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STROLL

Winchester

I'm Still
Here
Founder
**John
Zeisel**
And Wife
Jacqueline
With Annie

DELIVERING NEIGHBORHOOD CONNECTIONS



John and Jacqueline Zeisel • Courtesy of Priscilla Fitzgerald of Ambrose Photography

I'm Still Here

BY MICHAELA O'SHAUGHNESSY WITH CONTRIBUTIONS FROM MARY ANNE GRANT AND RESIDENTS JOHN ZEISEL AND BILL CUMMINGS

To many, mention of the word “dementia” incites dread: a diagnosis with the potential to evoke a sense of hopelessness. Despite the despair that dementia often elicits, Dr. John Zeisel’s nonprofit organization, I’m Still Here (ISH), offers only hope in its multi-layered mission to provide a full and vibrant life for people with dementia.

Raised in New York’s Rockland County, Zeisel graduated with a doctorate in sociology from Columbia University and an Honorary Doctor of Science degree from Salford University. In 1971, the Winchester resident and

ISH founder was selected as Harvard’s Graduate School of Design’s first Loeb Fellow (of which there have been over 400 in the past 50 years). During his ten years of teaching at Harvard, Zeisel helped architectural students gain a broader perspective in their approach to buildings. One way Zeisel did this was by introducing “user needs,” which is basically building for what people really need. “I was a sociologist teaching them how to build buildings that really work,” says Zeisel.

An internationally known expert in dementia care and designing

dementia-friendly spaces, Zeisel was first approached by a large Indiana nursing home chain in the early 1990s. His creation of the first memory care neighborhood (now an integral part of most Assisted Living Communities) initiated a lifelong journey in which Zeisel continues to find ways to improve the lives of people with dementia through the development of non-pharmacological programs. Having only stayed in a hospital once for a twisted knee, Zeisel has become the voice for how meaning and comfort can be provided to those who had

previously wandered through nursing homes without purpose.

As co-founder of Hearthstone Alzheimer Care, now Hopeful Aging, some of Zeisel’s most important lessons have been from staff who have been involved with designing and operating additional memory care neighborhoods, including Cummings Properties’ New Horizons buildings in Marlboro and Woburn. From this sharing of information and hands-on education grew the operational, conceptual and ethical background making up the ISH approach and principles. “We were actually doing it instead of sitting in a room and thinking about what it should be. We just did it and found out what worked,” says Zeisel.

The guidebook that developed from this compilation of best practices was the inspiration for Zeisel’s bestselling book, *I’m Still Here: A New Approach to Caring for Someone with Alzheimer’s*. “The book — translated into five languages — is a reflection of ten years of doing it rather than making up some theory,” explains Zeisel. His work is also highlighted in the award-winning public television documentary *Revolutionizing Dementia Care*.

Zeisel may have gotten his start designing buildings that benefit people living with dementia, but his greatest accomplishment is helping them find their personhood so they know who they are and how they can relate to others in a dignified manner. This emphasis on dignity, engagement, community and education can mean all the difference for someone with dementia. Providing them with as normal a life as possible can be as simple as putting them in front of a garden and handing them gardening tools.

“Everyone has different interests — some might like gardening while it is well known that many are inspired by music. Some like caring for others, while others, like those attending the North Andover Windrush Farm Equine Therapy program (featured on the cover), appreciate taking care of animals. We take the approach that recognizes the individual and what piques their interest,” says Mary

Anne Grant, the executive director of I’m Still Here.

Avoiding the term “patients,” ISH found that when people with dementia are invited to make decisions and participate, and those decisions are then respected, they regain the purpose that dementia and uninspired caregiving once took from them. Given the ability to live their lives doing all that they *can do* as opposed to being told what they cannot, their level of engagement rises alongside their quality of life.

“It’s a very positive approach to dementia care. We help people to live and be in life, not a journey to death,” comments Zeisel. “There’s liveliness and joy, not misery and sitting around, in changing the stigma with the treatment of dementia and doing it on a regular basis.”

In the first twenty years of the foundation, ISH developed several legacy programs like *Meet Me at the Movies*, a program in which they take five-minute movie clips of iconic films and bring them to a movie theater, and *Meet Me at the Museum*, which was later adopted by the Museum of Modern Art. Other programs include *Artists for Alzheimer’s* (ARTZ), which enhances the cultural and creative life of people living with dementia, and *It Takes a Village*, which embraces the local community through activities in local venues.

In 2018, ISH launched its *Innovation Program* to provide seed funding for organizations, facilities and individuals to develop new and exciting engagement programs for persons living with dementia and their care partners. Using art, music and yoga, in addition to horses and dogs, the programs do more than entertain; they help people be present. The funds they raise, in addition to awards like the \$25,000 from Seattle-based Maude’s Awards and \$100,000 from the Woburn-based Cummings Foundation, are used for program development so that they can be offered around the country.

“It is incredibly important for seniors to have access to engaging activities that contribute to their quality of life,” said Bill Cummings, a

Winchester resident and founder of Woburn’s New Horizons at Choate senior living community. “Having been extremely impressed with John’s longtime work through Hearthstone at New Horizons, the Cummings Foundation was delighted to support the I’m Still Here Foundation with two grants of \$100,000 each. We should all be appreciative that someone with John’s combination of compassion and innovative thinking has dedicated his career to this critical field.”

What is so unique about the programs ISH supports is that while they often sprout from a familiar concept, they go much deeper. Many of them center around an activity that is not only enjoyable but also helps others. For instance, instead of just bringing in dogs to pet and entertain, a program in Louisiana has residents grooming and caring for rescue dogs that they help save by getting them adopted. In that same program, elders with dementia join together with school-age students to bake and give out dog biscuits. In another program involving animals, funded at the North Andover Windrush Farm featured on the cover, residents visit an equine therapy center over the course of several weeks where they get to know “their” horse, then groom the horse to get it ready for children with autism to ride.

“The basic parts of their personality that deserve respect and dignity and personhood continue to exist. If you start to treat people like they don’t exist, they lose some of that personhood, so we created and continue to fund such programs,” says Zeisel.

There are also artistic programs like the one at the Martha’s Vineyard Center for Living which puts on a music program in the public arena every month. In Chicago, a university and medical memory center joined forces to send out art boxes to over 400 people living with dementia and their caregivers, which bonds persons living with dementia and their partners living at home through art.

Grant, who became involved in ISH about a year and a half ago, can appreciate a program involving

caregivers after caring for her own mother, who suffered from dementia. "It helps them strengthen their relationship and remember that they can still enjoy each other's company and do something together that is not only good for a person with dementia but good for the care partner as well. There can be a lot of laughter and joy with that kind of activity. We always try to think about the care partner. You really want to connect with that person, and having some support and guidance in how to do it can be very life-fulfilling."

It is that type of program that is behind ISH's recent award of \$25,000 from Maude's Awards, an organization

created to acknowledge and support programs like I'm Still Here that enrich the quality of life for persons living with Alzheimer's disease and related dementias and their care partners.

Using methods and scales, ISH measures the effectiveness of the programs with such things as engagement (mainly how engaged people are versus just looking around), depression (which decreases with engagement), anxiety/agitation, and falls, with the latter being negatively impacted by the former. Research shows that ISH programs have fewer falls because of how purposeful people are when they are engaged.

"When we are mindful and engaged, we pay attention to what we're doing because it's important to us. It's fundamentally being present and being here, not in the way we used to but in one that is still meaningful because our brains, bodies, souls and minds are engaged. What we also find with people who are engaged is that their balance is

better. In nursing homes and in assisted living around the country where residents are just wandering around doing nothing, they are more likely to have a fall," says Zeisel.

Going forward, ISH plans to hold seminars and educational activities that Zeisel hopes will help other organizations, facilities and community centers contribute to ISH neighborhoods, where people with dementia can be part of the community and not pushed aside.

"What I'm working on now looks at the things we engage in because they are fundamental to our existence. We didn't need to play bingo as we evolved over the last millions of years, but we did need to grow things, we did need to take care of each other, and we did need to communicate and write or draw things that others could understand.

I'm starting to realize that engagement is doing stuff necessary to live."

In that perspective, and others suggested by Zeisel in his open-minded research, we can come away with a valuable lesson from those facing this otherwise terrifying condition that can inform how we all find purpose in life.

"It's a very positive approach to dementia care."

THE
I'm Still Here
FOUNDATION

For information about how you can help support I'm Still Here Foundation programs or to find out more information, visit www.imstillhere.org.



Resident at Abe's Garden Community



Spending time with horses



Visit from a rescue dog



Caring for horses with John Zeisel at the MV Center for Living



Tony Smalls saying "hello"



Artists for Alzheimer's (ARTZ) program



A resident with a rescue dog at Oak House, which is part of Poydras Home in New Orleans