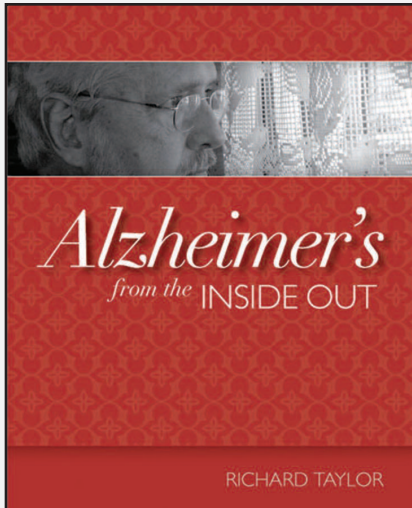


# Alzheimer's from the Inside Out

by Richard Taylor, Ph.D.



"After reading this book I have come to the conclusion that this is perhaps the most important book in the field of dementia care ever written ... These poignant essays come from the heart and soul of a sensitive and intellectually gifted man who has become a national champion and advocate for the millions of people living with this disease."

—Linda L. Buettner, Ph.D., CTRS, FGSA, Professor of Health Science, Florida Gulf Coast University

"Every family with an elderly loved one and every medical professional who works with elders should read this gripping and marvelous book!"

—Jacqueline Marcell, author of *Elder Rage* and host of *Coping with Caregiving* radio program

## Book Information

This collection of more than 80 short essays offers readers a rare exploration of the world of individuals with Alzheimer's disease. Written by a psychologist diagnosed at age 58, the essays cover complex and emotional topics faced by those with the disease—loss of independence, communication difficulties with caregivers, unwanted personality shifts, and never-ending uncertainty about the future. This is a captivating read for anyone affected personally or professionally by Alzheimer's disease, especially individuals with early-stage Alzheimer's disease, family caregivers, and professional caregivers, such as nurses, social workers, and counselors.

## Technical Information

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## Author Information

Richard Taylor has lived for 7 years with a diagnosis of Alzheimer's disease. A retired psychologist, he is now a champion for individuals with early Alzheimer's disease. Richard served on the board of the Houston and Southeast Texas chapter of the Alzheimer's Association and has started over 50 chat rooms worldwide for people with Alzheimer's disease and their loved ones.

## Availability

**Alzheimer's from the Inside Out** is available through local bookstores and online booksellers. Also available direct from Health Professions Press, P.O. Box 10624, Baltimore, MD 21285; toll-free (888) 337-8808; [www.healthpropress.com](http://www.healthpropress.com)

**Request a review copy today! Please contact Amy Perkins, Marketing Manager, Health Professions Press, 410-337-9585 or [aperkins@healthpropress.com](mailto:aperkins@healthpropress.com)**

# About the Author



**Richard Taylor, Ph.D.,** has lived for 7 years with a diagnosis of dementia probably of the Alzheimer's type. A former psychologist, he is now a champion for individuals with early-stage and early-onset Alzheimer's disease.

Richard served on the board of the Houston and Southeast Texas chapter of the Alzheimer's Association and is now a member of a special committee of the National Alzheimer's Association looking at how to evaluate and provide effective support to individuals in the early stages of the disease.

He has started over 50 chat rooms worldwide for people with Alzheimer's disease and their loved ones, and he is also the editor of an e-newsletter for people with early-onset, early-stage Alzheimer's disease and their caregivers.

Originally Richard started writing essays to better understand for himself what was going on inside of him. He now writes to share his experiences with other individuals with the disease and their caregivers. His insights into himself and the disease are always honest, direct, poignant, and even witty, and they speak to universal human fears and desires. His essays have been published in *Alzheimer's Care Quarterly*.

Richard lives in Cypress, Texas with his spouse, Linda, and his Bouvier des Flandres dog, Annie. His son and family live across the street from him. He spends his days playing with his two grandchildren, gardening, and writing.

# Praise for **Alzheimer's from the Inside Out**

"After reading this book I have come to the conclusion that this is perhaps the most important book in the field of dementia care ever written ... Dr. Taylor writes with passion and humor about a wide range of topics that capture the experience of living with a diagnosis of "probable Alzheimer's disease" ... These poignant essays come from the heart and the soul of a sensitive and intellectually gifted man who has become a national champion and advocate for the millions of people living with this disease."

–Linda L. Buettner, Ph.D., CTRS, FGSA, Professor of Health Science, Florida Gulf Coast University

"Among the millions with this cruel disease, Richard is rare in that his preserved memory, language, and thinking skills made possible these essays about his experience of the disease. He offers valuable insights to family and professional caregivers seeking to uphold the dignity of all people living with the disease. A debt of gratitude is owed to him, his wife, and his family for refusing to go gentle into that good night."

–Daniel Kuhn, M.S.W., author of *Alzheimer's Early Stages*

"Written with sensitivity, humor, and passion, **Alzheimer's from the Inside Out** describes the author's sometimes bumpy, but always insightful, journey with Alzheimer's disease. Telling his stories in a series of informative vignettes, Richard challenges us all to be more authentic and work to make life better for persons with dementia—not tomorrow, but today!"

–Virginia Bell, M.S.W., co-author, *The Best Friends Approach to Alzheimer's Care*

"I thought I understood what life was like for my Alzheimer's-affected parents—until Richard's story enlightened me with insight into an unimaginable world. Every family with an elderly loved one, and every medical professional who works with elders, should read this gripping and marvelous book!"

–Jacqueline Marcell, author of *Elder Rage* and host of *Coping with Caregiving* radio program

"Extraordinary, brilliantly insightful, inspirational, courageous, thought-provoking—there is no end to the positive descriptors that can be attached to this amazing book by Richard Taylor. **Alzheimer's from the Inside Out** is not only a *must read* for persons with Alzheimer's and their personal and professional care partners, it is, plain and simple, a *must read* book. In sharing his reflections on, as Richard puts it so uniquely, 'living with Dr. Alzheimer between my ears,' Richard prods the reader to reflect on universally vital questions about values and life in general and to laugh with him about human foibles. No matter how experienced and informed one is about Alzheimer's disease Richard's capacity to eloquently share his questions and insights causes the reader to stop and re-think and to do it yet again on the second or third reading."

–Carol Bowlby Sifton, family caregiver, clinical dementia consultant, editor of *Alzheimer's Care Quarterly*, and author of *Navigating the Alzheimer's Journey*

"By dissecting his own thinking process and the behavior of those around him, Richard Taylor gives us incomparable insights for appreciating the truths and troubles of Alzheimer's disease. He records in warm, honest detail the organic battle to maintain his personal identity and shares his thoughtful prescriptions for caring, communicating, and advocating."

–William "Bud" Hunnel, family caregiver and Former Board President, Alzheimer's Association, Houston and Southeast Texas chapter

"Dr. Taylor's journey into the fearful horizon of Alzheimer's disease reminds us that no matter what our affliction, we remain human to the end. His story is one of exquisite sensitivity to the sometimes excruciating twists and turns of living with a chronic illness that slowly, progressively, robs him of his sense of self ... This is an exceptional book, one that people diagnosed with AD and other dementias should read because they will see that they are not alone, that they are indeed comprehensible. For the rest of us, **Alzheimer's from the Inside Out** is a reminder that we care for people, not diseases."

–Robert E. Reichlin, Ph.D., licensed clinical psychologist and geropsychologist, private practice, & voluntary faculty, Department of Medicine–Geriatrics, Baylor College of Medicine

"Richard Taylor's advanced training in psychology, as well as his many years as a counselor, make him especially able to comment on the relationship changes that have accompanied his worsening dementia. Some people with dementia are unaware of the changes they go through, but not Taylor. He offers his own personal insight into the losses of dementia, and his book is a valuable contribution to the small collection of books authored by people with dementia as they experience their own decline."

–Charles Schneider, international Alzheimer's advocate, and author of *Don't Bury Me*

"We have treatments, theories, support groups, and resources, but until you read this book, do you really know what it is like to have Alzheimer's? Richard provides a realistic, candid journey through the heart, soul, eyes, and ever-changing mind of one who is living with this disease ... we get to walk in Richard's shoes, if only through his writing ... It is my feeling that medical professionals, paraprofessionals, family members, caregivers, and, yes, patients would benefit from reading this book to at least attempt to understand the journey that is Alzheimer's, from the inside out."

–Mischele Warner, M.H.S., family caregiver

"Practical tips, philosophical musings, and a call to action! This book highlights the challenges in coming to terms with one's identity following a diagnosis of Alzheimer's disease and is a reminder to doctors and caregivers alike of the importance of open and honest communication."

–Helen Regan, M.A., *Alzheimer's Disease International, United Kingdom*

"[Richard Taylor] has written a book about how dementia affects not only those who have the disease, but loved ones who stand by to witness the progression of this debilitating disease. Richard is so articulate that caregivers, family members, and medical professionals can now understand what a person with dementia is experiencing because of his first-hand account. His story will help everyone who reads the book gain more compassion and patience."

–Debbie Ricker, OTR/L, Executive Director, *The Memory Center of Orange County, California*

"Richard's words shed light on a very dark experience and the reader is led out of the darkness by his frankness, his humor, and most of all his spirit 'alive within me.' His penetrating and pleading comments related to caregiving cause the reader to take a deep breath, pause, and move forward with much greater insight into the complexity of these emotional relationships ... Through Richard's beautiful language and poignant reflections, we approach some clarity about the long-neglected and misunderstood phenomenological experience of those living with Alzheimer's disease."

–Naomi D. Nelson, Ph.D., Psychologist, *Baylor College of Medicine*

# Life with Alzheimer's

## Quotes from the Essays



"Sometimes I do and sometimes I don't understand you. Sometimes I'll tell you and sometimes I won't. I don't know why it embarrasses me when others act differently around me. I'm the one with the extra dead brain cells."

"Yesterday I asked my four-year-old granddaughter to help me fasten my Safe Return bracelet around my arm ... Am I reassured Safe Return will protect me, or am I daily reminded of my impending inability to know where and who I am? I am constantly aware I am wearing it. I thought after a week or two I would get used to it, like wearing a ring. I suppose I will always be aware of it until I am not aware."



"My relationship with my spouse, my family, and my friends has broadened and in some ways deepened. We spend more time really being together. We talk more, we hug more, we cry more, we laugh more and harder and longer together."

"I am an empty vessel into which I throw a hand and a half full of pills twice a day, and I desperately want the pills to reconstruct me into the person I was the day before the chase began—the day before I went to my neurologist."



"I pause in my conversation and search for clues and connections. I race up and down the corridors of my mind, frantically seeking to make sense of what's going on around me. Sometimes this process makes me even more lost, and I become lost about why I am lost!"

# A Conversation with the Author

**Q: Five years ago, you were diagnosed with dementia, probably of the Alzheimer's type. Your essays describe the vast changes in your life since your diagnosis. Would you share a few examples?**

There have been huge changes in the order and sense of freedom in my life. I am at risk, and so are others, when I drive. Therefore, I feel, act, and am like a prisoner in my own home. I am completely subject to others for a pass to visit the outside world. I cannot manage money very well; even transactions at cash registers are sometimes confusing. Therefore, I have no money of my "own", and I feel, act, and am like a prisoner of others to spend money to meet my own needs and wants. I am at risk for wandering and/or forgetting what I am doing at any given moment, which puts others, like my young grandchildren, at risk. Therefore, I can only spend supervised time with my grandchildren.

**Q: Your journey with Alzheimer's disease began after your daughter visited and noticed, "There is something wrong with Dad." What changes did she notice? What steps did you and your wife take as a result?**

There were subtle changes in my personality that people who interacted with me on a daily basis did not notice, but which stood out like sore thumbs to my daughter. To her, I was suddenly more argumentative, defensive, and sometimes even hostile to other people and their ideas. I was more dominant in conversations (an unconscious attempt to cover up for my lack of concentration), especially in those with more than two or three people. I did not listen as empathetically as I formerly had. I simply was not in her mind and heart the same "Dad" with whom she had grown up.

At first, my wife and I did nothing with the information but puzzle over it. Six months later at my yearly check-up with my internist, I mentioned my daughter's concerns. He acted on the information and sent me to a neurologist who then sent me to a neuropsychologist. One year later, the diagnosis of Alzheimer's disease was officially made.

**Q: Alzheimer's disease is a progressive disorder. Your essays do a wonderful job of describing your symptoms and your reactions to them as the disease advanced. How are you doing today, years after some of the essays were written?**

The disease seems to progress in uneven ways and at an uneven pace. I go for a while and don't seem to notice any new or more significant difficulties in thinking. Then I seem to drop off a cliff, free fall for a month or two, and land on another plateau.

My concentration has noticeably slipped. I am always in the midst of doing 10 things at the same time. Currently, I seem to finish a few of them, only to start 10 more. When I write there are now obvious breaks in my concentration. I jump from subject to subject. I can seldom recognize or understand my own errors in my writing and speech. Lately when people point out the errors I still cannot understand them. Word retrieval, especially when speaking, is becoming an annoying and more frequent problem. My personality is more volatile and sometimes changes abruptly. Interaction with others is still stimulating but it more quickly reaches a point where I tire and lose my ability to concentrate.

**Q: Soon after your diagnosis, you began writing about your experience with Alzheimer's. How has writing helped you to accept and cope with your diagnosis?**

I am not sure that my writing has helped me accept the diagnosis, but it sure has helped me cope with it. I feel okay (actually more okay, as much as the disease allows) when I can see, read, and re-read what is going on inside and around me. It is easier for me to feel better about myself when others in similar circumstances agree with what I am writing. I know I am not alone. Writing helps me integrate what I know and what I feel, and then re-check it by re-reading.

**Q: One of your essays addresses the issue of family members and friends disabling you, rather than enabling you. What do you mean when you say they disable you? How can caregivers enable people with dementia instead?**

I want to be all of who I once was for as long as I can (at least that is my feeling right now). I want caregivers to enable, help, and support me to be the parts of myself that I can no longer be by myself.

If I can't be alone with my granddaughters, at least according to the fearful eyes and hearts of my caregivers, then instead of them simply saying "no, you can't do it," I want my caregivers to work with me so I can alleviate their fears of what might happen if I'm alone with my granddaughters. I do not want to feel like I need a chaperone all the time. I do not want to feel like I cannot be trusted. Watch me at a distance. Put me in an environment where I cannot wander away. But, do not just say "no."

**Q: Who is your primary caregiver as your abilities decline? What is your relationship like? Is it changing?**

My spouse is my primary caregiver. My son left the air force and moved his family across the street to be closer to us. This disease is as stressful on the caregivers as it is on the person with the dementia, just in different ways. My family is not the exception to the rule.

Our feelings are more volatile now. Fear magnifies our emotions, mostly in a negative manner. We argue more about less and do so more intensely. It takes longer for us to figure out what just happened and sort out the moment from the fear and the Alzheimer's.

At the same time, we are closer. We spend more time together. We talk more, we hug more, we cry more, we laugh more and harder and longer together.

**Q: The essay "What's the Up Side to Having Alzheimer's Disease" describes the positive changes in your life since your diagnosis. So, all the changes haven't been bad?**

I am not sure one way or the other. If you paint a masterpiece because someone is threatening to harm your spouse, is that a good thing? If you suddenly start to enjoy today because you are constantly fearful that there may be no tomorrow (even though you don't admit it to yourself or others), is today better than a month ago? Yes and no? Yes, some things have changed for the better, temporarily. Ask me this tomorrow and I may have a different answer.

**Q: In one of your essays, you write that people sometimes say "you don't seem like you have Alzheimer's disease to me." How does this comment make you feel? How do you respond in these situations?**

At first, it was confusing. What should Alzheimer's disease "seem" like in me? Then it became reassuring. I knew I had the disease but at least others did not see it in me. Then it became annoying. How does anyone

know if you have a cognitive disease unless you are falling down or can't speak? Then it became disconfirming. I know for sure that I have the disease; I live with it every minute of the day between my ears. The fact that I am good at covering up the disease unconsciously doesn't make me feel any better. I know it is getting worse.

**Q: Why did you decide to share your essays with others? What do you hope readers will get out of your essays?**

I started to write to confirm for myself that I was still okay. I showed a couple of pages of writing to family and friends and they seemed to find themselves in the issues I was writing about. As I showed my writing to more people, more and more of them said they found personal value in it.

I hope that by reading my essays people who share my disease find that they are not alone with their thoughts and problems. I hope caregivers find better insights into their loved ones who may not be as talkative and verbose as I am.

**Q: You have become a powerful advocate for people living with Alzheimer's disease. Why have you chosen to spend your time speaking up and speaking out?**

I believe people who live with the diagnosis of Alzheimer's have an obligation to each other and to themselves to speak up and speak out about their treatment, feelings, and concerns. If they do not or if I do not, who will know how we feel? Who will know what it is like to have Alzheimer's disease? Cognitive diseases are by definition uniquely more difficult for others to treat and even imagine. We are all limited by our own mind's ability to know and to imagine.

**Q: What are your hopes for your future and the future of Alzheimer's care?**

I have given up hoping about anything, even my own future. I try to live in the present and wring as much joy out of it as possible. I gave up worrying about my future because I was pretty sure I knew what it would be. Thus far, it has not been as bad as I had anticipated.

There are governmental and institutional decisions that are going to be forced upon our society and upon those of us with the disease by the sheer number of people that will live with the diagnosis of dementia, probably of the Alzheimer's type. I am pretty sure these will be the wrong decisions when measured against human dignity and the enabling of individual human beings to be all they can be for as long as they want to be. But for now, for me, care is an individualized experience. I am focusing on me and those like me who are with me, now.

# Alzheimer's Disease

## Frequently Asked Questions

### **What is Alzheimer's disease?**

Alzheimer's disease (AD) is a progressive brain disorder that affects a person's memory and ability to learn, reason, make judgments, communicate, and carry out daily activities. It is the most common form of dementia, a group of brain disorders that gradually destroy brain cells. The most common form of the disease, late on-set AD, affects people over age 65.

### **What are the symptoms of Alzheimer's disease?**

People with AD generally experience a progression of symptoms. At first, the only symptom may be mild forgetfulness. Later in the disease, symptoms may include forgetting how to do simple tasks and having problems recognizing familiar people or places. Difficulties with speaking, thinking clearly, reading, and writing are also common. People with advanced AD may become anxious or aggressive and are often unable to care for themselves.

### **What are the causes of Alzheimer's disease?**

Currently, scientists do not fully understand the causes of AD. Age is the most common risk factor; the number of people with the disease doubles every 5 years beyond age 65. Family history and genetics are other known risk factors. A rare form of the disease, early-onset familial AD, is inherited and occurs between the ages of 30 and 60.

### **How is Alzheimer's disease treated?**

There are several medications that may temporarily delay memory decline and other symptoms of AD, but there are no drugs to stop the degeneration of brain cells. Every day scientists learn more about the disease, but currently there is no cure.

### **How many people suffer from Alzheimer's disease?**

It is estimated that 4.5 million people currently suffer from AD in the United States. By 2050, the number of Americans with AD could range between 11.3 and 16 million. According to a recent Gallup poll, 1 in 10 Americans said that they had a family member with AD and 1 in 3 knew someone with the disease.

### **How long can a person live with Alzheimer's disease?**

AD is a slow disease, starting with mild memory problems and ending with severe brain damage. The course the disease takes and how fast changes occur vary from person to person. On average, patients with AD live from 8 to 10 years after diagnosis, though the disease can last for as many as 20 years.

### **How accurate are tests for Alzheimer's disease?**

Doctors in specialized AD treatment centers can now diagnose the disease with up to 90 percent accuracy in a living person. Early and careful evaluation is important, because many conditions, including some that are treatable or reversible, may cause dementia-like symptoms. Examples of such treatable medical conditions are depression, nutritional deficiencies, adverse drug interactions, and metabolic changes.

### **What is the impact of Alzheimer's disease on society?**

More than 70 percent of people with AD live at home and receive most of their care from family members and friends. In the United States, current direct and indirect costs of caring for people with AD are estimated to be \$100 billion annually. As the baby boomer generation ages, these costs are expected to soar even higher.

Sources: Alzheimer's Disease Education & Referral Center ([www.alzheimers.org](http://www.alzheimers.org)) and the Alzheimer's Association ([www.alz.org](http://www.alz.org))