



MAKE
ALZHEIMER'S
COUNT!

The Make Alzheimer's Count campaign is an awareness campaign initiated by the Act Now Foundation (ANF), centered around the 2016 New Jersey Senate Bill 2961. This bill concerns the documentation of immediate and secondary causes of death on death certificates by those legally eligible in the state of New Jersey.

PRESS RELEASE

Assembly Democratic Legislation to Document Alzheimer's Disease-Related Deaths Becomes Law in New Jersey! Law Permits Illness to Be Cited as Secondary Cause of Death on Official Records.

(TRENTON) - Legislation sponsored by Assembly Democrats Carmelo G. Garcia, Joseph Lagana, Adam Taliaferro, Valerie Vainieri Huttie, Joe Daniels, Jamel Holley, Daniel Benson and Angelica Jimenez to ensure that fatalities linked to Alzheimer's disease are properly recorded in official records was signed into law on January 11, 2016.

The new law (S-2961) stipulates that Alzheimer's disease and related disorders may be listed as a secondary cause of death on a certification of death. Often, the primary cause of death on a death certificate is identified as an acute condition, such as pneumonia or heart failure. Alzheimer's disease and related disorders, however, cause a decline in brain function that may lead to problems with feeding and swallowing and can put an individual at risk for poor nutrition, dehydration and infection. This may significantly increase the risk of developing, and exacerbate the effects of, the acute condition that ultimately is listed as the primary cause of death on the person's death certificate.

"Although recent research suggests that Alzheimer's disease may be among the top three causes of death in the U.S., it's difficult to substantiate that without citing Alzheimer's on death certificates," said Garcia (D-Hudson). "Having Alzheimer's listed in addition to the immediate cause of death will help improve the accuracy of records and, hopefully, draw greater attention to an illness that impacts millions of Americans."

Detaching Alzheimer's disease from the immediate cause of death in official records undermines the reality that it is a grave illness that requires urgent action, Garcia noted. As such, under the new law, Alzheimer's disease may be listed as a secondary cause of death, provided that: (1) the deceased person has been diagnosed with Alzheimer's disease or a related disorder, and (2) it is determined, in accordance with accepted medical standards and with a reasonable degree of medical certainty, that Alzheimer's disease or a related disorder was a significant contributing cause of the person's death.

"Although data indicates that nearly 93,000 people died from Alzheimer's and related disorders in 2014, studies suggest that the true number of deaths attributable to these conditions may be greater than 500,000," said Lagana (D-Bergen/Passaic). "This discrepancy is due in part to the way deaths are recorded on death certificates. This law aims to create a more accurate picture to aid medical professionals."

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"It's important that we gain a more accurate picture of the number of deaths caused by Alzheimer's and related disorders, because it can have a significant impact on the way these illnesses are treated, how research is directed, and how funding for all of these things is allocated," said Taliaferro (D-Cumberland/Gloucester/Salem).

"Having more accurate data available on the number of fatalities related to Alzheimer's will lead to more awareness, more research and ultimately, a better overall understanding of this disease," said Vainieri Huttel (D-Bergen). "Something as simple as putting 'Alzheimer's' on death certificates has the potential to transform the way we see this illness."

"Deaths related to Alzheimer's disease often are underreported because another complication is listed as the sole cause of death," said Daniels (D-Middlesex/Somerset). "Particularly among older populations, there may be more than one illness that leads to death, and it's important for official records to reflect that."

"Properly recording how many individuals die due to Alzheimer's disease is the first step toward having more funding allocated for research," said Holley (D-Union). "Once we have data available that accurately lays out the impact of this illness, we will be better equipped to move toward a cure."

"When studies suggest that the actual Alzheimer's death toll is six times what's been reported, it's a signal that we have to change our approach to recordkeeping and data collection surrounding this illness," said Benson (D-Mercer/Middlesex). "Citing Alzheimer's disease as a secondary cause of death is a means of more accurately recording its prevalence and acknowledging its seriousness."

"There is huge discrepancy between the number of deaths actually recorded from Alzheimer's and related disorders and the real number believed to be attributable to these illnesses," said Jimenez (D-Bergen/Hudson). "Given that it's the only major cause of death that can't be cured or prevented, we need to improve data in order to boost research."

The legislation received unanimous approval from both the Assembly and the Senate.

Why Start This Campaign?

Currently Alzheimer's is the sixth leading cause of death in America. This information is collected through the date on death certificated collected across the country. It has been recorded that the number of deaths of Alzheimer's is grossly misreported and could be as far as third on the list of deaths in the US. A common cause of this is ignorance of medical history at the time of the signing of the certificate. What this campaign hopes to do is to create awareness of this issue in hope of having the deaths of our seniors correctly reported.

There is no known cure and a victim of this disease needs full time care. The average American household will be under immense financial strain to afford the care needed for this disease. Unfortunately, the allotment of funds for research and care is dependent highly on death statistics like

the aforementioned. The Make Alzheimer's Count campaign hopes that by calling for accurate reports, more funds will be allotted to the many New Jerseyans who need dementia specific care and services as well as increased research funding to come upon a cure for this costly disease.

How Will the Campaign be Implemented?

This campaign will run over 6 months through a series of seminars and events at local hospitals, offices on aging and community senior centers. These venues will allow the information to be disseminated to all our target audiences. These includes those who are legally qualified to sign death certificates, seniors and their families. Running simultaneously to the event will be a informational campaign with brochures and pamphlets for distribution.

What are the expected outcomes?

There are many long-term and short-term goals for this campaign. An initial goal will be to inform local physicians, nurses and medical examiners of Bill 2961 and how to comply with this law.

In keeping with the mission of ANF, ultimately, we would like to see the quality of life of all those affected by Alzheimer's improved. A successful campaign would lead to just that. Alzheimer's disease takes away power from those affected but this campaign stands to put power back into the hands of those seniors and their families. Knowledge of correct procedures and expectations of those who provide care to their loved ones. Families have the ability to demand that this information is on the death certificate of their loved one. The Alzheimer's patients themselves have the power to help combat this by stating their will that the information of their disease makes it on to their death certificate. The accuracy gained from these things would not only benefit Alzheimer's but many other illnesses and conditions that face similar problems of underrepresentation.

Additionally, through our efforts we would like to see more accurate statistics that reflect the length and breadth of Alzheimer's in our country.

Knowledge is power and we at ANF know and stand by the power of education in the lives of individuals and families affected by Alzheimer's. Make Alzheimer's Count campaign is committed to using this power of education to make changes in our community. It could be the difference between actual life and death of many of New Jersey's senior population. This disease is fast growing and to combat its effect, we need to establish dementia friendly communities in all areas. Make Alzheimer's Count is our way of reaching that goal.

Target Audience

- Primary - Hospitals, Medical Centers with Attending, Covering, or Resident Physicians, Registered Professional Nurses, Hospice Agencies, Coroners, Medical Examiners, and Funeral Directors

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- Secondary - Family caregivers and community members 50 years+

Strategic Plan to Follow

- Tentative launch date – Spring 2024
- Launch with Sponsored Hospital Group (Hackensack Meridian Health)
- To include key note speaker Senator Menendez, Senator Booker, & other officials at Campaign Launch
- Possible panel discussions and open seminar

For Additional Information, Please Contact:

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