

## “The Alzheimer’s Spouse: Finding the Grace to Keep the Promise”

By Mary K. Doyle. ACTA Publications: Chicago, 2019.

*A Book Review by Sister Kathleen Weber, CSC*



Mary K. Doyle, a renowned author and lecturer, wrote this small book for “couples struggling with Alzheimer’s because of the insidious way the disease destroys this most important relationship.”

“All our lives, our personal energy is funneled into making a success of our marriage. But once this Alzheimer’s intrudes into a marriage, we find ourselves joined to someone who can no longer fully participate in that relationship .... A person whose declining health means a continuous and predictable stream of losses for both of us.”

The disease attacks its victim and the spousal caregiver as well. The formerly independent spouse becomes clingy while doing one bizarre thing after another. Their moods, reasoning, confusion, irrational behavior, etc., change from moment to moment. Brief moments of clarity often disappear as quickly as they had come. “We need to think for both ourselves and our spouses every minute of every day and all night long ... We have become their everything.” The responsibility for a successful marriage belongs to the caregiver alone.

The world of the spousal caregiver becomes as marginalized as that of the Alzheimer’s spouse as the disease intrudes into every aspect of their married lives. In this book, Ms. Doyle hopes to “offer insights gained from years of personal reflections about the predicament of the Alzheimer’s spouse, and bring to the table practical suggestions about caring not just for our loved one, but for the relationship we both worked so hard to build.”

She emphasizes throughout the book that caregivers are not alone. As the journey continues, each smile, touch and loving word becomes more precious, but every day also brings sorrow. As many of you have experienced, it took this family three years to get a diagnosis so they at least knew what they were dealing with. The author, already a caregiver, could then function as part of a team. She suggests congratulating yourself on everything you do correctly. This will help you recognize all that you do successfully.

Although Alzheimer’s is not a normal part of aging, 50 percent of seniors over 80 have some aspects of dementia including memory loss, confusion, disorientation, inability to learn new things, etc., plus depression, irritability, hallucinations, and paranoia, which are specific to Alzheimer’s disease. Scientists are still studying the causes of Alzheimer’s as they work for a cure. The process of the disease varies among individuals depending on pre-existing conditions, lifestyle and personality. Effects are visible in talking, thinking and reasoning. Personality changes may or may not be present. Later stages require assistance with all activities of daily living. Death can occur within a few years or after decades, depending on the person’s health

and age at the time of developing the disease.

Ms. Doyle explains that caregivers become their spouse’s memory.

“Their critical decisions about things like health care and finances become our responsibility. We are their money manager, nurse, advocate, housekeeper and physical assistant ... In addition to tending to our own needs, other family members, holding down a job, and managing our household.”

Spousal caregivers must do the heavy lifting, personal care, and monitor medications, safety and irrational actions. Knowing how to redirect the Alzheimer’s spouse’s attention increases. The safety and their dependence on the caregiver makes them eventually stick to the caregiver like glue.

“All of this takes a terrific toll on the spousal caregiver. Stress, exhaustion, depression, anger, irritability, worry, etc., effect the immunity and pre-existing health conditions of the ‘well’ spouse, causing 30 percent of caregivers to die before their ill spouses. The ‘well’ spouse cannot handle all this alone. A moment of saving grace only comes when we finally understand that although it is our

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# “My Stroke of Insight: a Brain Scientist’s Personal Journey”

By Jill Bolte, Ph.D. Penguin Group: New York, 2006.

*A Book Review by Sister Kathleen Weber, CSC*



*Sister Kathleen Weber, CSC*

Jill Bolte Taylor, Ph.D., is a neuroanatomist from Terra Haute, Indiana. Dr. Taylor became fascinated at an early age with how the brain works, having grown up with an elder brother who was later diagnosed with schizophrenia. In 1991, she received her doctorate and began teaching at Harvard Medical School where she worked in postmortem investigations of the human brain. At that time, she also became involved with the National Alliance on Mental Illness (NAMI), an organization dedicated to improving the lives of those with mental illness. “In my soul, I felt that I had found not only a cause worthy of my effort, but also an extended family.”

On December 10, 1996, Dr. Taylor suffered a brain arteriovenous malformation (AVM), an undiagnosed congenital bleeding disorder, which caused a hemorrhagic stroke in the left side of her brain.

“I woke up to discover that I had a brain disorder of my own. I was having a stroke. Within four brief hours, I watched my mind completely deteriorate in its ability to process all stimulation coming in through my senses. This rare form of hemorrhage rendered me completely disabled whereby I could not walk, talk, read, write, or recall any aspects of my life.”

Two weeks later, a golf ball sized blood clot was surgically removed. Because of her neurological training, Dr. Taylor knew that, in time, the brain is able to repair itself. Her complete mental and physical recovery took eight years. Dr. Taylor’s book is about her “stroke of insight into the beauty and resilience of the human brain. It is my hope that this book will offer insight into how the brain works both in wellness and in illness.” Dr. Taylor also hopes that readers will share her work to help others recovering from brain trauma as well as their caregivers.

Following the severe pain in her head Dr. Taylor felt “as if the integrity of [her] mind/body connection had somehow become compromised. I felt as though I was observing myself in motion ... For the first time I considered the possibility that I was perhaps having a major neurological malfunction that was life threatening.”

As time passed, Dr. Taylor “could no longer clearly discern the physical boundaries of where [she] began and where [she] ended. I sensed the composition of my being as that of a fluid rather than that of a solid. I no longer perceived myself as a whole object separate from everything. I now blended in with the space and flow around me. I pleaded, remember, please remember everything you are experiencing! Let this be my stroke of insight into the disintegration of my own cognitive mind.”

As the blood from the AVM filled the left part of her brain, Dr. Taylor was unable to concentrate on anything long enough to make it happen. She knew she needed to get help, but could not make that happen. She vacillated between moments of thinking clearly to being unable to think at all. The part of her brain that housed numbers was useless. She sat with the phone, but she could not call for help.

After 45 minutes, she was able to dial a phone number and her colleague answered. Only then did she realize she could not speak or understand what he was saying, but she knew he would get her help. Only then could she relax knowing she had done all she possibly could. She was also able to call her doctor and with unbelievable strength and patience managed to get out enough for her doctor to figure out who she was and what was wrong. With the same patience, her doctor told her slowly to “get to Mount Auburn Hospital.” Dr. Taylor knew that the more blood that spilled into her cortex, the more cognition she would lose. “I feared that my cognitive mind was becoming so disabled, so detached from its normal ability to function, that I would be permanently disabled. For the first time in my life, I understood that I was not invincible.”

After arriving at the hospital in a semiconscious state, her decline was rapid. Her head suffered tormenting pain and she was unable to move. She could hear nothing but the pounding of her heart, which made her bones vibrate “with ache and [her] muscles twitched with anguish.” She had no memories of her previous life. “I was still me, but without the richness of the emotional and cognitive connections my life had known.”

“My consciousness drifted into a time warp, rendering me incapable of communicating or functioning at either the accustomed or acceptable pace of social exchange. I, now, existed in a world between worlds .... I was not only an oddity to those around me, but on the inside, I was an oddity to myself.”

Dr. Taylor thought in a new way and could not communicate in the same way. She was gathering new information, but could not communicate quickly enough for the world around her. Because she was thinking in pictures, it was too difficult to get from the general picture to specific details. She could not process information like a normal person and the medical community was unable to communicate with someone in her condition.

“I wanted my doctors to focus on how my brain was working rather than on whether it worked according to their criteria or timetable. I still knew volumes of information and I was simply going to have to figure out how to access it again.”

The doctor announced that Dr. Taylor needed surgery to remove the remains of the AVM and a large clot. Otherwise, the hemorrhage could reoccur. Initially, Dr. Taylor made it clear that she would not allow the surgeons to open her head to remove the blood. She felt unable to survive another blow to her body. However, in a few days she agreed to allow them to operate knowing that in the next few weeks, she had to get strong enough to survive the surgery. She had to learn that whatever motion she could perform, despite the effort it caused her, was important. Focusing on her final goal of sitting up was

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# Holy Cross Health's Two Hospitals Once Again Recognized for Excellent Stroke Care

self-defeating because it was so far away. She had to take baby steps and rejoice as she achieved each one. Her celebration was sleep! "I had to be able to repeat that effort with grace and control before taking the next step. Every little try took time and energy, and every effort was echoed by a need for more sleep."

Dr. Taylor had to relearn almost all of her former skills, mostly through the hard work of her mother. Mathematics, reading and counting money were among the most difficult. "There is no question in my mind that it was the power of the unconditional support and love that gave me the courage to face the challenges of recovery."

After surgery, she had to make the decision to recover with all the pain and determination that it would require, and succeeded. "My stroke of insight would be: peace is only a thought away, and all we have to do to access it is silence the voice of our dominating left mind ... I needed the people around me to believe, to grow, learn and recover."

Sleep seemed to be the key ingredient. It protected the brain from too much sensory stimulation or noise. Nothing, according to the author, was as important as the healing power of sleep. She needed people to love her, not for who she had been but for who she would become. As the right and left hemispheres realigned, her brain became different, as did her likes, dislikes and interests. She needed others to know that she still had values. "I needed to have dreams to work toward. I needed help and love from others while learning to accept help graciously."

Dr. Taylor learned to feel emotions as they moved through her body and learned she could hang on to that emotion or just let it flow through her body. "Paying attention to what emotions feel like in my body has completely shaped my recovery."

After three months, her mother taught her to drive again. By mid-March Dr. Taylor began to live on her own with the assurance that her mother would be there if necessary. That step gave her the courage for a public presentation agreed to long before the stroke. Her recovery was well on its way and in eight months, she was back to work full-time. Her complete recovery took eight years. "I remain active in advocacy for the mentally ill. Helping people liberate their own inner peace, joy and magnificent beauty has become my personal agenda."

I found this book extremely interesting. For those who have suffered strokes, it can provide the hope they need to recover. For caregivers the author repeatedly explains what is helpful and what is not. In the appendix, she includes 10 assessment questions and a list of 40 things she needed the most.

**The Holy Cross Caregiver Resource Center's library provides access to this book and other resources. Call 301-754-7152.**

Holy Cross Hospital and Holy Cross Germantown Hospital once again earned the American Heart Association/American Stroke Association 2019 Get with the Guidelines® - Stroke Gold Plus Achievement Award with Target: Stroke<sup>SM</sup> Honor Roll Elite, for the ninth year and second year in a row respectively. This national and state recognition affirms these hospitals' commitment to providing consistent, high-quality care that saves lives and improves outcomes for stroke patients.



Holy Cross Health's two hospitals, Holy Cross Hospital and Holy Cross Germantown Hospital, are designated as Primary Stroke Centers by the Maryland Institute for Emergency Medical Services Systems (MIEMSS) for delivering top-quality stroke care.

At Holy Cross Health, patients benefit from our education programs and family support groups, including a dedicated stroke support group at Holy Cross Germantown Hospital, helping patients and caregivers learn to prevent second strokes and to cope with life after illness.

To learn more about stroke care at Holy Cross Health, visit [HolyCrossHealth.org/Stroke](http://HolyCrossHealth.org/Stroke) or for information about the Stroke Support Group at Holy Cross Germantown Hospital, visit [HolyCrossHealth.org/Support](http://HolyCrossHealth.org/Support).

## KNOW THE SIGNS OF STROKE

<b>B</b>	<b>E</b>	<b>F</b>	<b>A</b>	<b>S</b>	<b>T</b>
<b>BALANCE</b>	<b>EYES</b>	<b>FACE</b>	<b>ARM</b>	<b>SPEECH</b>	<b>TIME</b>
Does the person have a sudden loss of balance?	Has the person lost vision?	Does the person's face droop?	Is one arm weak or numb?	Is their speech slurred or strange?	What time did symptoms start?

**TIME IS CRITICAL... CALL 911!**

Be Fast was developed by Intermountain Healthcare, as an adaptation of the FAST model implemented by the American Stroke Association. Reproduced with permission from Intermountain Healthcare. Copyright 2011, Intermountain Health Care.

# Review of “The Alzheimer’s Spouse”

Continued from cover



responsibility to assure these tasks are accomplished, we don’t have to, nor can we do them alone.”

As the disease progresses, communication becomes more difficult. The spouse with Alzheimer’s disease cannot follow a conversation or remember what was said more than a few minutes ago, and when misunderstandings arise, they usually cannot be solved. “Neither challenging what they say nor defending ourselves is helpful when Alzheimer’s is involved.” Do not argue with them. However, sometimes lies are necessary. Often they can keep the ill spouse from distress without causing any harm.

We cannot correct the spouse’s misunderstandings, but listening “without contradicting or judging” will help with their frustration. Unconditional love and understanding will also help. The spousal caregiver can share his/her emotions in a support group or with a therapist. When the Alzheimer’s spouse is upset by hallucinations or paranoia, listen carefully but do not try to correct them. Redirecting them is usually all that can help. We must listen with our hearts.

Conversation skills are lost along with memories of former married life. Brain damage claims old memories and the ability to form new ones. Alzheimer’s destroys happy marriages. The whole family suffers as the disease takes its toll on both spouses. Nothing can compare to the shock the first time the Alzheimer’s spouse forgets who you are. Family members suffer and these emotions can cause conflicts among each other. Early onset patients threaten the family in a

different way. Children and teenagers are deprived of attention and love of one parent because of the disease and of the other who must pay more attention to the ill spouse. Situations like these can cause lifelong scars on children. Sharing of feelings among family members needs to be strongly encouraged. “A united family can better remember its past and mourn together, in sympathetic harmony, the losses they endure.” Ms. Doyle explains that after the deaths of parents, the adult children share a strong bond strengthened by the adversity they shared.

Family caregivers often procrastinate about bringing professional caregivers into the home, but they can be helpful in many ways. They share the workload — the Alzheimer’s spouse’s may be more compliant with strangers — and the caregiver spouse may have companionship. These and additional benefits hopefully outweigh sharing your home with outsiders and trusting them with the care of those you love.

As the disease progresses, adjustments may be necessary for the comfort of the Alzheimer’s spouse. “Every stimulant causes concern and uses our spouse’s energy.” The author suggests avoiding crowds, activities late in the day and anything that exceeds the spouse’s energy. Otherwise, it may be difficult to care for them that evening and even the next day. She includes a checklist containing many more suggestions for outings, tracking techniques, airport hazards, etc.

Ms. Doyle describes marriage as a partnership of give and take in which partners care for themselves and each

other. Alzheimer’s disease overrides this relationship. One partner assumes 100 percent responsibility of everything for both parties. “Not only have we lost those to whom we turned for help in making our own most critical life decisions, we have lost loved ones who previously made many of these decisions by themselves.” The Alzheimer’s spouse, in turn, becomes angry and resentful because they still believe they are fully capable of doing all this on their own. Care and help from the spousal caregiver is seen as a threat to the other’s autonomy. Often legal issues, like powers of attorney, need to be adjusted. Legal and financial issues vary from state to state but are never simple. “The key is finding all manner of service providers in whom we can place our trust with confidence: physicians, attorneys, housekeepers, painters, plumbers ...”

Self-care is another very important part of spousal caregiving. If it isn’t at the top of the list, it should be. The caregiver is sharing responsibility for the Alzheimer’s spouse. Lack of self-care can lead to illness and death. Psychological distress and depression can exacerbate health problems. Caregiver support groups, respite care, and scheduled time off are all necessities.

After spousal caregivers have read and digested the helpful suggestions in this book, I would suggest keeping it under your pillow. Hopefully it will remind you to first care for yourself and keep it handy for continued reference.

## OPEN HOUSE

The Holy Cross Medical Adult Day Center and the Caregiver Resource Center are hosting an open house for families and care providers in honor of National Adult Day Services Week.

Join us for a tour, light refreshments and entertainment; meet our staff; and learn more about Holy Cross Health’s senior services.

**DATE:** Wednesday, September 18, 2019  
4 to 6 p.m.

**LOCATION:** Holy Cross Resource Center  
9805 Dameron Drive  
Silver Spring, MD 20902

**RSVP:** Call 301-754-7150 or email  
holycrossmadc@holycrosshealth.org

# Vascular Contributions to Cognitive Impairment and Dementia

Article by the National Institute on Aging



Vascular contributions to cognitive impairment and dementia (VCID) are conditions arising from stroke and other vascular brain injuries that cause significant changes to memory, thinking and behavior. Cognition and brain function can be significantly affected by the size, location and number of brain injuries. Two forms of VCID—vascular dementia and vascular cognitive impairment (VCI)—arise as a result of risk factors that similarly increase the risk for cerebrovascular disease (stroke), including atrial fibrillation (a problem with the rhythm of the heartbeat), high blood pressure, diabetes, and high cholesterol. Symptoms of VCID can begin suddenly and progress or subside during one’s lifetime. VCID can occur along with Alzheimer’s disease. People with VCID almost always have abnormalities in the brain on magnetic resonance imaging scans. These abnormalities include evidence of prior strokes, often small and asymptomatic, as well as diffuse changes in the brain’s “white matter”—the connecting “wires” of the brain that are critical for relaying messages between brain regions. Microscopic brain examination shows thickening of blood vessel walls called arteriosclerosis and thinning or loss of components of the white matter.

## Forms of VCID

**Vascular dementia** refers to progressive loss of memory and other cognitive functions caused by vascular injury or disease within the brain. Symptoms of vascular dementia may sometimes be difficult to distinguish from Alzheimer’s disease. Problems with organization, attention, slowed thinking, and problem solving are all more prominent in VCID, while memory loss is more prominent in Alzheimer’s.

**Vascular cognitive impairment** involves changes with language; attention; and the ability to think, reason and remember that are noticeable but are not significant enough to greatly impact daily life. These changes, caused by vascular injury or disease within the brain, progress slowly over time.

**Post-stroke dementia** can develop months after a major stroke. Not everyone who has had a major stroke will develop vascular dementia, but the risk for dementia is significantly higher in someone who has had a stroke.

**Multi-infarct dementia** is the result of many small strokes (infarcts) and mini-strokes. Language or other functions may be impaired, depending on the region

of the brain that is affected. The risk for dementia is significantly higher in someone who has had a stroke. Dementia is more likely when strokes affect both sides of the brain. Even strokes that don’t show any noticeable symptoms can increase the risk of dementia.

**Cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy (CADASIL)** is an extremely rare inherited disorder caused by a thickening of the walls of small- and medium-sized blood vessels, which reduces the flow of blood to the brain. CADASIL is associated with multi-infarct dementia, stroke and other disorders. The first symptoms can appear in people between ages 20 and 40. CADASIL may have symptoms that can be confused with multiple sclerosis. Many people with CADASIL are undiagnosed.

**Subcortical vascular dementia**, previously called Binswanger’s disease, involves extensive microscopic damage to the small blood vessels and nerve fibers that make up white matter in the brain. Cognitive changes include problems with short-term memory, organization, attention, decision making and behavior. Symptoms tend to begin after age 60, and they progress in a stepwise manner. People with subcortical vascular disease often have high blood pressure, a history of stroke, or evidence of disease of the large blood vessels in the neck or heart valves.

**Cerebral amyloid angiopathy** is a buildup of amyloid plaques in the walls of blood vessels in the brain. It is generally diagnosed when multiple tiny bleeds in the brain are discovered using magnetic resonance imaging.

## Treatment and Management

Vascular contributions to cognitive impairment and dementia are often managed with drugs to prevent strokes or reduce the risk of additional brain damage. Some studies suggest that drugs that improve memory in Alzheimer’s might benefit people with early vascular dementia. Treating the modifiable risk factors, such as high blood pressure, can help prevent additional stroke.

For more information about vascular dementia and VCI, see NIA’s list of resources by visiting <https://www.nia.nih.gov/health/vascular-dementia-and-vascular-cognitive-impairment-resource-list>.

*This article was reprinted with permission from the National Institute on Aging (NIA), [www.NIA.NIH.gov](http://www.NIA.NIH.gov).*

**NOTE TO FAMILY CAREGIVERS:** As time passes and caregiving situations change, you may find you no longer need this newsletter or the services of the Holy Cross Caregiver Resource Center. If you find yourself in this situation, please call Sister Kathleen Weber at 301-754-7152 to have your name removed from the mailing list. These resources are provided to assist you and not to endorse any particular entity, service or event.

## FREE Caregiver Support Groups

For more information or to register, call 301-754-7152.

*Support groups are held at the Holy Cross Resource Center, 9805 Dameron Dr., Silver Spring, Md., unless otherwise noted.*

### Adult Children Caring for Aging Parents

Mondays from 6 to 8 p.m.; Tuesdays from 3 to 4:30 p.m.; or Thursdays from 10 to 11:30 a.m.

### Caregivers of Ill or Aging Spouses

Wednesdays from 10 to 11:30 a.m.; Thursdays from 3 to 4:30 p.m.; or Fridays from 10 to 11:30 a.m.

### Caregivers of Seniors

First and third Thursdays from 2 to 3:30 p.m. at the Benjamin Gaither Center, 80-A Bureau Dr., Gaithersburg, MD 20878.

### Telephone Support Group

For spouses and adult children. Tuesdays from 6 to 7:30 p.m. Call 301-754-7152 in advance for the code.



## Caregiver Resources

**The African American Health Program** has recently launched an Aging Subcommittee to help meet the needs of the African American population. The group is currently gathering data on the needs in the African American community and how best to meet them. For more information, contact Rachael Ruffin, MSPH, at 240-777-1202 or [rachael.ruffin@montgomerycountymd.gov](mailto:rachael.ruffin@montgomerycountymd.gov).

### Palliative Versus Hospice Care

Palliative and hospice care provide comfort care to reduce stress and offer symptom relief. Both address physical and psychosocial relief. Palliative care can be provided along with curative treatment. Hospice care is for those with a prognosis of six months or less who are not seeking curative treatment.

Holy Cross Home Care and Hospice, a member of Trinity Health At Home affiliated with Holy Cross Health, provides comprehensive, interdisciplinary care to patients who can be treated at home in lieu of hospitalization, require follow-up after a hospitalization or are facing the terminal stages of an illness. For more information, call 301-557-4663 (HOME).