

SPECIAL YEAR-END ISSUE

# Alzheimer's TODAY<sup>®</sup>

The Official Magazine of the Alzheimer's Foundation of America

**Children's Book Teaches  
About Alzheimer's and Love**



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**TREATMENT OPTIONS**

The first step in accessing an intervention is the engagement of a qualified dementia health care provider for a complete evaluation. This could be a geriatric medicine specialist, a neurologist or a geriatric psychiatrist.

**Non-Pharmacological approaches**

For mild cases, non-pharma approaches should be tried first: music therapy, aromatherapy, exercise or physical therapy, pet/animal therapy and, for some, psychotherapy. If these fail or if symptoms are persistent or severe, medications may be necessary.

**Pharmacological approaches**

All medications carry risks that need to be discussed and weighed against possible benefits. Dementia-focused providers, especially geriatric psychiatrists, may recommend medications from the antidepressant class (selective serotonin reuptake inhibitors, SSRIs) or from the atypical antipsychotic class. Though often effective, use of antipsychotics is generally a last resort and should be approached with caution, as these have been associated with an increased risk of death. Use of sedative hypnotics should generally be avoided as they often worsen confusion and cause falls.

**Clinical trials**

Experimental non-antipsychotic medication clinical trials are ongoing. Information about where these are offered and how to begin the process of enrollment can be found at [clinicaltrials.gov](http://clinicaltrials.gov).

**CAREGIVERS NEED CARE**

Although these behaviors—collectively referred to as NPS—contribute directly to caregiver stress and burnout, often they can be successfully addressed by working with professionals using a variety of intervention approaches.

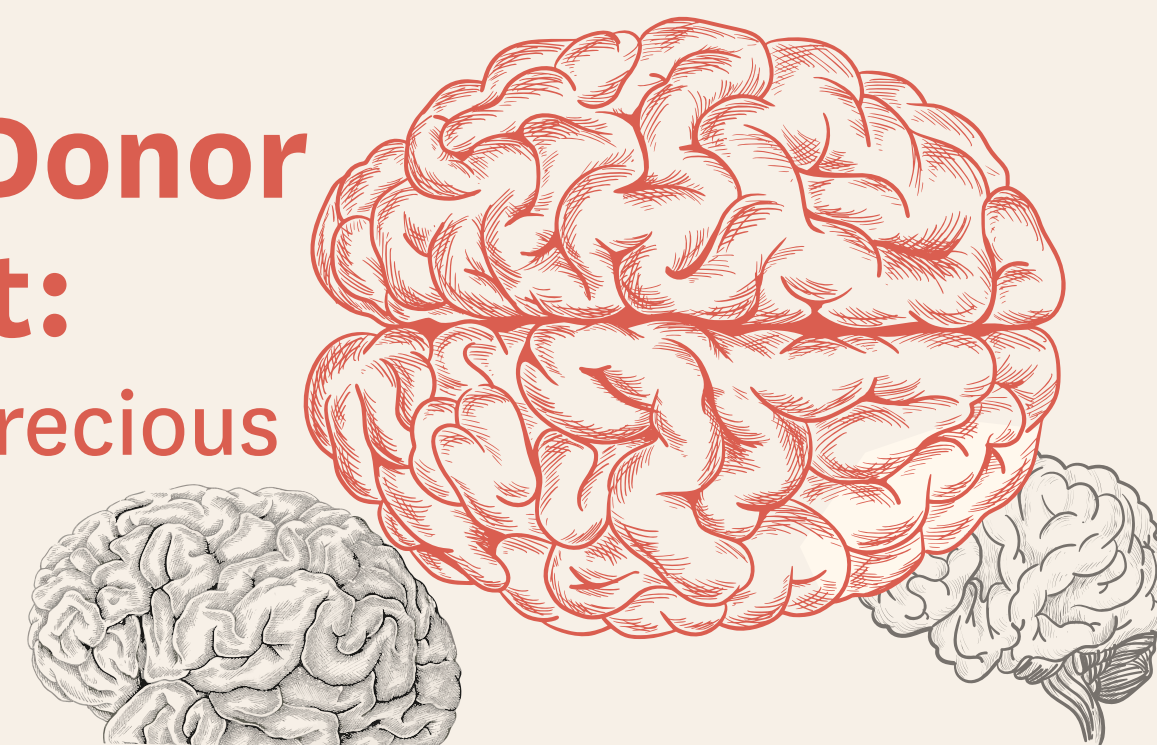
Seek support, guidance and resources by contacting the AFA Helpline, staffed by licensed social workers trained in dementia care, available 7 days a week by phone (866-232-8484), text (646-586-5283) or webchat at [alzfdn.org](http://alzfdn.org).

**ABOUT THIS ARTICLE**

This article is based on a brochure, “What Are Neuropsychiatric Symptoms? A Caregiver’s Guide,” written in consultation with Medical, Scientific and Memory Screening Advisory Board Member Jeremy Koppel, MD, co-director of the Litwin-Zucker Center for the Study of Alzheimer’s Disease, Feinstein Institutes for Medical Research.

Interested in receiving a copy, please contact the AFA Helpline, at 866-232-8484, text at 646-586-5283, or webchat at [alzfdn.org](http://alzfdn.org).

# Brain Donor Project: Leave a Precious Final Gift



Tish Hevel says most people plan carefully for what will happen to their belongings, their property and their money when they die, but she wants to make sure they include their most important asset, their brain. She formed a nonprofit, The Brain Donor Project, to help them do just that.

Your final act could very well advance the science of brain disease. It starts with completion of a simple online form. Go to [braindonorproject.org](http://braindonorproject.org) to learn more. Soon you’re referred to a brain bank, given instructions to share with your family, and when the time comes, plans are in place to leave a precious, final gift.



Traditional methods of studying the brain are insufficient.

Neurological disorders “affect the brain at a very, very fine level so there are all kinds of very small structures in the brain, neurons and the connections between the neurons, that we cannot visualize with imaging, that we can’t study without actually looking at the brain tissue,” Dr. Joshua Gordon, director of the National Institute of Mental Health/NIH, said.

Tish Hevel has made it her mission to raise awareness of this need. For this former journalist and public relations professional her quest arose from her personal experience with her father’s Lewy body dementia. It started with



Tish Hevel and her dad Gene Armentrout

“Dementia illnesses are out of control right now,” she says. “Our chances of being diagnosed increase as we age. We’re all living longer. It’s easy to see where this is leading, where the urgency lies. We’re desperate for answers.”

Researchers are looking for those answers. The most effective way to find them is through examining human brain tissue.

“Access to tissue is a stumbling block for a lot of science to get done,” says Dr. Walter Koroshetz, director of the National Institute of Neurological Disorders and Stroke/National Institute of Health (NIH). He said brain disorders are the leading cause of disability in the United States.

many internet searches to try to understand the disease. Which led to more questions.

“We didn’t even know what brain donation was. It kept coming up.”

Her father was already a full-body donor, so Hevel assumed

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## Focus on MCI in Alzheimer’s disease

### Learn about a research study



**SEE IF YOU MAY QUALIFY:**  
[LightwaveStudy.com](http://LightwaveStudy.com)



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Hevel, her dad, and sister Annie McManis

**BRAIN DONOR PROJECT** *cont'd from p. 27*

assigning his brain for separate research would not be a problem after he died in 2015. She was wrong.

“It was super complicated at the time. I wanted to see if I could do anything to help.”

She reached out to NIH for advice and turned her personal quest into The Brain Donor Project, which she started in 2016. Her mission was twofold: to raise awareness of the critical need for donated brain tissue and to simplify the process of becoming a brain donor.

Hevel said NIH heard from researchers that they had problems getting access to human brain tissue because most brain banks imposed some level of barrier. So the NIH created the NeuroBioBank to make the tissue more readily available. The Brain Donor Project supports NIH’s NeuroBioBank.

Many people think if they check the box on their driver’s license everything will be taken care of, Hevel says, but that’s not the case because unlike other organs the brain isn’t transplanted so it is overlooked.

“There are too many misconceptions,” she says.

Fear that brain donation will be costly for the family is another misconception.

“We’re only working with the brain banks of NIH so there’s no cost.”

A third misconception is that the removal will be disfiguring but

the brain is taken from the back of the head, so an open casket funeral is still possible.

Close to 20,000 people have taken the first step to donation by registering on the Project’s website, **braindonorproject.org**. Thirty percent of them are people with unaffected, healthy brains. Because of privacy reasons, Hevel doesn’t know the exact number of donations that have resulted, but estimated it to be “well over 1,000.” She cites two big motivations.

“For some it’s altruistic. If we can spare some future family, we’ll give this gift on our way out the door when we’re finished with it. It’s comforting to know something positive can come from it. We felt that way too.”

Another motivation is that the NIH brain bank will supply a summary of its neuropathological findings based on an autopsy of the brain.

“That’s really important for families to have,” Hevel says. “It’s key information for children and grandchildren because soon there may be avenues for editing or repairing their genes.

“People assume dementia is a natural part of aging, but that’s not necessarily true.”

Hevel still draws inspiration from her father, a former president of a regional brokerage firm who died at 78.

“We really miss him, but doing this work I feel his presence. He’s with me.”

Photos courtesy of Tish Hevel

# Dementia Risks in the LGBTQ+ Community

LGBTQ+ is an acronym that brings together many different gender and sexual identities that often face marginalization across society. It stands for: lesbian, gay, bisexual, transgender, queer, questioning, intersex, asexual and the “+” holds space for the expanding and new understanding of different parts of diverse gender and sexual identities.

Although there is greater social acceptance of LGBTQ+ identities in cities like New York and San Francisco, this does not hold to be true in many parts of this country and the world. Sixty-four countries have laws criminalizing homosexuality. Among the penalties are death and forced psychiatric treatment.

“Recent data suggests that social acceptance of LGBTQ+ people in the United States has plateaued and may even be reversing,” said Jennifer Reeder, LCSW, SIFI, AFA’s director of education and social services.

“Aside from the here and now, it’s important to take into consideration the long history of discrimination experienced by LGBTQ+ people,” she said. “There is no federal law that explicitly protects LGBTQ+ people from discrimination, and not all state and local nondiscrimination laws include protections based on gender identity.

“This lack of protection from their federal,

state and local governments creates great mistrust in systems that have already proven to be discriminatory. This can impact a person’s willingness to share their true identity, as well as seek support before there is a medical crisis.”

An older LGBTQ+ adult who is experiencing symptoms of dementia has already likely experienced stigma and discrimination for most of their life from healthcare and social services providers. It is terrifying to become vulnerable and reliant on these providers, Reeder says.

When LGBTQ+ older adults do access services, their history of experienced stigmatization can affect their willingness to disclose their identity. Forty to 60 percent of older LGBTQ+ adults in their 60s and 70s say their healthcare provider does not know their sexual orientation.

**HEALTH DISPARITIES**

According to the CDC, health disparities are preventable differences in the burden of disease, injury, violence or opportunities to achieve optimal health.

These disparities are inequitable and are directly related to historical and current unequal distribution of social, political, economic and environmental resources.

“Historically, LGBTQ+ adults have lower rates of health insurance coverage,

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Lindsay Snow | Dreamstime