

My name is Karla Benkula, I live in Topeka KS, and I would like to thank you for the opportunity to speak with you today.

In February of this year, I came before you and introduced my mother, Lois Benkula, and shared her story with you. At the age of 72 she was diagnosed with dementia and was placed in a nursing facility here in Kansas. When she became a resident of the nursing home mom was still lucid enough to realize she was losing her life as she knew it and the person she knew herself to be. When she initially arrived at the nursing home she entered with a medication list of four prescribed medications: one for her dementia, an anti-depressant, thyroid medication, and an antacid.

Six months after she became a resident at this facility her case worker with Sunflower stopped coming to visit her every three weeks due to budget cuts. This is when my mother stopped getting regular baths and was not being kept clean. My mother asked me to tell the staff to give her a bath, which I did, but she remained unkept. It was also at this time that mom began refusing her medication because she said it made her feel funny. She would see them put the medication in her food, so she wouldn't eat. She would see them put it in her drink so there were times she wouldn't take liquids, and at other times she would "cheek" her meds and spit them out in the trash. She was even aware that it was the blue pill that made her feel funny. Finally, the nursing staff contacted me saying mom wouldn't take her meds and I told them that by law she had the right to refuse any and all medication she was being given. My statement was met by silence. A few minutes later, I went to mom's room and told her she had the right to not take the medications being given to her. Please let me remind you that at this point in time my mother was still capable of being able to carry on, and follow, a conversation with someone.

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 mom had been sent to a geriatric psychiatric hospital in Abilene, KS for evaluation because she was "acting out". I told the DON that I wanted to come and see her first and I was told that mom had already been transported to the hospital that morning, without my knowledge or consent. I was denied contact with my mother by the hospital saying I was not allowed to see her for 30 days. When she returned to the nursing facility 30 days later I was told that at 73 years of age she had been diagnosed as being bi-polar (a diagnosis that was later declared incorrect and unfounded upon seeking a second opinion with psychiatrist) and was now taking medication to treat this "mental illness". She was prescribed four different anti-psychotic medications.

While on these medications, when mom was actually awake, she wouldn't laugh, smile, speak, or show any emotion of any kind. She sat and blankly stared at nothing. It was as if her soul was gone.

When mom initially refused her medication, she was denying consent through her actions— a decision which she was capable of making at the time. This denial was not respected by her physician or the facility staff. Instead, she was sent to a psychiatric hospital where she was falsely diagnosed with a mental illness she does not have so "legal" justification of chemical restraint could be gained to make the facility's job less demanding. I was not contacted, or informed by the facility, prescriber, pharmacy, or the psychiatric hospital as to why she needed to be placed on these medications or why psychiatric hospitalization was deemed necessary to begin with. The medications she was prescribed was for bi-polar and schizophrenia and was labeled with a warning stating they were not approved for use in treatment practices for dementia. The warnings also stated that the drugs may increase the risk of death in older adults with dementia-related conditions.

With the help of a Kansas State agency resources I was able to move my mother to a nursing home in Topeka one year ago. Her medications were re-evaluated by the doctor and she was taken off all prescribed medications that weren't determined to be relevant to her medical needs. Within a few weeks the difference in my mother's health, appearance, stamina, and cognitive abilities were amazing. She would laugh, smile, have conversations, and danced again. The health and color of her skin was healthy again, she was kept clean, and she even started having her nails painted again. Mom still has bad days filled with anxiety and fear, but those bad days don't happen often. Last November mom was put under hospice care for failure to thrive and losing weight. She is still at the nursing home, she is doing better, and has begun to gain a little weight. Over the past few months I noticed mom was a little more tired than before, but the difference was subtle enough that I thought it was due to the progression of her age and her dementia. Then a few weeks ago I noticed she was sleeping at odd times of the day or evening and, again, I thought her body was just getting tired. Then, last week, I got a call from her hospice caretaker letting me know that mom "sure is sleeping a lot". My instincts kicked in and I called the nursing home and checked her medication list. I found out that, once again, the physician had prescribed an anti-psychotic medication, one that is for bipolar/schizophrenia and also warns that it is not approved for use in dementia related treatment plans and may increase the risk of death in older adults with dementia related conditions. This medication was prescribed in October of last year. I was never contacted by the by the staff or physician and given information, or the opportunity to discuss, the perceived need to prescribe this medication. I was not given the opportunity to give or deny consent for this medication. When I called the DON and the Administrator I was told that they never saw mom exhibit any behaviors that would warrant the need for an anti-psychotic medication, in fact she was very easy to care for, even on her bad days. They looked through her records to find physician notes as to why he would prescribe this drug and couldn't find any. They also couldn't find where I had given consent. I gave a directive that she is be weaned off of the medicine beginning immediately, which began that next morning after the doctor had been notified by the Administrator. I also found that mom, without my informed consent, had recently been prescribed a medication, at a large dosage, for seizures and another medication for neuropathic pain caused by shingles.... she's never had a seizure in her lifetime and she hasn't been diagnosed with Shingles. A warning on the label of both of these medications state they could cause behavioral changes or suicidal thoughts! So, why?! Why were these medications prescribed and without informed consent?! Please know that I do have a meeting set up the with facility Administrator, DON, and doctor to discuss this occurrence, the reasons for the prescription of these three medications, and alternatives for any legitimate health concerns.

Studies show that anti-psychotic drugs almost double the risk of death in older people with dementia and when these drugs are given without the informed consent of the patients, or their representatives, the choice of whether or not to take this risk is being taken away. These drugs are being used as a chemical restraint for staff convenience, to discipline or punish a resident, as was the case with my mother for refusing her meds, and to control people who are difficult to manage. This unnecessary use of chemical substances as a restraint is no different than using physical restraints and this inappropriate use of anti-psychotic drugs violates the rights of these individuals.

I can only give testimony of one person and the affects it has had on my mother's life and health, but there are thousands of stories like hers. The difference is that many patients and families don't understand their rights let alone even know they have these rights. This is why the passage of House Bill 2704 is so important...it is literally a matter of life and death for so many that are not able to speak for

themselves. Many don't have a family member to advocate for them, that's why WE MUST advocate for them. We have a god given duty to protect those who can't protect themselves and although we can't protect them from everything, we can protect their right to have a say in their healthcare and the prescribed treatments being given to them. It is the responsibility of our state government to pass HB 2704 to help ensure that the rights of our citizens are adequately protected.

I want to thank you for your time and consideration today and for allowing me to advocate for those who can't advocate for themselves.