

My name is Cheryl Zuccola. I have a brother [...] who is a brain injured resident in a Skilled Nursing Facility in [...],* MA. My brother's injury began in December of 2005. I would like to submit a statement for the record on Nursing Home Reform Act, Turning Twenty.

I am not unfamiliar with the Medicaid, Mass health system. Unfortunately, my daughter suffers from Bipolar II, Chronic Asthma and other health issues. Now I am also dealing with my brother's complex condition of Anoxic Brain Damage. I have become friends with many disabled individuals and family members. I have also become enemies with Administration, and some staff members of the Skilled Nursing Facility. This is due to the fact that I have tried diligently to raise many concerns to the Quality of Care and practices at this home. It has and is exhaustive, emotional, heartbreaking, mind boggling, frightening, stressful, sleepless nights, frantic, panic, nail biting, anger, sorrow, eye opening experience!!!! Reality of what still needs immediate attention despite the millions of pleas from family members, advocates, and Legislature.

This is one day in the life of my brother's and family's journey;

Drive an hour each way to the facility. Still exhausted from the night before. Exhausted and angry again because we have the same conversations about the same health concerns, issues, quality of care. The lack of communication, medications, ADL's, CNA's, etc, etc, etc... The constant we understand and we will address these issues, again. The cover ups, the mismanagement, it is just overwhelming to say the least. I would think that the staff and management of these facilities would understand by now what should be done. It is as if you were talking to cement. No matter how many meetings you have to rectify the situations at hand, it is astounding that the very next minute you are in awe with what happens the minute you walk out the door of that meeting. You're facing the same challenges you just discussed two minutes ago. Why? Why? Why?

How many years more will the residents and family members have to endure the hell they live in each minute? How many more battles, conversations, neglect, letters, reports, phone calls, emails, legislature, I understand, we are working on it's, the problems will be resolved, etc, does it take to be heard?? Are all of us not telling the truth? So many people with the same issues? We are angry, fed up with the system. My insides are rotting away with the thoughts of, are the staff caring for my brother today? Are they adhering to our Care Plan? Are the CNA's being trained properly? Are his braces on correctly today, did he get washed, did they check to see if he needs to be changed, does he need to be repositioned, is he comfortable, did they remember to shower him, take off his catheter, give him ROM, medications in order, are his arms, legs, bottom, getting skin breakdowns due to him being in the same position for hours, did staff pass on the correct information to other shifts, is his face clean, is he perspiring, did they brush his teeth, put lotion on, ensure his feeding tube is not clogged, or did staff remember to shut off the feeding tube when changing him, is he in the 30 degree angle so he doesn't aspirate, is his air mattress inflated correctly, is his wheelchair aligned properly, do they have the equipment such as nebulizers, oxygen tanks, on hand???? On and on it goes. This is the real deal. This is what happens at these so called "homes".

Staff getting slapped with a wet noodle for not doing their jobs correctly. Fear of retaliation for speaking up. It does exist, it is happening!!!! Still with all the laws in effect, how do we fix this relentless system???

Money, Insurance, and lack of punishment is what is severely lacking. It is the very core to why the culprits of mismanagement and abuse still exist.

Ask my mother how she feels each time she visits??? You leave notes, talk to staff, everything is still the same. It doesn't really matter what you say. Her heartbreaking daily reminder of what she has to deal with every day, every waking minute.

Just one interview with the many families and residents of these facilities quoting what they have to say says it all. Quoting the truth of their way of life.

I am not ungrateful to the people who are fighting and have fought to bring justice. I am honored, grateful and hopeful to those I have met along this journey. To the individuals who are living in the real world as my family is. Thank you.

Sincerely,
Cheryl Zuccola

***NCCNHR Note: Names of individuals and cities have been removed to protect the identities of those involved.**