

I'm Still Here: A Breakthrough Approach To Understanding Someone Living With Alzheimer's

Reviewed by Diana Anderson, MD, MArch, LEED® AP



Author Affiliation: Dr. Anderson is a 2008–2009 Tradewell Fellow at WHR Architects, Inc., in Houston, TX.

I'm Still Here: A Breakthrough Approach To Understanding Someone Living With Alzheimer's (2009), John Zeisel, PhD, Penguin Group (USA), New York. 262 pages, \$24.95. ISBN 978-1-58333-335-8

When medical students are taught about the communication skills required for “breaking bad news” to patients and families, it is emphasized that once the diagnosis is said aloud, nothing more is heard or acknowledged by the patient except for the sound and meaning of that very word. Alzheimer’s is one of those words. Many patients can recall in detail how their diagnosis was disclosed, even if they remember little of the conversation that followed. Often after that initial diagnosis and discussion, patients leave the hospital or doctor’s office with nothing in their hands except follow-up appointment slips and sometimes prescriptions. *I’m Still Here* would be a wonderful resource to hand to a patient or family member on

that particular day, acknowledging a deeper understanding of this condition, the strength of nonpharmacologic treatments, and most importantly, an offer of hope for continued loving relationships and quality of life.

The author, Dr. John Zeisel, has spent years developing a greater understanding of the effect of Alzheimer's on the human brain, relationships, and one's way of life. His background includes sociology and architecture; he is the president of Hearthstone Alzheimer Care and the founder of Hearthstone Way, an innovative and practical approach to the care of people living with dementia. Dr. Zeisel developed ARTZ, the Artists for Alzheimer's program, which develops guided museum tours and other cultural experiences for those living with the disease. ARTZ is discussed in several chapters of the book; it is not limited to the visual and dramatic arts, but includes theater, film, music, and the circus arts. The book includes a number of wonderful narratives about watching those living with Alzheimer's attend circus shows and museum tours, thereby helping them to focus for a longer period of time and enhancing their ability to perceive and express their observations and access both long- and short-term memories.

Reading *I'm Still Here* from both a medical and architectural perspective offered numerous lessons. A unique quality of this publication is that it targets a wide audience, not only patients and family members who have experienced the condition themselves or through a loved one. Physicians, designers, artists, and almost anyone else who would like to gain a deeper understanding

of the human condition and appreciation for the brain's capabilities will gain new knowledge from this invaluable resource.

Although this book targets a wide audience, designers and architects will gain particular insight from Chapter 6, entitled "Treatment by Design." Here, Dr. Zeisel makes his case for eight identified design characteristics that support the day-to-day living of those with Alzheimer's: exit control, walking paths, privacy, shared spaces, gardens, homelike quality, sensory understanding, and supports for independence and empowerment. This chapter explains the correlated findings of these design features in reducing what Dr. Zeisel terms the 4 A's of Alzheimer's: agitation, anxiety, aggression, and apathy. There is a wonderful discussion of evoking the five human senses of seeing, hearing, touching, smelling, and tasting within spaces to gain multiple sensory cues about our surroundings and thus help the brain determine the type of space we are in. The notion that the architecture, interior design, and landscaping of dwellings can augment memories and the ability to function independently highlights the hardwired capabilities of the brain that everyone has and may retain far into the illness. It was hopeful and enriching to learn that expressing and recognizing emotions in human facial expressions, responding to touch, responding to and making music, and discerning landmarks for wayfinding are all abilities that last to the end of life, even with Alzheimer's.

Emphasized strongly throughout the book are ways to access the parts of people's brains that are

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working well, thus relieving stress on the parts affected by the illness. Dr. Zeisel sends the strong message that all is not lost, and what is out of sight is not necessarily out of mind, as the old adage implies. In addition, people living with Alzheimer's retain essential powers of observation even though reflections about what is seen may be more of a challenge. This book can be likened to a key, unlocking many of the misconceptions surrounding this neurological condition and focusing on the aspects of health rather than disease, which is all too common in the medical and media-driven world today. The book also has a chapter entitled "The Gifts of Alzheimer's," reminding us that there is life after such a diagnosis; in it many personal stories from those who have developed insights into personal relationships with loved ones diagnosed with the disease are shared with the reader.

Each of the 11 chapters of the book begins with a powerful quote to introduce the featured theme. Perhaps the quote that stood out the most in my reading of the text was the one by Malcolm Gladwell: "Why is it that some ideas or behaviors or products start epidemics and others don't? And what can we do to deliberately start and control positive epidemics of our own?" Dr. Zeisel's book *I'm Still Here* no doubt has begun a positive epidemic to further the understanding of Alzheimer's disease by communicating the experiences of real people and ways in which we can reach our loved ones. The notion of Alzheimer's as a treatable condition rather than a hopeless one is exemplified in this must-read work.

Dr. Zeisel is also the author of *Inquiry by Design* (2006 revised edition), a classic and useful resource for environmental researchers and design professionals who wish to conduct and understand research about physical environments better.

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