

Should it be called Alzheimer's

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I was once diagnosed with Alzheimer's, and because of that I became an advocate for dementia as I believe they all fall under the same umbrella and all need a cure. Throughout my time as an advocate I have had the opportunity to speak to many people who have some form of dementia and they always took issue with the fact that no matter what form of dementia they had, be it Lewy Body or Frontal Temple Lobe, they were always referred to as having Alzheimer's. There was a wide spread belief that organizations that had the word "Alzheimer's" in their title only dealt exclusively with Alzheimer's and did not concern themselves with other types of dementia. This was not the case; many only used the term Alzheimer's because it is the best known and most common of all the dementias.

Another issue was that when people researched dementia they tended to use the term Alzheimer's and not consider any other names. The public identified dementia with Alzheimer's irrespective of actual diagnoses. In many cases people were using the term Alzheimer's to explain a diagnosis of dementia even though they did not have it because it was easier for people to understand, but this created lots of confusion.

Fast-forward 10 years and I have found out that I do not have Alzheimer's, they think I have Semantic Dementia or SNAP; however, when I tried telling people this they get confused as most have never heard of it, eventually I got fed up of explaining it and reverted back to using the term Alzheimer's. I found it much easier. Now that I have been on both sides, I find it hard to understand why those with other forms of dementia other than Alzheimer's get so upset when the proper term for their dementia is not used. Many organizations use the name Alzheimer's as part of their name, which leads many folks to believe such organizations only support Alzheimer's; however, this is far from the truth, as they support all forms of dementia. And then of course you have those who try to distinguish themselves by using the disease name, and organizations that are not inclusive of all of the other forms of dementia and that is sad. You also have those that use the term dementia and try to claim they are different as they support all types. That is kind of a myth. As person who is living with dementia it really does not matter what you call it. It just matters what you do to help fund the cause, so we can find a way to slow it down or find a cure. We must find a way to improve our lives, so we can still live our life to the fullest. To me that is more important than a name.

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