have been there for that day, because I did see at the end a team of wonderful people caring for those who are ill - the PT, the OT, the hairdresser and her assistant - and they were all treating my mom with dignity, respect and caring, making such a difference to the quality of what turned out to be one of her very last days.

I have to confess, I had a really difficult time trying to figure out what I was going to say to you guys today. Dianne Johnson gave me plenty of time. She contacted me last summer, she told me about the date, and she told me about your wonderful organization. During the intervening months, then, I experienced the death of my mother. My siblings and I continue to deal with how to best care for my older brother,

Jim. My own son turned 21 this summer, and I've been navigating a lot of transitions in his care. After-school babysitters are harder to find for 21-year-olds than cute little elementary school kids. Kindly pediatricians gently suggest it's time to find a doctor who will know something about the aging population with special needs, and those kind of doctors turn out to be few and far between. The State of Minnesota launches a movement to close down perfectly well-functioning facilities that care and employ adults with special needs in the quest for finding elusive, competitive job placements that are far beyond the capabilities of my son, who is a lovely, lovable fellow, with not only Down's Syndrome, but also autism and verbal apraxia.

Then, of course, we had the election, and then we had the Women's March, with pro-life women being excluded from it, and then we had the March for Life a few days later getting no attention. So, every time I tried to sit down and think of what I could possibly say to you, I just kept hitting up against a wall. I know, in this current climate of divisiveness and crude discourse, people are looking for something that will calm them and soothe them and not divide. And in all modesty that is usually one of my strong points. I've been asked to speak at all kinds of conferences and contribute to books where the pro-life and the pro-choice communities are in dialogue, because I can write things and talk about contentious life-and-death issues in ways that sometimes bring people together. When I was applying for promotion of full professor, the review that I was most proud of was one that described my work as "irenic." Okay, first I was confused. I had to look it up. But when I looked it up then I was proud, because it means "aimed at peace," or "a part of Christian theology concerned with reconciling different denominations and sects." But no matter how hard I thought and prayed about this talk, nothing irenic came to mind.

Then, one morning a few weeks ago, I just woke up with this thought in my head, and there was nothing particularly irenic about it. The strongest witness to whether we truly believe in the dignity of another human being is this: When she is at her most vulnerable, do we take care of her or do we kill her? There is no question - we are slip-sliding into a world where killing is increasingly being considered a perfectly legitimate and sometimes even compassionate alternative to caring for the vulnerable.

There is evidence suggesting that 96% of women who receive a prenatal diagnosis of Down's Syndrome for their child chose to kill that child instead of caring for that child. We only have that number because that's a disability that turns out to be so easy to identify before birth that tests for it are routinely offered to women as part of what is euphemistically referred to as prenatal care. I have no doubt that the choice to kill rather than care is presented to many women, who are presented with other troublesome indicators during their pregnancy, as a perfectly legitimate, sometimes even compassionate alternative. What was it that caused me to make it so clear to my OB/GYN, the ultrasound technicians, and the genetic counselors, that that was not an option they even dare raise with me? It wasn't any intellectual argument; it wasn't anything in an encyclical; it wasn't anything in the Catechism. It was the witness of wonderful people, who cared for my brother, Jim, and matter-of-factly

illustrated every day that that is the proper reaction to a vulnerable person, and it's really not an impossible thing to do, and there are countless rewards and blessings in doing that.

Just the other night, I watched a documentary film called *The Euthanasia Deception*, consisting of testimonies of people in Holland, Belgium and Canada, talking about the effects of legalizing euthanasia. One of the most striking lessons from that movie is that opening the door to assisted suicide legitimizes killing as one of the many equally valid, equally moral options, which professionals are supposed to present to people, for people with various types of illnesses and vulnerabilities. The doctors and the ethicists from those countries in this film emphasized again and again that euthanasia was almost never chosen by people enduring unbearable physical pain. They emphasized again and again that palliative care can control any amount of physical pain. Euthanasia was chosen, in those situations when it was actually chosen - and that's a whole other issue - in order to spare loved ones the burden of caring. Particularly compelling in this movie were some of the stories of children, who were mourning that they had not been given the option of caring for their dying parents.

We all know that the movement to legalize euthanasia is aggressively pushing its way across our country. In 2017, Compassion & Choices is targeting for legalization laws in the states of Maine, Maryland, Nevada, Utah, New York, Delaware, Iowa and Hawaii. It has been on the horizon here in Minnesota for a couple of years now. What can we do to stop this move? I think the single most important thing we need to do is to continue to be wonderful people, continuing to witness to the act of caring for, rather than killing, those among us who are most vulnerable.

Most of you here probably know about the work of Jean Varnier. He is the founder of L'Arche, an international federation of small residential faith-centered communities, where people with and without disabilities live together in friendship. And some of you here probably know the work of the theologian Stanley Hauerwas. Well, Hauerwas has spent a lot of time thinking and writing about some of the most vulnerable among us - those with cognitive disabilities - and he became great friends with Jean Varnier. Hauerwas was puzzled by the same thing that puzzled me so much as a lawyer. What are we thinking, we Americans, that leads us to such contradictory directions in our policies about the most vulnerable? We pass laws like the Americans with Disabilities Act, and even portions of the Affordable Care Act, that make strong legal statements that the most vulnerable among us deserve equal treatment and equal care. Yet, at the same time, we rejoice at technological developments allowing us to identify disabilities earlier and earlier in pregnancies, and the absolute number of people born with Down's Syndrome every year continues to drop.

Hauerwas described it like this: "Our modern humanism entails that we care for them once they are among us - once we are stuck with them - but, at the same time, humanism cannot help but think that, all things considered, it would be better if they did not exist." We live in a world where it is commonly accepted that what makes a person human, or gives a person dignity, is our autonomy, our capacity for self-

definition, for living one's life, developing one's potential, charting one's own identity and course in life, and freely sailing down that course. Now, we know as Christians that that is simply false. We are not autonomous; we are dependent on each other and on God. We do not create ourselves; we are created by God, with all of the attributes and limitations that He sees fit to give us. But the world around us is more and more shaped by a truly aggressive acceptance of this autonomous, self-creating ideal as the marker of human dignity.

Hauerwas says that people with cognitive disabilities are particularly troubling to modern societies because they are not self-sufficient and autonomous. They are dependent, and they need people to take care of them. He writes, "Even more, they do not evidence the proper shame for being so. They simply assume that they are what they are, and they need to provide no justification for being such. It is almost as if they have been given a natural grace to be free from the regret most of us feel for our neediness." Hauerwas continues that those who choose to live with and to care for such people, like those in the large communities, like those of you who continue to do this difficult work, offer a powerful, prophetic witness to the possibility of a world that does not accept that autonomy fallacy.

There are many examples of modern thinkers who keep trying to defend their theoretical commitments to this autonomous ideal, and they try to reconcile that with their own practices of taking care of loved ones in their lives who don't live up to that ideal. The most famous is probably Peter Singer, the Princeton philosopher who is most notorious for his utilitarian arguments that we should kill fetuses, newborn babies, and elderly people suffering from dementia, if the money, care, or attention that we have to devote to that person could be better spent in alleviating the suffering of more other people. When Singer's own mother became ill with Alzheimer's disease and reached a point in her life when she could no longer recognize Singer, or his sister, or her grandchildren, Singer and his sister hired a team of home health care workers to look after their mother and spent tens of thousands of dollars in the process. When challenged afterwards by people for the inconsistencies in his arguments, he just said his theories are right; he just couldn't live up to them when it came up to his own mom.

The Dutch philosopher, Hans Reinders, wrote, "There is no point in arguing with a skeptical spectator that he or she should care about the disabled. Instead, it is crucial for a liberal society that people exist who are willing to engage in the practice of caring for the disabled and, I would add, the sick. After all, significance found in sharing one's life with another person, a significance that usually comes as a surprise, cannot be found outside of the activity itself." Now, I'm not saying we should stop trying to make impassioned arguments against normalizing the growing acceptance of killing, rather than caring for, the most vulnerable among us. And we do have to be as wise and as canny as serpents to strategize about ways to combat the aggressive work of groups like Compassion & Choices to normalize killing instead of caring for those who are sick and who are dying. But those arguments will probably not be nearly as effective as your witness. All of you wonderful people - you nurses, and you doctors,

and you caregivers, and you members of orders who support nurses, and doctors, and caregivers, who reject the idea that killing is an acceptable alternative to caring - you are all prophets.

I thank you for your shining and powerful witness in your daily lives and in your countless conversations with loved ones and patients. Every once in a while, when the going gets tough or you feel discouraged about where things are headed, take the time to pat yourselves on the back for being among the wonderful people. Our Lady of Lourdes is smiling down on you. Thank you.