

DEMENTIA DEFENSIVE

N.J. families facing Alzheimer's more openly

Though help sought earlier, there is still much to learn about immediate care

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Alzheimer's is coming out of the shadows in New Jersey, but many families struggling with it aren't being guided to services that could help them cope.

Those are the key findings from a statewide survey done by Fairleigh Dickinson University's PublicMind for Alzheimer's New Jersey.

The survey found 89 percent of people concerned about memory loss went to see a doctor about the problem, and 87 percent received a formal diagnosis of Alzheimer's or some other form of dementia.

These are unexpectedly high numbers for a disease surrounded by such fear and stigma that families often have avoided seeking medical help in the past and doctors have been reluctant to give that diagnosis to patients.

"I was surprised by the percentage of people who responded saying they did indeed seek a medical diagnosis when they suspected their loved one had Alzheimer's," said **Kenneth Zaentz**, president and CEO of Alzheimer's New Jersey. "It was much higher than I thought it would be and higher than some other data I've seen in past."

Previous studies done nationally have shown that when families begin to suspect a loved one has Alzheimer's, they may put off a

diagnosis for years, until the memory problems become so severe that they can no longer be avoided.

And as recently as 2015, a national report showed that only 45 percent of people with Alzheimer's or their family members were told of the diagnosis by their doctor, either because the doctor wasn't sure about the diagnosis or didn't think the patient would benefit from knowing.

But organizations like Alzheimer's NJ have been working hard to educate the

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public on the importance of getting a diagnosis of Alzheimer's as early as possible. Zaentz says the new findings by the PublicMind survey in New Jersey suggest that effort may be paying off.

"The only thing I can attribute it to is that perhaps we done, over the years, a better job than other areas of the country about educating people about the importance of getting a diagnosis," he says.

However, only about half of those who responded to the PublicMind survey said their doctor suggested support programs to assist them after the diagnosis was made.

"That's where more education has to occur, to have physicians become more aware what services are

available," Zaentz says. "I'm not saying a physician has to be an expert on everything that's available in the community, but it's at least important to let the family know that, yes, this is not a diagnosis anyone wants to receive, but there are services that can help."

The Fairleigh Dickinson survey was conducted in late September and involved 805 adults in New Jersey, about 30 percent of who said they either are or have been a caregiver for someone with dementia.

The survey results regarding a diagnosis of Alzheimer's are based on those who had direct experience with it.

About one-third of them said they received the Alzheimer's diagnosis from a neurologist, and a similar percentage said the diagnosis came from a combination of physicians.

For six percent, the diagnosis was by a geriatrician, and 18 percent said their primary care doctor was the one to deliver the diagnosis.

Even at a time when people are more willing to go to a doctor when they see possible signs of Alzheimer's, Zaentz says the diagnosis remains a difficult one for families and patients to receive.

"People go through stages with news like that," he says. "They're in shock. They



don't want to believe it. Some people are in denial. Some don't understand what the progression of the disease is going to be, or they don't fully understand how many changes this disease is going to bring to their lives, not just the person but also the caregiver."

Still, health experts agree that seeking a diagnosis as early as possible is always better than denying the problem or putting it off. For one thing, memory loss that resembles the symptoms of Alzheimer's is sometimes caused by other medical conditions that can be identified and treated.

"Some of kinds of dementia that someone might have are reversible," Zaentz says. "For example, people can get dementia due to a urinary tract infection. A wrong medications interacting can cause dementia. So certainly it's important to get a diagnosis to find out, what exactly am I dealing with? Is it something that's more treatable?"

And even if the diagnosis is Alzheimer's, early detection can:

- ▶ Give the patient more time to adopt lifestyle changes that might help slow the progression of the disease.
- ▶ Allow the patient to be considered for a clinical trial that could result in receiving a promising medical treatment for Alzheimer's.
- ▶ Provide the family with more time to do advance

planning, which also gives the patient a greater say in his or her future care.

- ▶ Offer the family and patient more opportunity to connect with support groups, organizations and services that can assist them in dealing with the many medical, emotional and financial challenges that comes with this disease.

But to take advantage of those services, they have to learn about them. Based on the survey findings, Alzheimer's New Jersey will be looking for additional ways to educate both the medical community and the public about the help that's out there.

"There are definitely services available," Zaentz says. "I wouldn't say it's anywhere near perfect, and clearly there are more services needed, but for families to say, 'OK, I have this diagnosis and feel like I'm afloat on the raft without a paddle,' that is not the case, so knowing they are not alone and there are places they can turn, that's important."

Alzheimer's New Jersey, formerly known as the Alzheimer's Association Greater New Jersey Chapter, is a resource for families and patients, and also can help point people to other resources and services they might need.

More information is available at the Alzheimer's NJ website at alznj.org or by calling the organization's

Helpline at 888-280-6055.

Other good sources of information and help for families dealing with Alzheimer's include:

- ▶ The Office on Aging in your county has expertise on local resources for patients with Alzheimer's and for caregivers. You can find contact information for your county office visit state.nj.us/human-services/doas/services/agencies/index.html.
- ▶ The National Academy of Elder Law Attorneys offers services provided by lawyers specially trained to give legal guidance to families dealing with dementia. You can find elder law attorneys in New Jersey at naela.org/findlawyer.
- ▶ The Aging Life Care Association offers the services of professional care managers, many of whom have a background in nursing or social work and specialize in helping make sure that older adults and families get the help and services they need. You can find an Aging Life Care professional near you by using the search tool on the association's website.
- ▶ The Veterans Administration offers a broad range of services to veterans dealing with any form of dementia. More information is available at va.gov/geriatrics/alzheimers_and_dementia_care.asp.



Families affected by Alzheimer's and volunteers help raise funds for support and services at a walk in Jersey City.

Courtesy of Alzheimer's New Jersey