

My name is Karla Benkula, I live in Topeka, KS, and I would like to thank you for giving me the opportunity to tell the story of my mother, Lois Benkula.

Let me introduce my mother, Lois. Lois was a woman who was full of life and very much a free spirit. She was a cheerleader in high school, had roles in high school plays, and was crowned Miss St. Joseph in 1959 in St. Joseph, MO. Soon after my father was discharged from the Air Force she found herself being thrown into the role of being a single parent, left to raise an infant daughter alone. She and I faced life together and we found great strength in our journey together. She worked as a secretary at an advertising company during the week and on the weekends she and I would clean the same office to make ends meet. She worked hard and became a very savvy business woman becoming the Director of a business school in Tulsa, OK and even to own her own business school in Decatur, AL at one point in her life. She loved to entertain in her beautiful Victorian home that she restored, she loved her church and was actively involved in the Stephens Ministry. She traveled the world and experienced many wonders in her life. She and I were a team and nothing could keep us down. From her I learned the value of hard work, compassion, to find joy in the small things, and the value of family. Momma always had strong instincts and was never afraid to stand up for what she believed in to be true and right. She instilled this strength in me which is what brings me here today.

At the age of 72 momma was diagnosed with dementia and instead of accepting her fate she chose to try to stay strong and overcome. This was very hard for her because her illness wasn't cooperating with her will to stay the person she was. When the time came to place her in a nursing home there was only one facility with an opening. The facility was more than an hour away so I was only able to visit her on weekends, but I would call the facility every evening and speak with her by phone. Being true to who she was, she wanted to feel useful and have a purpose. She asked the facility many times to give her a job to do and eventually they would let her help clear the tables and sweep the floor after meals. As time passed, this was taken away from her leaving her feeling useless.

At this point in time, momma was still lucid enough to remember her home she no longer lived in, some of her friends and family she no longer spent time with, and her independence she no longer had. She grieved these losses and became more afraid of losing who she knew herself to be. Her life became no more than getting out of bed each morning and being shuffled to a TV room left to stare at a TV screen all day except to take meals. When she initially arrived at the facility she was prescribed only five medications of which only one was for dementia. The other four medications were supplements. As time passed, without my knowledge or consent, she prescribed other medications. I began to notice that my mother was not being kept clean: her hair was greasy, her skin was dirty and had sores, and her clothes were dirty. She would ask me to tell the staff at the nursing home to give her a bath, which I would do, but she remained unkept. She also began refusing the medication they gave her because it made

her “feel funny”. She would see the medication in her food so she wouldn’t eat, she would see them put it in her drinks, and times she would hide it in her mouth and spit it out in the trash. Finally, the nursing staff contacted me saying she wouldn’t take her meds and I told them by law she had the right to refuse them. My statement was met with silence.

Two weeks later while I was at work, the facility contacted me saying they were going to email documents to me that needed to be signed and faxed back immediately. I asked what the documents were for and I was told that my mother had been sent to a geriatric mental hospital in Salina, KS for

evaluation. I asked why she was being sent there and I was told it was because she was “acting out”. I told the DON that I wanted to come and see her before they took her there and I was told she had already been transported earlier that same morning – without my knowledge or meeting with me to discuss her situation first. I called the facility in Salina, KS to find out their location so I could go see her and I was told I wasn’t allowed to visit her and I could see her when she was returned to the nursing home. I was denied contact with my mother for 30 days. When she returned to the nursing home my mother was an empty shell. I was told she was diagnosed as being bipolar and was now taking medication to treat the mental illness.

Mom, when she was awake, wouldn’t laugh, smile, speak, or show any emotion what so ever. She was unable to participate in a conversation or look anyone in the eye. She literally just sat and blankly stared at nothing. It was if her soul was gone. I told the DON that I didn’t want her on whatever medication that was causing this and I was told they would lessen her dosage, which they did. The only difference it made was that she didn’t sleep as much when I came to visit her. One day I made a surprise visit in the middle of the week. When I arrived I was told that mom no longer remembered me as I was, but only as an infant. I was also told that she was smearing feces around her room which was all part of the final stages of dementia and she probably wouldn’t last long. My heart broke. The Activities Director said she would take me back to see her and on the way to her room she was told that my mother did in fact remember me and her behavior was not what was described to me. I found out her medication dosage was only lessened when the facility knew I would be there. Please note that this is only one example of many similar experiences.

There were also other problems I encountered with this facility so I was already in the process of trying to find another facility to place momma in and using any and all resources I could find to help. Each time I found a facility with an opening she was denied approval saying she was reported as being combative by the facility she resided at and they couldn’t put their current residents at risk. She wasn’t combative....she was too drugged to be combative and prior to that she was only following her instincts, knowing things weren’t as they should be, and trying to save herself the best she could. Her dementia wasn’t advanced to the point of not knowing who she was, where she was, and she knew things weren’t as they should be.

Finally, through the help of one of my resources, I was put in contact with an organization that came with me to visit my mother. I was asked permission to see the list of medications that was being given to my mother so I requested a copy from the staff which was reluctantly given to me. I was even told I would have to wait a few days to get it. With my persistence, they finally gave me a copy of the medication list on the spot. It was only then, as it was reviewed by the organizations representative that was present with me, did I find out that momma was being given anti-psychotic medications. I was never informed by the facility. I also found that she was taking several other medications that I wasn't told about.

With help from agency resources I was able to move my mother to a nursing home here in Topeka one year ago. Her medications were immediately evaluated by the doctor and she was taken off almost all of them as they weren't relevant to her medical needs. Within a few weeks the difference in my mother's health, appearance, stamina, cognitive abilities were amazing. She laughs, she smiles, she can have a conversation, and she dances again. Her skin, and skin color, is healthy, she is kept clean, she even has her nails painted. Momma still has dementia and it is advancing...nothing can change that. But at least she can now grieve the loss of herself and her life as she once knew it. That right was taken from her the day she was put on anti-psychotic medications.

Chemical restraint takes away a person rights, dignity, and sense of self. It, in a sense, puts a person's soul to sleep. Just because a person has dementia doesn't mean they are no longer a person with thoughts, feelings, and rights. They still have the right to grieve the loss they are experiencing, to process those feelings, to hold on to memories for as long as they are able to, to be the person God created. They are still beings with feelings, please don't take that away from them too. They are going through so much already. When a person acts out it's usually because they have a need that's not being met. Instead of chemical restraint, train care givers to recognize when a need is not being met, how to find out what that need is, and respond appropriately. It only takes a minute to hold someone's hand, to give reassurance, even get them a glass of water if that's what their immediate need is. Please believe that this makes a difference. So many residents in facilities don't get physical contact anymore, or if they do it's very minimal, and it makes a difference. They feel lost, lonely, cast aside, without purpose. They don't have the privileges they once had and it's not by their choice. I respectfully ask that you will consider what I have said today and imagine yourself in the shoes of others.

Thank you for your time.