

Monthly newsletter for people caring for those affected by Alzheimer's disease or another form of dementia.

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The Importance of Dementia as a Cause of Death

By Kathryn Cherkas, MPH, and Leila Thayer Malone, MPA

This article primarily focuses on the importance of listing dementia as a cause of death in official death records. It does not discuss the grief, sadness, and other emotions caused by the death of a loved one with dementia. If you've lost a loved one to dementia and are seeking resources, please visit alz.org.

Recently, the Santa Barbara Public Health Department released its [report](#) on the top causes of death in the county. At the top of the list is cancer, followed by heart disease, unintentional injury, and in fourth spot is Alzheimer's disease. Throughout California, Alzheimer's disease is the third leading cause of death. It's also important to note that of the top ten causes of death, Alzheimer's disease is the only one for which we do not have a cure, effective prevention strategies or treatment.

However, it is likely that these figures are skewed due to the underreporting of Alzheimer's disease and other dementias as a cause of death on official death records.

A "cause of death" is defined by the Centers for Disease Control (CDC) as the "disease or injury which initiated the train of events leading directly to death". Dying *from* or *with* Alzheimer's disease or another form of dementia can therefore be understood to mean dying from the condition(s) caused or worsened by dementia symptoms.

For instance, many people with Alzheimer's disease will lose the ability to swallow and can aspirate on their food and drinks. This can cause pneumonia from which the person may not recover. In these cases, it is not uncommon for the doctor to indicate the cause of death as pneumonia.

But because dementia initiated the sequence of events which lead to the person's death, it may be more accurate to state the cause of death as Alzheimer's disease. Note that the pneumonia might not have occurred if not for the effect that Alzheimer's disease had on the person's ability to swallow.



You might be asking yourself, why does listing dementia on a death certificate matter? Well, listing Alzheimer's or another dementia as a cause of death, when appropriate, is important for two major reasons: 1) accurate mortality data can identify gaps in health inequities across groups; and 2) identifying the true burden of the disease encourages greater funding allocations from organizations such as the National Institutes of Health (NIH).

Seeing Alzheimer's reported as the fourth leading cause of death is alarming, but it only gives it more attention and awareness, which can help break down the stigma surrounding the disease—one of the big reasons people do not want it listed on a death certificate, either for themselves or a loved one.

Each year, data about deaths are collected and analyzed. Data on age at death, cause of

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death, and also on diseases that impact quality of life are all important pieces of information used by researchers, lawmakers, and philanthropists to determine where their focus should be directed. Accurate mortality data, therefore, is necessary to identifying trends and to finding solutions to public health problems.

It also can help in encouraging clinicians to specialize in certain healthcare areas. There is already a shortage in the number of geriatricians — doctors who specialize in the health of older adults — and we do not see a positive projected growth despite knowing the growth in the aging population over the next few decades. By presenting accurate mortality data, there could be greater interest sparked in the next generations of clinicians to specialize or further their education in the area of gerontology or neurology.

Data on death trends are also used to determine where limited funding should be allocated. Often, decisions about what research projects should be funded are made based on the need for a solution. Diseases that are not at or near the top of the list of causes of death simply do not receive as much attention, and therefore research into those diseases is not as well-funded.

At this point, it should be noted that it is the responsibility of a medical professional — doctor, coroner or medical examiner — to determine the cause of death. This determination is usually based on their knowledge of the person’s health conditions and/or the results of an autopsy.

So what can you do to help with accurate data collection? Although family members are not directly responsible for what is written on an official death certificate, they can encourage their doctor to include dementia as a cause of

death. This is an especially critical role if the doctor making the determination is not aware of the person’s dementia diagnosis.

Here’s a scenario to illustrate how this situation may come about:

John was diagnosed with Alzheimer’s disease by his family practitioner in 2005. He has since lived with his wife Betty at their home and aside from occasional check-ups, John has not gone back to the doctor or to a hospital.

In 2021, John aspirated on his food. Betty cared for him at home and was in contact with their family doctor, but John’s health declined over the next several days. He was unconscious when he was admitted to the hospital, and died later that day. The attending physician was not aware of John’s dementia diagnosis and listed the cause of death as acute pneumonia.

In this instance, Betty may be the only person who could clarify to the attending physician that John’s dementia did play a role in his death and should be listed as a cause of death. John was barely able to swallow due to his advanced dementia and this is what initiated the chain of events which lead to his death.

Though it might not seem important in the moment, having an accurate cause of death listed on a person’s death certificate can have major consequences to how researchers determine public health crises, inequities, and other issues that have real-life consequences.

For more information about death certificates and why they’re important, go to [cdc.gov](https://www.cdc.gov).



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alzheimer's association

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Santa Barbara
Chase Palm Park
November 5, 2022

Register at alz.org/walk




Virtual Group for teens and young adults

Limited Series
August 17th, 24th & 31st
3 - 4:30pm
Hosted on Zoom

RSVP bit.ly/alzteens

Contact: Kathryn Cherkas
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What's happening to Grandpa?

- Learn more about Alzheimer's and other forms of dementia
- Share your experiences with other young people who get it
- Make connections with other young people in similar situations
- Learn about ways to use humor, health and heart in caring for others (and yourself!)

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