

March 23, 2019

Greetings, Chairman Burke, Vice Chair Huffman, Ranking Member Antonio, and members of the Senate Health, Human Services, and Medicaid Committee!

My name is Rhonda Lowe and I am speaking to you on behalf of my brothers, Kevin Hughley and Kenneth Hughley. I am speaking to you also in honor of our parents, Crystal and William Hughley who were unyielding, unwilling victims of the disease, Alzheimer's. I am writing this on a Saturday morning and suffice it to say I have a hundred gazillion things to do however none it is as important than to let you know that my brothers and I are in **SUPPORT** of Senate Bill 24, the Alzheimer's Disease and Dementias Task Force.

I believe it is a first step only quite frankly. What I do not want to see is that this task force gets caught up in detail and minutia when the results of their findings and their recommendations are needed yesterday. Figure it out, send the report to the Governor and the General Assembly with a definite and defined purpose, timeline for implementation and the financial resources to make it happen and make it post-haste. The same type of attention that is dedicated to cancer should be dedicated to this disease and more! Additionally, I would like to see more than 1 Alzheimer's patient and more than 1 care-giver. Remember who you are doing this for and remember, there is more than one type of Alzheimer's Dementia. I believe that broader sampling needs to be represented.

So here is why we support the taskforce: for mom, we began to notice little things happening to her such as missed or confused appointments, however we didn't really give that a second thought since that happens to everyone. Gradually, our very independent mother began to not want to go anywhere by herself, did not drive on the freeway and restaurants that she frequently visited, she would get lost. Bills began to not be paid (mom was anal about savings, credit and bill pay). She began to tell us stories about things happening to people that when we investigated, simply were not true. This is a horrible disease, however there are things that you can smile about later that happened along the way such as the cruise she went on with my family and forgot to pack her clothes. She had her meds, however clothes were still sitting on her couch waiting to go into the suitcase. It was sad and scary although we can laugh about it now and if she were with us, I think she would laugh also. We knew something was happening but you have to understand that we were children of super heroes and things like that do not happen to them. We still needed to depend on them; we were not ready to take the umbilical cord and un-attach it. Mom knew something had changed and gladly gave up driving (her decision) and following that pretty much succumbed to whatever direction we all decided on together. We let her make her own decisions for as long as possible and at some point, she gave us that duty as well. Mom lingered and continually descended into the world of Alzheimer's oblivion for almost 7 years until she announced during one visit we had with her after the Christmas of 2016 that "by the weekend" she would be home. In fact, she passed away less than 2 weeks later, January of 2017. She was finally free and went home, away from day cares, dark basement group homes, the assisted living homes, nursing homes and blessedly the disease.

Our dad; he always had all the answers as well. He was sharp and debonair; when he walked in a room, he controlled the room. When we built our house, dad worked as our general-general contractor; we worried about nothing. Dad fought tooth and nail to keep his independence however it was stolen from him little by little. Dad was a stutter so we were used to letting him take his time getting his words out. So if he was searching for the right words due to memory, we didn't really notice. Dad was also a proud veteran of the Air Force and a retiree of the US Postal Service as a person who worked on the elevators and other machinery as he would tell us. The work he did stole his hearing (uh, no, nothing that we could prove and get him help financial or otherwise for his care, in case you were wondering). Our belief is that the lack of hearing quickened and enhanced his trip down

Alzheimer's hill. Dad fought against giving up his last bit of control, driving. Dad had been transported to the hospital the September of 2016 as a precaution one night, stayed the night but did not have the wherewithal to tell the nurse to call his children whose numbers were listed on a emergency card he carried with him in his wallet. The day team just happened to look further in his records and saw the emergency contact information and called us from there. The hospital claimed that they had computer problems and could not access all of his records. In order for the doctor to release him that day, he had to give his keys up. It took us almost 3 hours to convince him and honestly, after that, he was never the same. Our brother was married in 2016 however I am sure the celebration was tempered because our parents could not be involved. Dad loved sports, goodness he loved sports. The Cavs won the championship that year. Dad also loved tuna sandwiches and RC cola. Dad was moved from his assisted living home after being there only 5 months or so into the memory care unit where he lasted maybe 3.5 months. He deteriorated rapidly. Again, the Cavs won the championship - we bought him also sorts of championship clothing and my husband made his favorite meal. Neither meant anything; there was no recognition. Dad passed kind of still struggling to live, however live free of Alzheimer's and that happened and we are okay with that. Anything to be free of that disease.

So, here is the thing, when they were both diagnosed, there was very little help from the medical professionals, social workers, anyone; just sad nods. The doctor told us in front of my dad that "well, he has lived his life". People and the medical profession have no patience with this disease, the patient nor the care-giver. We worked blindly. We continued to fight for their dignity. One time when mom was released from the hospital, they tried to send her to a group home that really was a dark basement (run by friends I found out later; some friends). Who vets these places; why were they a choice on the hospital's list? She was there a few days before we "sprung" her and moved her into the Waterford. I mean appointments were set up, bank visits were made, however this was a situation that we were not familiar with. We needed, in fact everyone who visits this world of Alzheimer's needs to be taken by the hand and guided. This is such a very lonely disease. Cancer has their groups of supporters and resources who are very present, assertive and in every moment, but we felt like we had nothing and no one. I ran into someone in the emergency room with their mother and when we exchanged pleasantries, we asked what each other was in for. The person said, my mom is in because she has stomach cancer. I said my mom is in because of dementia. She rubbed my hand and said, I am glad my mom doesn't have Alzheimer's! What does that mean? What a crock! Both moms passed away and in fact her mom went first. I guess she felt her disease was seen as more respectable. Maybe she is right because of the minimal support this disease, that a lot of us will suffer from or intimately watch a close love one suffer from gets.

In summary, if this task force is dedicated to providing a process, financial resources, checks and balances, then again we are all for it and will continue to exhibit our support. I guess what we are saying is don't play with us and don't make this a "temporary, life-long" task force. Respectfully, answers and guidance are needed now.

Sincerely,

Rhonda Lowe