

# **Book Reviews**

## Where Two Worlds Touch

## A Spiritual Journey through Alzheimer's Disease

Reviewed by Patty Sutherland

[https://www.forewordreviews.com/reviews/reviewers/patty-sutherland/] February 27, 2014

Shifting elegantly from academic to personal, this memoir offers spiritual insights into Alzheimer's caregiving.

Where Two Worlds Touch: A Spiritual Journey Through Alzheimer's Disease joins a growing number of paradigm-shattering books that are confronting the belief that an Alzheimer's disease diagnosis is a tragic thing. Quite to the contrary, Jade C. Angelica says that if one chooses to lean into Alzheimer's rather than recoil from it, Alzheimer's can be a consciousness-shifting experience.

Angelica has a master of divinity degree from Harvard Divinity School and a doctor of ministry degree from Andover Newton Theological School. She was empowered to write *Where Two Worlds Touch* while caring for her mother. "Through my unique perspective and experiences," Angelica shares, "I have noticed that persons with Alzheimer's have the potential to inspire us, teach us, love us, heal us, amuse us, befriend us, calm us, comfort us, touch us—physically, emotionally, intellectually, and spiritually—energize us, enlighten us, empower us, forgive us, nurture us, open our hearts, bring out the best in us, and bring meaning and purpose to our lives."

Where Two Worlds Touch is a dense read that effortlessly dances from serious to





A Spiritual Journey Through Alzheimer's Disease JADE C. ANGELICA

heart-wrenching stories from the trenches of Alzheimer's "carepartnering." Angelica segues in and out of the several years she spent as the primary carepartner with her mother as they journeyed through Alzheimer's, using their daily struggles and joys as a vehicle to explore the past. For example, Angelica's conflicted feelings about her mother's inability to protect her from childhood sexual abuse and other longstanding issues between them dissolved into an unconditional loving forgiveness by the time her mother passed away.

Angelica's training in improvisational theater became the catalyst for her realization that its axiom to always make ones improv partner look good translated beautifully to Alzheimer's caregiving: "When we affirm persons with Alzheimer's by saying yes to their choices and realities, we are stepping into direct relation with them; we are recognizing and acknowledging their divine essence."

The consciousness-raising and worldview-shifting insights found in *Where Two Worlds Touch* might have a positive systemic impact on society if it were to become the go-to book for those whose lives are touched by Alzheimer's.

Disclosure: This article is not an endorsement, but a review. The author of this book provided free copies of the book to have their book reviewed by a professional reviewer. No fee was paid by the author for this review. Foreword Reviews only recommends books that we love. Foreword Magazine, Inc. is disclosing this in accordance with the Federal Trade Commission's 16 CFR, Part 255.

#### Jade Angelica, Where two worlds touch: A spiritual journey through Alzheimer's disease. Skinner House Books, Boston, MA, 2014; 360 pp. ISBN 978-1-558-96711-3 (sbk), \$16.00

In the introduction of *Where two worlds touch: A spiritual journey through Alzheimer's disease*, author Jade Angelica identifies her purpose for sharing her story and discoveries "to reassure caregivers that they and their loved ones with Alzheimer's need not suffer in isolation or be overwhelmed by fear, loss, and responsibility on this journey." The title alone inspires the reader to the possibilities of connecting with the person living with Alzheimer's disease. From the beginning of this book, Angelica draws the reader emotionally into her personal journey with her mother who lived with Alzheimer's disease. Using improvisation methods, she opened the doors to communicate with her mother and discovered beauty in moments with her mother. Her experiences and observations of persons living with Alzheimer's disease contest the belief that the illness steals a person's capacity for any meaningful relationship with others.

In the chapter "The Value and Beauty of Every Person," Angelica leads a theological discussion of hope that "inspires us to accept the loss, decline, suffering of Alzheimer's...to overcome it and transform it into an experience that is essence, life-giving." Throughout the book are several inspiring poems such as "Heart Memories" by Louis Eder that exemplify the spiritual journey of caregiving.

The book provides insight into the art of care giving and guidance for caregivers, "On healing when there is no cure," "Forgetting, forgiving, reconciling" and "Nourishing compassion." The last section of the book provides additional resources for caregivers. This is an exceptionally well-written book.

I plan to encourage nursing homes and memory care assisted living facilities to acquire this book and pass it along to their staff and family caregivers. I recommend this book to healthcare educators to share with their students. Angelica's story will be an excellent starting point for discussion.

#### Linda M. Beuscher

Vanderbilt University School of Nursing/Vanderbilt Center for Quality Aging, Nashville

"Books about Alzheimer's disease seem to proliferate with the fecundity of rabbits, so it can legitimately be asked whether another such volume is needed. The answer is a resounding yes in the case of *Where Two Worlds Touch*. The Rev. Angelica has achieved the Herculean task of telling us some new things about Alzheimer's and about her dealing with her mother's struggle with the disease. The reader rapidly becomes absorbed not just in the story of a parent with Alzheimer's but the more general tale of a mother and daughter over the course of a lifetime. The author writes with a delicate, plain-spoken prose style that makes the book a joy to read. Most important of all, she applies a stark, sometimes startling honesty to her memories of this time."

-Eric Hoffer Honorable Mention Award, The US Review of Books

#### **Book Review**

Where Two Worlds Touch: A Spiritual Journey Through Alzheimer's Disease

By Jade C. Angelica

#### **Reviewed by Bradford Goff**

For the newcomer to Alzheimer's Disease, encountering this relentlessly progressive and deadly disease is always at first like the colliding of worlds - known versus unknown, health versus disease, hope versus despair, life versus death, faith versus darkness.

So, when a book comes along that addresses this life-shattering disease, such as *When Two Worlds Touch: A Spiritual Journey Through Alzheimer's Disease*, one certainly must admit there is something immensely appealing that such a notion can come out of this shadow-filled "valley" called Alzheimer's.

In her sad but sweet, learned, and ultimately inspired guide for entering the "valley" - with an invitation to follow and potentially come out at the other end kinder, wiser, and more spiritually fulfilled - Rev. Jade C. Angelica takes us through her very personal ten-year experience as caregiver to her mother during her course with Alzheimer's disease, to her death. Rev. Angelica, who has a Masters of Divinity degree from Harvard Divinity School and is founder and director of the Healing Moments Alzheimer's Ministry, is clearly a wise and caring theologian but also a skilled researcher, teacher, writer and expert in this field of Alzheimer's study and treatment.

For any of us who may be dealing with parishioners, patients, or loved ones – or might read this book because we too may someday suffer this affliction personally – this book is always soundly based with up-to-date information about the illness and is filled with well-annotated quotes and references to many clinical and spiritual experts in the field. And, although the disease still remains terminal for all, this book's core premise that this can be a life-filled and rewarding process from the beginning to the very end – for both caregiver and Alzheimer person – obviously has profound health and spiritual implications for any reader. Even though never sugar-coated in its messages, this easily readable, intentionally lay-oriented book is designed to reduce anyone's deepest fear of even opening the cover. But it never shies from the reality that this process is

long, painful, frightening, infuriating, at times fraught with helplessness and even despair, and ultimately requires compassion, acceptance, and surrender, before reconciliation. But still for the caregiver, family member, and loved one, there is promise herein for the potential rewards and greater appreciation of life's mysteries, in spirit.

Clearly, the facts of this still poorly understood disease are not easy to hear. There are currently estimated to be 5.2 million Americans of all ages with Alzheimer's disease, and future projections remain staggering: an estimated 7.1 million by 2025, and then between 13.8 million to 16 million by 2050. Clinical studies have led us to several highly suspicious proteins that accumulate and produce abnormal plaques and clumps in brain cells of the majority of victims, but strangely not all. Genetic makeup is proving to be a profound contributor, which may ultimately guide researchers to identify pharmacological "silver bullets." But even the most promising of drugs in stage 2 trials fail to reduce cognitive decline compared to placebo. However, one study does support reasonable improvements in cognition and global functioning in patients with mild disease, which inspires hope. But with such mixed data, drug companies are reluctant to continue research in the face of equivocal findings, even on potentially promising drugs, given massive costs of clinical trials. This begs for widespread advocacy to continue all efforts.

We are still far away from anything akin to a cure. Yet, as Rev. Angelica aptly points out in one of her early chapters, there can be "healing when there is [still] no cure." How can this be? To find this out, she had to not only make her way to a "healing" for her progressively deteriorating, terminal mother, but also a personal healing. Not an easy course, as she had lived in a family where her mother was continuously alcoholic, often ungiving, and critically rejecting for years into the author's adult life, leading Rev. Angelica to sever ties for many years. She discloses her history of alcoholism and recovery, entry into the ministry, and pursuit of her personal, professional, and spiritual journey as her mother's illness was diagnosed and required increasing attention and intervention. Hers was a big decision to risk re-opening old wounds and reengage in her mother's life, at first long-distance in Boston. But, after a surprisingly loving reception from her impaired mother, she made an even riskier choice to return to lowa to oversee her mother's care during the final three years of life. The choice was life-changing for her and ultimately paved the way toward discovering "healing" interventions.

She introduces us to some tools that helped her engage a person in progressive cognitive decline, with failing organized thinking, memory, and the verbal skills for logical expression. Despite cognitive losses, still present were the myriad of wild emotions and responses to ongoing everyday life experiences and the same

wide array of internal reactions and drives, just without cognitive boundaries sadness, joy, gratitude, libido, anger, fear, rage, hurt, and love. The challenge was how to be with these feelings in the moment and promote meaningful engagement, even a deepening love.

Rev. Angelica happened upon improvisational theater techniques as a means for connecting in positive ways. She teaches us that improvisation is about "accepting the offer that has been extended to you by your scene partner, considering it valid, and then doing or saying the next logical thing." Furthermore, "no-saying" can more often than not be "blocking the offer," leading inevitably to "a very bad scene." By implication, the "dance of yes and no" in dealing with a person with Alzheimer's, perhaps most clearly represented in our common clinical intervention of "reality orientation" for persons with dementia, may not be the most helpful approach, "as it is about changing people and correcting people." And "being constantly corrected is annoying." How profound, and simple, and begging for practical implementation in the theater of life!

This book is filled with dozens of simple yet profoundly wise examples, demonstrations, and creative improvisations that beautifully provide affirmations to persons profoundly impaired, but still profoundly human, and worthy of all that they might want and need each day of living. Rev. Angelica writes, "learning that saying yes in the context of Alzheimer's is not necessarily about agreement or approval. It's about adopting an attitude of acceptance and affirmation."

# This is a story of hope, inspiration, beauty, dedication, and finally spiritual love.

The author joins other experts in dispelling the notion that the person with Alzheimer's is "gone," an empty vessel, and therefore useless. Clearly, this may be true from an economic standpoint, so the Alzheimer's person may easily be seen as a burden on family or society. But she points out, "If a person is considered 'gone,' spending limited time and attention elsewhere becomes an easier choice. How I wish everyone could see what I see looking back at me from the sea of wheelchairs: beauty within vulnerability, in-the-moment happiness, gratitude for any kindness, earnest efforts to engage in life at every opportunity, and especially for Mom and me, celebration of one more day together."

This book, in many ways, is a full celebration of life in all its aspects. It is about the unpredictability of life, anticipation of the good future, hope for health and recovery, healing of old wounds, getting desperate news, appreciating the present, deepest loss, absolute helplessness, complete surrender, sorrow, precious memories, forgetting, forgiving, reconciling, and moving on. There are no points left untouched in this self-less, giving, and uplifting tribute and memoir – which would seem from its simple title to at least offer some basic tips in making

it through one of life's most challenging and devastating disease processes, a grueling endurance test where life just leaks away, leaving nothing in the end. No such thing! This is a story of hope, inspiration, beauty, dedication, and finally spiritual love. One can only be left thanking Rev. Angelica for this gift to us all - loved ones, family members, caregivers, present and future persons with Alzheimer's - all of us. She lifts us up with her dedication, inspiration, and spirit.

Bradford M. Goff, M.D., has served as chairman of the Department of Psychiatry and Behavioral Health Sciences of Lutheran Medical Center in Brooklyn, NY since 2001. Throughout this time period, Dr. Goff has also served part-time at a private practice of psychiatry. He is also a consulting psychiatrist with Calvary Hospital. Prior to joining Lutheran Medical Center, Dr. Goff was the director of Inpatient Psychiatric Services at North General Hospital. Dr. Goff received his medical degree from State University of New York, Downstate Medical Center and completed an internship at the Baylor University Medical Center in Dallas, TX, with residency training at the Timberlawn Psychiatric Hospital in Dallas, TX. Dr. Goff is a Distinguished Fellow of the American Psychiatric Association, and is a member of the New York District Branch of the American Psychiatric Association, the Medical Society of the State of New York and the American Society for Emergency Psychiatry. Dr. Goff is Board Certified in Psychiatry and Neurology.

"The consciousness-raising and worldview-shifting insights found in *Where Two Worlds Touch* might have a positive systemic impact on society if it were to become the go-to book for those whose lives are touched by Alzheimer's."

-Patty Sutherland, ForeWord Reviews

*"Where Two Worlds Touch* is a timely manifesto that will forever change the way our society cares for individuals with dementia. This is a must-read book for all caretakers of patients with Alzheimer's disease. Angelica is a prescient observer of the human condition and has done a wonderful job of providing rich anecdotes, clear prose, and novel strategies that really work. Given that there is currently no cure for Alzheimer's disease, it is imperative that our society develop and follow a humane standard of care for these individuals. Where Two Worlds Touch provides a blueprint for how we can ameliorate the suffering and dramatically improve the quality of life for Alzheimer's patients."

—Justin Feinstein, Clinical Neuropsychologist, Laureate Institute for Brain Research

Angelica, Jade C. (2014) Where Two Worlds Touch. A Spiritual Journey Through Alzheimer's Disease. Boston: Skinner House Books.

"It's not that she doesn't recognize me—sometimes she does. It's her *anger*. The way she gets mad at me." The speaker was talking about her 94-year-old mother, sitting about six feet away, seemingly oblivious to the heart-wrenching comment. Her mother has Alzheimer's disease.

The National Institutes of Health estimates that as many as 5 million Americans age 65 and older have Alzheimer's. The Alzheimer's Association offers numerous statistics. Alzheimer's is the sixth leading cause of death in the United States. Today, an American develops Alzheimer's disease every 68 seconds. In 2050, this trend will decrease to every 33 seconds. In 2013, Alzheimer's cost the nation \$203 billion. By 2050 the price-tag is expected to rise to \$1.2 trillion. (<u>https://www.alz.org/alzheimers\_disease\_facts\_and\_figures.asp</u>.) Given the odds, we, too, may be victims of this plight. "Longevity is currently identified as our greatest risk factor for getting Alzheimer's," says author Jade Angelica.

So it should therefore come as no surprise that books about dementia, and Alzheimer's in particular, have proliferated. Why another? As scholar, minister and the daughter of an Alzheimer's patient, Jade Angelica offers fresh insights in her 2014 publication *Where Two Worlds Touch. A Spiritual Journey Through Alzheimer's Disease*. This is a dense but engaging work packed with information and insightful quotes from numerous disciplines and cultures and written against the backdrop of the author's personal experience. The result is a blend of data, wisdom, manual, and memoire, offered to caregivers, mental health practitioners, and all those she calls *carepartners*. Yet, other spiritual seekers will also find inspiration here because, ultimately, this book is "about discovering life-giving possibilities in every corner of life".

Observing that 94-year-old patient on a med-surg unit, I found myself wondering. What is this woman thinking? Is she thinking at all? Where "is she"? What happens when "the person is no longer there"? Thinking back, I wondered where our children's favorite pediatrician "had gone" when *she* developed Alzheimer's in her mid 40s. Did she, too, cease being a person?

Angelica turns this question on its head. It is not, she argues, what the person thinks or even if the capacity for thought is retained that identifies one's humanity. Rather, humanity itself, the very fact that we exist, defines this identity. Taking on Descartes, Angelica reasons that *cogito* (I think) does not equal *sum* (I am). For Angelica, personhood does not depend on cognition. A parent, she argues, does not cease to be human when he or she no longer remembers, forgets how to act socially or converse rationally. Thought does not equal humanity. Nor does the absence of memory and rational thought mean that the person no longer has value. For Angelica, there is value and beauty in every living person. She counters Descartes with her own definition. "Since love and relationship, more than cognition, define who we are and enliven our beings, I offer this alternative, inclusive, everlasting definition of selfhood: I long to give and receive love—therefore, I am."\

Well, that's a beautiful theory, the reader might say, but tell it to the tens of thousands of caregivers in homes and facilities across America! What real value do all those slumbering dementia patients have? They are alive, responds Angelica, alive to teach us how to be with them and how to be with ourselves. In the process, they draw out the best in us. These are "the gifts of Alzheimer's."

Angelica analyses as a theologian with a strong grounding in the psychology and medicine of her topic. But her narrative remains grounded in her own 10-year experience. Sparing neither her mother, her family, nor herself, with the candor of one who has faced her own demons, she describes her fears upon learning of her mother's condition. She recalls an unhappy and abusive childhood. She relates the power struggle with an unnamed sibling. She agonizes over the decision to move from Boston—leaving friends and academic work—back to Dubuque, Iowa. Once the decision is made, Jade become her mother's daily companion and advocate for the next three years. While the transition isn't easy, a new and deeper relationship emerges. Angelica's interest soon extends beyond her mother to the other residents of the facility. Her observations and interactions bring unanticipated insights into this disease and how to be with those it afflicts. She sees the negative effects of "reality orientation" imposed by staff who "correct" residents in hopes of restoring them to what they were. She explores new ideas and discovers "habilitation therapy" for Alzheimer's patients "to maximize their functional independence and morale."

With this insight, Angelica then draws from her training in improvisational theater. She develops techniques for working with her mother. Rather than correct an apparently off-the-wall statement (reality orientation), Angelica seeks to follow the thread of conversation and to "make the scene partner look good." She explains that "the world of improv teaches us to say the next logical thing when someone makes an offer." This insight will be fundamental to Healing Moments, the organization she eventually founds, dedicated to "Alzheimer's/Dementia Education and Advocacy."

But, because this book is ultimately about something deeper and even less tangible, Angelica explains how "the improv way of being in the world can open doors to spirituality," a path she describes as having gifted her with a number of "spiritual elements" mostly based on mindfulness and being in the moment.

Having followed Angelica's reasoning early in the book (personhood and its corollary, genuinely human care) and understood her insights into improvisational theater and spirituality, the reader might assume that the basic question has long since been dismissed: Is there really any point—other than human kindness or self-sacrifice—in caring Alzheimer's patients? Yet this question haunts author and reader throughout. And it gets answered in multiple ways in chapter after chapter for reasons that point in two directions. On the one hand, loving care will have a powerful effect on the patient. Citing Dr. Allen Power, "Even people with advanced dementia can experience well-being and growth." On the other hand, persons with Alzheimer's give back to those who care for them: "In these places of loss and suffering—places where we don't expect to find anything of value or of beauty—springs the possibility that we will open ourselves to meeting our loved ones with Alzheimer's in mutuality, to receiving grace, and to experiencing gratefulness."

The final section on "Forgetting, Forgiving, Reconciling" will remind some readers of Dr. Ira Byock's *Four Things That Matter Most*. But, once again, they will find here a candid, first-person narrative in which the author shares her story. They who feel similarly "trapped" may discover a path to their own mental and spiritual health.

Some readers may be distracted by the number of quotations and authorities cited. (I counted as many as five on two pages.) Personally, I found the sayings thought-provoking, and the references helpful. The academically-inclined reader will want to refer to the copious footnotes tucked away at the end. Those seeking to do more reading or research on the topic of Alzheimer 's disease will appreciate the extensive bibliography.

Whether, by the end of this book and despite the arguments and authoritative sources, the reader remains skeptical of the "value" of Alzheimer's, most will agree having encountered in Angelica a dynamic writer who challenges the way Alzheimer's Disease is generally perceived—and feared it like the plague. A sense of admiration surfaced in me in reading Angelica's final statement. Having lived the painful experience of a *carepartner*, she can still say: "I see how and why caring for Mom was, indeed, an especially good fortune in my life. There is perhaps no greater gift than the opportunity to alleviate another human being' suffering though compassionate caring." The book is called *Where Two Worlds Touch. A Spiritual Journey Through Alzheimer's Disease* by Jade C. Angelica.

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\*\*"I am so very impressed by this exceptionally well-written and well-researched book. Jade Angelica deserves rave reviews for her unique balance of compassion, insight, and scientific support on a very complex issue. I strongly recommend *Where Two Worlds Touch* for caregivers of individuals with Alzheimer's dementia."

-Robert A. Stern, Clinical Core Director, Boston University Alzheimer's Disease Center, Boston University School of Medicine

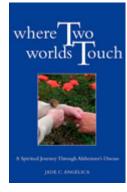
"Any caregiver who has felt duty-bound to support a spouse, parent, or other loved one with Alzheimer's disease will find a path to compassionate care as they follow Jade Angelica's personal transformation from a wounded, distant daughter to her mother's loving companion in *Where Two Worlds Touch*. Embedded in wisdom from a variety of spiritual traditions, Jade's inspirational story provides a new and hopeful way for caregivers to approach the daily challenges of Alzheimer's disease and connect meaningfully with loved ones."

—**Cordula Dick-Muehlke**, Associate Clinical Professor, Department of Family Medicine and Division of Geriatrics, University of California, Irvine School of Medicine



## The surprising grace of Alzheimer's; even those who aren't caregivers can benefit from author's insights

Michael Leach | Jun. 4, 2014



WHERE TWO WORLDS TOUCH: A SPIRITUAL JOURNEY THROUGH

ALZHEIMER'S DISEASE By Jade C. Angelica Published by Skinner House, \$16

"What really knocks me out is a book that, when you're all done reading it, you wish the author that wrote it was a terrific friend of yours and you could call him up on the phone whenever you felt like it. That doesn't happen much, though." -- Holden Caulfield, The Catcher in the Rye

*Where Two Worlds Touch: A Spiritual Journey Through Alzheimer's Disease* was that kind of book for me. So when I was done reading it, I called the author up. "Hello, is this the Rev. Jade Angelica?"

"Yes?"

"You don't know me, my name is Michael Leach and I'm writing a review of your book for the *National Catholic Reporter* and I just want to tell you it's the best book on Alzheimer's I've ever read and I want to thank you. I've underlined practically the whole thing. It looks like a flight map."

She laughed. "I'm so grateful," she said. "When I started it, all I wanted to do was reach people and be helpful."

"You reached me. My wife has advanced Alzheimer's and you taught me stuff I didn't know. I'm going to say in my review that even those who aren't caregivers will benefit from the book. The spirituality for living a good life is just so real." Then I asked Angelica what I usually ask writers before they begin their books. "What is the one thing you hope readers get out of it, the one thing they'll take away and remember the rest of their lives?"

continued

She thought for a moment. "Value ... the value of people with Alzheimer's and dementia, and the beauty of those who love them. The book is about meeting persons with Alzheimer's and falling in love and respect for them. They give us a unique opportunity to exercise our innate compassion. We need to see them as they are -- gifts from God -- of value to us and to society. Caring for my mother brought out the best in me -- and in her."

In 2008, Angelica moved from her ministry in Boston to Iowa to care for her mother full-time until she died in 2011. "I knew that caring for her would be the most important work of my life." She began a spiritual journey through the glass darkly of Alzheimer's into a world of clarity and compassion. Her story isn't about losing her mother while she seemed to be disappearing day by day. She focuses not on what was lost but on what both of them found.

"I tried to write the book as a spiritual companion for family caregivers and anyone who loves someone with Alzheimer's," she said. "More than 5 million people are suffering with some form of dementia. By embracing them with a holy vision and an open heart, it's possible for caregivers on this sacred journey to bear witness to the surprising grace of Alzheimer's as I did. It isn't easy, but it's possible that they'll notice and receive unexpected gifts, and experience awe and gratitude for the ways that Alzheimer's can touch their hearts and give meaning to their lives."

Angelica has a Master of Divinity degree from Harvard Divinity School and a Doctor of Ministry degree in faith, health and spirituality from Andover Newton Theological School. Her mother was diagnosed in 2001 while Angelica was ministering to abused children in Maine. Angelica made multiple trips home each year and honored her mother and what she was going through by studying about Alzheimer's and identifying unique ways to communicate, connect and enhance relationships with people who have dementia. She founded Healing Moments, an Alzheimer's ministry that provides practical and creative strategies to caregivers throughout the country.

Angelica started the book as an academic treatise, but while living in Iowa, she could not help but write it as if having a conversation over a cup of coffee late at night with a friend starting the same journey. Her author's voice is warm, authentic, and learned without being knowing. She quotes medical and psychological experts and more so spiritual writers, including St. Augustine, St. Teresa of Avila, Teilhard de Chardin, Marcus Borg, Karen Armstrong, Richard Rohr and Benedictine Sr. Joan Chittister. Most of all, she shares stories, hers and others', and eases us into their lessons so that our caregiving experience becomes a spiritual discipline.

*Where Two Worlds Touch* is supremely practical, with instructions on every stage of the disease, from initial acceptance, to caring for someone at home and, later, while in a nursing home, which Alzheimer's heavy hand often makes necessary.

I loved her insights on discerning what a loved one is thinking when she cannot communicate, how to meet needs she can't express. Persons with Alzheimer's communicate with heart speech all the time, and we can, too. There's a marvelous riff on the value of improvisational theater techniques -- à la Second City -- which for a caregiver is simply the ability to say yes. "To accept what's happening and what's said as true and valid -- even when our scene partner offers a new or surprising direction," Angelica writes.

The word yes is comforting, and almost always what the other person is looking for. Doing improv is the only intelligent thing you can do when you don't have a clue what's going on, and it relaxes both of you. A light heart is good; a light heart works. Angelica has a wonderful chapter on forgetting, forgiving and reconciling that is of value to everyone, as well as one on time: "Choose love. There is always time enough for love." I could go on but there is no space.

The book ends with a glossary of terms, a reading list and interesting notes. It's one to keep on your nightstand and read for your own spiritual nourishment, just as you would a book on meditation. It's that beneficial. If Alzheimer's teaches you anything, it's the healing value of living moment by moment and meeting whatever needs present themselves without judgment. I'd also recommend that every clergyperson have two or three on hand to give to a parishioner who is a caregiver.

After my chat with Angelica, I went back to the book and looked up the last two paragraphs of a chapter that moved me deeply, "The Last Word." Angelica's mother dies and Angelica is with her. She reflects:

"The last word. The last step. The last kiss. The last breath. The last good-bye.

"I am so grateful and happy that I didn't miss them."

[Michael Leach is editor at large and publisher emeritus of Orbis Books.]

Telegraph Herald, Dubuque, Iowa. January 25, 2014.

# A shared, spiritual journey

Jade Angelica and her mother Jeanne Heinzelman visit at a Dubuque care center. The elder woman was diagnosed with Alzheimer's disease in 2001. Angelica wrote a book, "Where Two Worlds Touch," about the experience.

Thonline: Angelica discusses her book.



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# New book closely examines Alzheimer's

#### BY MARY NEVANS-PEDERSON

TH staff writer • mnpederson@wcinet.com

The numbers are daunting — more than 5 million Americans have Alzheimer's disease with that number projected



Angelica

ease, with that number projected to rise to 13.8-16 million (Americans older than 65) by 2050. The dreaded incurable disease

progresses relentlessly, robbing its patients of memory and other cognitive and physical functions until they die from its complications.

Jade Angelica knew little about Alzheimer's when her mother, Jeanne Heinzelman, of Dubuque, was diagnosed with it in 2001. Thirteen years later, Angelica's book, "Where Two Worlds Touch," about her "spiritual journey through Alzheimer's disease," is being hailed as a definitive resource for caregivers, families, physicians, Signing: Jade Angelica will sign copies and read from her book, "Where Two Worlds Touch," from 1 to 2 p.m. Sunday, Jan. 26, at River Lights Bookstore.

pastoral workers and anyone who seeks a deeper understanding and connection with someone with Alzheimer's.

Angelica threw herself into research about the illness that "frightened" her. She read dozens of books and attended just as many workshops and conferences. The knowledge she gleaned from those, as well as what she learned, often by instinct and by trial and error, from years of helping to care for her mother are beautifully interlaced in her book.

By her description, the book is, "like a tapestry, woven together by poetry and stories drawn from my own experiences and those of other Alzheimer's caregivers, informed by literature in the Alzheimer's field of research, and grounded by spiritual and theological resources."

It's the book she wishes she had had. "I feel like an explorer (into the mysterious world of Alzheimer's), sending back my notes," Angelica said. She has lived 32 of her 61 years on the East Coast, but again lives in Dubuque after returning to care for her mother, who died in 2011.

Through personal reflection, recounting of her troubled past and observations of other caregivers and patients, the author covers a wide range of subjects in chapters like, "The Value and Beauty of Every Person," "The Present Moment," "The Most Important Memories," "Nourishing Compassion" and "Companionship on the Journey." Although she includes much scholarly ma-

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WHERE TWO WORLDS TOUCH Rev. Dr. Jade C. Angelica. Skinner House Books. Boston, MA. 2014

Review by Rabbi Richard F. Address, D.Min www.jewishsacredaging.com

Jade Angelica introduces us to her approach to caregiving for people with Alzheimer's by reminding us that it is about "the power and potential of true encounter". That "true encounter", inspired in many ways by Buber, Heschel and a host of others, is a motif that is unpacked in her readable and informative narrative about her personal journey with her mother. "Where Two Worlds Touch" joins a growing list books and articles that have begun to address the growing challenges to families and society that are emerging with the aging of the baby boomers.

The number of cases of Alzheimer's is expected to rise from the current 5 million, to an anticipated 15 million by mid century. As Angelica points out, and as every statistic also confirms, we face a major challenge in that there very well may not be enough trained care-givers to handle this surge in cases. Who will take care of us, and who will pay for that care, is a societal challenge that, for the most part, remains ignored. This has the potential of being one of the major social justice issues in the next few decades.

Angelica hints at this challenge within the context of her highly personable account. What the reader will find here is someone who understands the complexities of care-giving and the special and highly personal reality of someone living with Alzheimer's. The emphasis on "living" is a key one in the book. This is not a book that leaves you depressed and fearful. Rather, one can sense a respect for life throughout the pages. This approach may be due, in part, to Angelica's training as a minister and a spiritual director. There is a deep reverence for life, no matter at what stage.

In the section on The Value and Beauty of Every Person, one of Angelica's distinct messages is presented through metaphorical wonderings about the meaning and purpose of the lives of the cognitively impaired, and an invitation to readers to consider the counter-cultural possibility that persons with Alzheimer's have not lost their soul or their "self." Inspired by the work of Baylor University Gerontologist, James Ellor, Angelica challenges those who describe persons with Alzheimer's as "empty shells," to come close and to stay long enough to recognize that people with cognitive loss, who can't read or speak, may still have a thing or two to teach us. Realizing that this sets up a contradiction for most, the author offers that "contradictions are often the greatest teachers of all...Consider this possibility: Rather than being useless, people with Alzheimer's and dementia could be our most important teachers in the school of love and life." (p.75,76) This possibility is explored throughout the book, but specifically in the later section, Nourishing Compassion.

Love and life form the foundation of an appreciation of what Angelica sees as a relational approach to care-giving. She sees in these encounters a sacred opportunity for meaningful encounters and lessons that can be learned. No one is "useless", no matter at what stage of life they are. A key in this journey of caregiving then is the on-going relationship that one must maintain with the person needing care. Angelica moved her life from Boston to Iowa to care for her mother, faced her own demons and fears of a past family of origin issue, and found a sense of calling in her mission. That relationship allowed a new sense of love to grow, even as cognition declined. As she writes: "Since love and relationship, more than cognition, define who we are and enliven our beings, I offer this alternative, inclusive, everlasting definition of selfhood: *I long to give and receive love—therefore, I am.*" (p.102)

Angelica does understand that Alzheimer's is, for now, a terrible and terminal diagnosis. There is a struggle to find a sense of meaning in this reality. She looks at this in her section on "Healing When There Is No Cure". I am reminded often when these discussion take place of the prayer in the daily Jewish prayer that states that Jews pray for "healing", but not a cure. It is as if the authors of this prayer understood that a "healing" can take place without an actual cure. Angelica examines this in her discussion on the spiritual dimensions of caring for someone with Alzheimer's. Is hope possible in a situation where there is no "hope"? She channels a sense that every person has value, no matter at what stage of life, and that rather than seeing "hope" as an external possibility, hope is from within. Conscious and compassion based care-giving can be the source of that hope. It is manifest by presence, by touch (she mentions the values of compassionate massage) by being present with the person where the person is, and all of this embraced by the power of love. We can "be hope" for someone by these actions and our presence, and in doing so, we can make a difference in this person's life.

Angelica raises the issue of time as it reflects upon the care-giving journey. She makes the point that Alzheimer's allows for the gift of deepened relationships and a more profound appreciation of time. The challenge, of course, is that not everyone who is in the position of caring for a loved one with Alzheimer's, has the ability, insight and sensitivity to see in this journey; a journey that can encompass years, a sacred possibility. This takes us back again to the need for a major educational program that would address the challenges of caring for someone with Alzheimer's and dementia. If the statistics are true about the expected rise in cases and the fact that Alzheimer's related causes are one of the most frequent causes of death in this country, then there is a great need for a major program of awareness. Part of that program needs to include, as the book suggests, a comprehensive approach to self care. The stresses and strains of care-giving, the impact on a care-giver's health, both mental and physical, is a growing concern to all communities. It can even be argued that we need to create a new vocabulary that better describes the life stage that surrounds the person and the family that is dealing with this issue.

"When Two Worlds Touch" is a moving and personal description of one person's journey of care-giving. It is uplifting and sensitive and, in subtle ways, raises deeply challenging questions for a society that is aging.

"Every chaplain, theologian, caregiver, and healthcare professional can find profound truth captured on each page of *Where Two Worlds Touch*. Jade Angelica builds from the narrative of her experience as a caregiver, and invites the reader to journey with her into the highly significant theo-philosophical literature that has arisen in the last decade around the experience of the deeply forgetful and those who care for them. The reader will find that there is a place for love and hope and continuing selfhood in an experience that is more than just half-full if we can see it rightly. This is a beautiful book and the deepest I have read on the topic."

-Stephen G. Post, author of The Moral Challenge of Alzheimer Disease

*"Where Two Worlds Touch* is one of the finest accounts of the spiritual journey of Alzheimer's, for both the caregiver and care recipient, that I've read. Jade Angelica gives us the gift of an honest, reflective account of journeying through Alzheimer's with her mom. Jade brings to the journey and to the telling of it the fruit of years of theological study and reflection, meditative practice, improvisational theater techniques, spiritual direction, and a pastoral heart. It was a journey fraught with personal, emotional, and spiritual difficulties, but it was in the crucible of Alzheimer's disease where her relationship with her mom was transformed and healed. As she notes in the introduction, this book may not be comforting or helpful for everyone. But for those who want to reframe Alzheimer's to focus on the gifts that remain and who want to be stretched in mind, heart, and spirit--this is the book to read."

-Nancy Gordon, Director, California Lutheran Homes Center for Spirituality and Aging

"Angelica's life story as an estranged daughter, a Harvard theological student, and eventually the primary caregiver for her mom has led her to a place where she can hold the hands of other caregivers and share her hopeful credo, that two worlds can indeed touch, even if one world is altered by distance and disease. I have decided to gift each of my support group members with a copy of Where Two Worlds Touch."

-Joanne Koenig Coste, author of Learning to Speak Alzheimer's

"Jade Angelica is a sojourner from the land of Alzheimer's bearing witness that all there is not lost. Her testimony is even more outrageous: We can experience in that far country depths of being alive, and in love, that the worlds of perfect health may never understand. *Where Two Worlds Touch* is a treasure chest of spiritual gems, the boon of an adventure into and out of the valley of the shadow of death. If you or someone you love are in the land of Alzheimer's, read this spirited-inspired travel log and find your way home."

-Michael Verde, Founder and Director, Memory Bridge

*"Where Two Worlds Touch* is a perfect blend of sacred/spiritual and everyday insight for caregivers. Angelica bravely describes her relationship with her mother pre-dementia, helping readers to understand that they can have meaningful relationships with loved ones who have Alzheimer's, even when those relationships have been fraught with difficulty in the past. The book offers practical tools, such as improvisational techniques, and spiritual reflection to help readers transform the lives of people with dementia and their own lives as well. Angelica helps care partners to approach people with dementia in a creative way that does not focus on what the person cannot do. Instead, the focus is on entering into the person's reality, which often leaves us surprised, excited, and humbled at the abilities and memories that remain."

—**Melanie Chavin**, Vice President of Program Services, Alzheimer's Association, Greater Illinois Chapter

"Inspiring! Angelica's day-to-day journey with her Mom through Alzheimer's to death is a deeply informative story of caring and growing in the process. Through the sharing of her story she makes a profound case for the need to be with and for another who suffers from the disease. She also gives many clues about how to do it. I suggest that it's a "must read" for anyone who has a family member or friend with Alzheimer's, and for everyone who works with Alzheimer's patients as a nurse, an aide, or volunteer."

—Janaan Manternach, co-author, *Alzheimer's Disease: A Handbook for Caregivers, Family and Friends* 

"Jade Angelica has written an intensely personal yet also universally applicable treatment of Alzheimer's disease that is real, honest, and wise. Blending sound research with helpful and often moving accounts of caring (in every sense of the word) for those with Alzheimer's, her writing is clear and engaging and provides a great deal of practical advice."

-Stephen Sapp, Professor of Religious Studies, University of Miami, Coral Gables, FL

"Grounded in research and inspired by poetry, spiritual insight, and personal reflection, this testimony to the transforming power of love touches at the root of what makes us human--the ability to maintain relationship despite seemingly insurmountable obstacles. Jade Angelica's indomitable spirit uses every means available to her creative imagination to seek and eventually find a means to heal and be healed through relationship with her mother, who is succumbing to the diminishments of Alzheimer's Disease. This is spiritual direction at its best--alert to Divine guidance while attending to present-moment reality. Ms. Angelica allows knowledge to remain in the background as she deftly gains insight into the nuanced communication of her slowly diminishing mother. Warmly, open-heartedly, keenly, perseveringly, their relationship yields to mutual transformation. This is a testimony to the power of love at work in those who willingly receive. Thank you to Jade Angelica for this witness to the power of the human spirit to prevail in the midst of chaos, darkness, and confusion--a true story of the reality of resurrection for those vulnerable enough to see."

—**Martha L. Campbell**, Former Director, Spiritual Guidance Program, Shalem Institute for Spiritual Formation, Washington, DC

"Jade Angelica captures the essence of being an Alzheimer's care partner. She transforms a task frequently perceived as complex, difficult, and discouraging, into one that is a joyful, rewarding experience for both partners. By being fully present and "saying yes" to her partner's reality, she accepts and validates her partner's persona and joyfully joins her in the world of dementia. *Where Two Worlds Touch* is a practical and spiritual guide for all who choose to travel the journey through Alzheimer's disease together."

-Charles J Farrell, MD President, Carolyn L Farrell Foundation for Brain Health

"This book, in recounting one mother and daughter's poignant caresharing journey into Alzheimer's disease, reflects on the spiritual dimensions of struggle, suffering, and companioning. The author offers wise counsel and practical ideas in rethinking the carer role, sharing through improvisation, and effectively advocating for the personhood of the cared for. Ways to transform the carer role are offered. Spiritual themes addressed throughout the book offer unique and important perspectives on independence and quality of life for both care partners. The book is a first-person account of a journey, yet it speaks to universal concerns. It is a thoughtful and hopeful addition to the literature about dementia and caregiving."

—Marty Richards, author, *Caresharing: A Reciprocal Approach to Caregiving* and *Care Receiving in the Complexities of Aging, Illness or Disability* 

"This tender and fiercely challenging account of a daughter's encounter with her mother's journey into Alzheimer's disease takes issue with our cultural consensus around the tragedy of dementia. By refusing to collude in her mother's progressive loss of personhood, the author discovers a deep path of engagement, forgiveness, and growth, including startling moments of joy and the spontaneous flow of love. Jade Angelica's intensely personal story becomes translucent to the universal yearning and wisdom of compassion, illuminating what it might mean for any of us to give, and receive, care. Through this experience, she demonstrates that the opportunity to serve and advocate for a dependent loved one can be as much a gift and a blessing as it is also a burden. Her testimony calls into question our collective denial of our continuing connection to our warehoused elders, and lifts up their humanity as a summoning to authentic presence and spiritual discovery."

-Kendyl Gibbons, Unitarian Universalist minister

"Jade Angelica has given a blessed gift to all persons whose lives are touched by Alzheimer's or other dementias (and that is all of us)! Wise and witty, Where Two Worlds Touch teaches us to see the whole person who is still very much present within the reality of progressive memory loss. Dementia cannot be cured, but Angelica teaches us that life can remain good, filled with love and laughter, even as cognitive ability declines."

—John T. McFadden, co-author, Aging Together: Dementia, Friendship and Flourishing Communities

"Jade Angelica has written an engaging and reflective book that is both personal and political. The commandment to honor your parent is not always easy. Angelica's focus on the care of people with Alzheimer's highlights this and brings out the often unspoken challenges of the practical, emotional, moral, and spiritual work we need to do to protect the most vulnerable members of our society."

-Rabbi Sara Paasche-Orlow, Spiritual Care Director, Hebrew SeniorLife, Boston

*"Where Two Worlds Touch* is an accessible and compassionate guide to understanding and loving someone with Alzheimer's. Through her own personal experience and spiritual training, Jade Angelica offers a shift in perspective about Alzheimer's that shines a loving light on what is still there instead of what is lost. This is the book I wished for when my grandmother had Alzheimer's."

-Lisa Genova, author of Still Alice