

Delve Deeper into *The Genius of Marian*

A film by **Banker White** and **Anna Fitch**

This list of fiction and nonfiction books, compiled by Susan Conlon, Hanna Lee and Erica Bess of Princeton Public Library (NJ), provides a range of perspectives on the issues raised by the POV documentary *The Genius of Marian*.

The Genius of Marian is a visually rich, emotionally complex story about one family's struggle to come to terms with Alzheimer's disease. After Pam White is diagnosed at age 61 with early-onset Alzheimer's, life begins to change, slowly but irrevocably, for Pam and everyone around her. Her husband grapples with his role as it evolves from primary partner to primary caregiver. Pam's adult children find ways to show their love and support while mourning the gradual loss of their mother. Her eldest son, Banker, records their conversations, allowing Pam to share memories of childhood and of her mother, the renowned painter Marian Williams Steele, who had Alzheimer's herself and died in 2001.

ADULT NONFICTION

Coste, Joanne Koenig. *Learning to Speak Alzheimer's: A Groundbreaking Approach for Everyone Dealing with the Disease*. Mariner, 2004. Coste's book offers a practical approach to the emotional well-being of both patients and caregivers that emphasizes relating to patients in their own reality. Her accessible and comprehensive method, which she calls habilitation, works to enhance communication between care-partners and patients and has proven successful with thousands of people living with dementia.

Gruman, Jessie. *Aftershock: What To Do When The Doctor Gives You, Or Someone You Love, A Devastating Diagnosis*. New York: Walker & Co., 2007.

Social psychologist and medical journalist Gruman draws on her own experiences as well as those of other patients to offer a 10-stage approach to decision-making after learning of a difficult medical diagnosis. Chapters such as "Find the Right Doctors and Hospitals," "Pay For Care," and "What Will I Do About Work" provide sensitive yet practical advice to empower individuals and their families to move forward after the initial moments of shock.

Leavitt, Sarah. *Tangles: A Story About Alzheimer's, My Mother, and Me*. New York: Skyhorse, 2012. Through a spare and touching graphic memoir, author Leavitt shares the range of emotions her family experiences as they watch her mother, an Ivy League-educated, quick-witted, and passionate woman, deteriorate as a result of early-onset Alzheimer's. Like Pam White's husband, Leavitt's father must adapt to his new role as full-time caretaker while still recognizing the joy his wife brings, and the family leans on each other in many ways to cope with the stress of the day-to-day and the heartbreaking loss of such a vibrant mind.

Sheehy, Gail. *Passages In Caregiving: Turning Chaos Into Confidence*. New York: William Morrow, 2010. The best-selling author of *Passages* draws on her own 17-year experience caring for her ill husband to offer comprehensive and practical advice on each stage of the eight outlined stages of caregiving, from "Shock and Mobilization" to "The Long Good-Bye." Especially useful may be the content directed towards the "sandwich" generation" of individuals caring for aging parents as well as their own children.

Walker, Jeanne Murray. *The Geography of Memory: A Pilgrimage Through Alzheimer's*. New York: Center Street, 2013. In this critically acclaimed and touching portrait of a mother and

daughter, award-winning poet Walker offers an honest account of her mother's passage into Alzheimer's. In writing about the moments shared between the two, as well as their individual stories and memories, she offers a perspective on caregiving that is unexpectedly filled with gratitude and hope for those who must endure the hardships of the disease within some capacity of their lives.

ADULT FICTION

Block, Stefan Merrill. *The Story of Forgetting: A Novel*. New York: Random House, 2007. Seth Waller, a teenager from Austin whose mother has recently received a diagnosis of early-onset Alzheimer's (EOA), is committed to learning everything he can about the disease. Abel Haggard, a 70-year old man living on a farm just outside Dallas, lives in his past memories, which include reflections on his own family's struggles with EOA. Told in alternating voices of these two characters, Block shares a complex story about memory and the purpose of life.

Dean, Debra. *The Madonnas of Leningrad*, New York: HarperCollins Publishers, 2007. Bit by bit, the ravages of age are eroding Marina's grip on the everyday. An elderly Russian woman now living in America, she cannot hold on to fresh memories, yet her past is preserved in her mind's eye. Vivid images of her youth in war-torn Leningrad arise unbidden, carrying her back to the terrible fall of 1941, when she was a tour guide at the Hermitage Museum. As the Luftwaffe's bombs pounded the city, Marina built a personal Hermitage in her mind—a refuge that would stay buried deep within her, until she needed it once more.

Genova, Lisa. *Still Alice*. New York: Gallery Books, 2009. At fifty years of age, Dr. Alice Howland has it all – a loving husband, three grown children,



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and a celebrated career as a researcher and professor of cognitive psychology at Harvard University. After becoming completely disoriented during a jog through very familiar surroundings, Alice seeks a medical consultation that reveals a terrifying diagnosis – early onset Alzheimer’s disease. A neuroscientist with a family history of the disease herself, Genova writes with unique perspective about Alice’s struggle with the loss of abilities, independence, lifestyle and sense of self.

NONFICTION FOR YOUNGER READERS

Brill, Marlene Targ. *Alzheimer’s Disease (Health Alert Series).* Tarrytown: Marshall Cavendish Corporation, 2005. This book, designed for teens, delves into what Alzheimer’s is and what it’s like to have it. The book also explores the history of the disease and how to deal with it in your own life.

Weitzman, Elizabeth. *Let’s Talk About When Someone You Love Has Alzheimer’s Disease.* New York: PowerKids Press, 2003. Part of the “Let’s Talk Library,” this book is a useful tool for discussing Alzheimer’s disease with a younger child and focuses on assurance that a grandparent with Alzheimer’s is still the same beloved person they have always been, despite more recent changes in behavior. Causes and symptoms are addressed, as well as how the situation may take a toll on other family members. The book includes full-color images and straightforward, page-length answers to common questions.

FICTION FOR YOUNGER READERS

Anderson, Jessica Lee. *Trudy.* Milkweed Editions, 2005. A look at Alzheimer’s from one young girl’s perspective. Trudy’s Pop starts

acting strangely, and Trudy and her Ma can’t figure out what the problem is. Once Trudy’s Pop has been diagnosed with Alzheimer’s, Trudy and her mother are faced with some tough decisions.

Glass, Sue. *Remember Me: Te Acuerdas de Mi.* McHenry, IL: Raven Tree Press, 2002.

A young girl struggles with her grandfather’s mysterious behavior, worried about why he is having trouble remembering her and wondering if she had done something wrong. After finally sharing her concerns with her mother, who explains what Alzheimer’s disease is, they decide that the girl will become the memory keeper for her grandfather. The book includes full-color illustrations and is told in full English and Spanish.)

Newbery, Linda. *Sisterland.* Oxford: David Fickling Books, 2004. When Hilly’s grandmother becomes ill with Alzheimer’s disease, her family is turned upside down by revelations from her life during World War II.

Shriver, Maria. *What’s Happening to Grandpa?* New York: Little Brown, 2004.

Kate has always loved visiting her grandfather every summer; they would tell stories, laugh, and sing together. One summer, after Kate’s grandfather forgets she is visiting, he comes to live with her family. After learning that her beloved grandfather’s troubling behavior is a result of Alzheimer’s disease, she works with her grandfather on a scrapbook project to both help him remember the past and preserve his memories for the future. In addition to serving as a guide for difficult conversations, the book includes a list of recommended organizations and additional resources.

Sonnenblick, Jordan. *Curveball: The Year I Lost My Grip.* New York: Scholastic Press, 2012. When career-ending elbow surgery prevents pitcher Peter Freidman

from joining the high school baseball team, he starts spending more time with his grandfather, a well-known wedding photographer who has shared his knowledge of the camera with his grandson. When Peter begins noticing his grandfather’s odd and forgetful behavior, he talks about it with his mother, who refuses to admit anything is wrong. After a friend in his photography class suggests the issue might be Alzheimer’s disease, Peter needs to find a way to make his mother realize his grandfather needs help before it’s too late.

Williams, Carol Lynch. *If I Forget, You Remember.* New York: Delacorte Press, 1998.

It’s the summer before seventh grade, and Elyse Donaldson vows to write her first novel. At the same time, Elyse’s grandmother, whose Alzheimer’s disease has taken a turn for the worse, moves in with her family. At first excited to confide in her grandmother about all of the crises in her life – her widowed mother is dating again, neighborhood bullies, her first real crush, an always-perfect sister – she is angry and resentful about the changes in her grandmother. She realizes, though, that capturing and preserving her memories is a way to cope with the devastating disease.

