

Dementia is Not the Problem, it's the People Around Us

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I've advocated for people living with dementia for 11 years, I thought I had pretty much seen it all. Then something this happened last week. I never realized how having dementia can lead to your loss of freedom.

It started with a friend of mine who lives in Georgia. She was impacted by the fires as she lived in a mandatory evacuation zone. She was living with a person who also had some cognitive issues and he decided to stay. This turned out to be the wrong decision.

Someone found the person living with dementia and took her to the emergency room at a local hospital for smoke inhalation treatment. On the way, she mentioned she had Alzheimer's. But when the person told the medical staff at the hospital, he said something different. That she only pretends to have Alzheimer's but is really mentally ill. The medical staff believed him and they treated her like a street person and suspected that she might be suicidal. That changed everything. They asked a psychiatrist to evaluate her and started a 72-hour hold so she would not hurt herself or others, as they evaluated her for a mental illness.

The ordeal terrified her. She was greatly stressed by not being able to communicate. Her dementia made it hard for her to process information and to speak coherently. After many hours of being held against her will, by which time the team had spoken to her family members who did not help as they also are in denial, the psychiatrist realized that they no longer needed to hold her.

Unfortunately, even though they released her, they never evaluated or treated her for smoke inhalation-the reasons why she came in.

This incident sent chills to my body because I also live with dementia. Because dementia does not allow me to communicate clearly, I too am at risk for being locked up for a possible psychiatric illness if a caregiver or another person alleges I am a danger to myself or others. Until my psychiatric evaluation is complete, I can be held against my will. During that time, I will have lost my freedom.

Are there, right now as you are reading this, persons who suffer from dementia who are locked up? I don't know how frequently this happens, but when it does, the person living with dementia is at the mercy of others. I hate that.

Is there a better way to treat dementia patients? Is there a better way to learn who they are and what challenges they face, without locking them up? Depriving them of their freedom makes them vulnerable in many ways. We need to search for a better way to inform medical professionals what they need to know, so that dementia patients can be treated for what they need, which may be medical treatment, rather than being locked up for possibly being dangerous, which they are not.

My friend left me with these words "there are many people who become homeless, ripped off, avoided, and institutionalized my heart is with everyone who has to find some way to survive when least able and want them to have a voice, their story told".

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