

# Why did it take so long to see the light?

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## Opinion

Going down the path of Alzheimer's is a very terrible role for the person who must take care of them. It's a road no one wants to take willingly. But when you do it does something to you; you go to a point where there is no return from it. If you have been there you know what I am talking about. The only good news is that there are many others like you who are in the same leaking boat that you can relate to and tap into resource as needed. They are there to cheer you on or to pick you up from the gutter when the day seems hopeless. Those caregivers form a unique bond. When it's all said and done they are able to pick themselves up again.

Many just want to forget about all they have gone through, while others continue to help other caregivers to some point. Then there are a few who take the role of being champions and do so much more for the cause. On the other hand, you have those living with dementia or should I say dying with it. Many can no longer speak to anyone, including their own caregiver. They don't seem to have the same level of support or resources. This has been going on for so many years. It just seem the caregiver has more available resources than the patient who is actually slowly wasting away. There are so many more caregivers out there defending the caregiver but not enough standing up for the person dying with dementia.

Did you ever wonder why this is? I have been complaining about this for so many years and been blaming others for why we don't have resources and people to help us as we go through this slow and painful death. It finally hit me, it's because the caregivers are the only survivors in this battle. They went through boot camp. Then the long battle of decline. This has lead to the building of personal feelings and pressures that one had to learn to deal with. This has built some very strong people in the end. When they are finally able to rise again they decide to only help those that went through the same thing as they did. They can relate to their pain they want to forget about the pain their loved one went through. So in the end people like me who are living with dementia have no voice. No one speaks up for them and they continually suffer to the end because none of those caregivers thought about supporting the other side.

Then of course you have all of the organizations that are looking for money and there ongoing support. While they say they are for Alzheimer's and other dementias they are really for the caregivers because those are the people that will be around to keep giving them the money in the future. Those of us with dementia don't seem to matter to them and that is why we keep getting the short end of the stick. So I guess I will need to plead to all of you to do something to stop this damn disease so that we will not need to chose a sides and all of the organizations will need to adjust their mission statement. Until then I guess all of us with dementia will continue to take a back seat and lose our rights. I can tell you as long as I am alive I will fight to change that. Frankly I am tired of people telling me what they can do for the caregivers.

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