

To Governor's Nursing Home Safety Task Force
From: Joan Tonne Brzezinski (Family)
Date: October 27, 2009

I have followed the Tribune Articles and attended the first 3 hours of the Chicago Meeting on 10/29 at the Thompson Center.

My husband Tom died in a nursing home on July 27, 2009 at the age of 59. He was diagnosed with Frontotemporal Disease (FTD) at the age of 53. FTD is a **brain disease** which most likely started sometime in early 40's. Tom was also deaf, spoke very little and could do nothing for himself. **Early Onset Dementia** is no longer rare and growing rapidly. Tom became violent and was very strong.

Brain disease is not a mental illness. It is a disease like cancer or a bad heart.

Not every one with FTD becomes violent there are a number of other ways FTD patients behave. Beginning in December 2007 and ending with his death Tom was in 3 nursing homes, thrown out of 2, in and out of 3 Psychiatric Units at different hospitals too many times to count. Regular trips to the hospital for an injury or observation were also too frequent to count.

When the doctors first told us Tom could not come home the social workers at the hospital searched for a Nursing Home. Our daughter and I had previously visited more than a dozen on our own knowing this day would come. None we looked at would take Tom because he was violent strong and young. The Social workers also found dead end after dead end. After more than 30 rejections before one said they would take him. Within 6 hours of his arrival there they called to say they wanted him returned to the hospital he came from. The hospital that discharged him would not take him back. He was sent somewhere else to be evaluated. That nursing home took him back a week later. Within 2 months they refused to keep Tom and we had to start looking again.

The same thing happened within four months of Tom's arrival at the second nursing home. More than 50 rejections later a new Nursing Home was found for Tom.

At the 3rd Nursing Home there continued to be countless trips to the hospital for Tom that meant missed and or disrupted days of work for myself and our daughter Theresa. Tom could not speak for himself and could not go without someone with him so one of us would have to be there. The last months of Tom's life I was at the nursing home 5 – 6 days a week letting the staff know his family cared and making sure his needs were met. His glasses, clothes and possessions were all lost or stolen.

Theresa accompanied him to a doctors office visit to find him dressed in size 52 pants he weighed 110 pounds. His shirt said "Tommy Girl". She was embarrassed and mad she went back to the nursing home to let they know. Not much changed.

At the meeting I learned that most of the concerns were with criminals. Everyone that spoke made it seem like they got thru the system easily and minimum problems. That the problems were after they were in the homes.

Our family worked day and night so did the social works to find a Nursing Home 3 different times for Tom. Only to find there wasn't really a place where anyone was up to speed or prepared to care for someone with Early Onset Dementia a **brain disease**. Madden would not take Tom because he was not Mentally ILL. Both staff and residents were afraid of Tom. We could only imagine how Tom felt inside

or what he knew. No one knew if he was cold, hungry in pain, going to lash out at the person he just passed, tear down the drapes in the room or toss his roommates TV across the room.

I hope and pray that this task force considers this as part of the issue.

Tom was a kind and gentle person through out his life before FTD. He was one of ten children. Tom's dad was one of 13. His parents are 85 and 87 still working. Before Tom there is no family history of Early Onset Brain Disease.

Please feel free to contact me at any time.

Regards,

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Our Daughter Theresa is 25 years old and writes the following.

I really think your letter has a strong message. It sums up our horrific experiences, and I think, hope and pray it will speak volumes to those who read it. I haven't been following the news as well as you have, but there is one thing that has stuck in my mind. Most of the articles have been about how these horrible "criminals" are in the nursing home system and how they're so dangerous. I will never forget the day my dad was "missing" in one of his nursing homes when I arrived. Several staff members and myself went looking for him. The terrifying scene of what I found will always be burned in my mind. I walked down a hall and found dad over another resident's bed with his hands on the person's oxygen mask. What he was doing I don't know...but from that day forward I feared for the day daddy's disease and path of violence really caused some real physical injury to another person. It was a hard thought to stomach....that my nice, gentle father....could cause so much harm to someone and not even realize it or know that he did it.... So I agree... There is more to worry about than the so-called "criminals" in the system. I do believe that is an issue as well, but I believe that there has to be a place for people like dad. I wish our long journey on no one, and hope that no one faces such disappointment in the system and sense of loneliness and not knowing where to turn for help for dad.