Since its first diagnosis in 1901 by German psychiatrist Dr. Aloysius Alzheimer, Alzheimer’s Disease has been the prognosis for approximately 5.4 million Americans. As the Baby Boomer generation approaches the most common age demographic for the disease – sixty-five and older – that number is expected to nearly triple to an estimated 13.5 million. There is currently no cure for Alzheimer’s, although certain treatments may temporarily improve symptoms; research and awareness are very much a vital piece of the fight against Alzheimer’s.
We spoke with Dr. Vahram Haroutunian, an Alzheimer researcher and director of the Mt. Sinai NIH Brain and Tissue Repository at the James J. Peters VA Medical Center, about the importance of Alzheimer’s awareness. “I think in general the public is aware [of Alzheimer’s], but they do not necessarily think of it as a disease,” he told us. “Therefore it is sometimes taken for granted that aging is associated with senility. There is this idea of, ‘Oh well, that’s not unusual, he’s old.’ But the fact is that it is unusual. It is not an inevitable consequence of aging. The long-term goal of the entire Alzheimer’s research community is to eradicate this disease so that everybody can live to be eighty or ninety or one hundred and not be at risk.”

The NIH Brain and Tissue Repository, known as the Brain Bank, is a part of a multi-state consortium that stores donated brains for study by neuroscientists. The study of brain tissue is a key component of progressing research toward a cure and Dr. Haroutunian was quick to point out that the donation of a well-functioning brain is just as important to
research as a brain with neurological disorder. “The Alzheimer’s community, victims, and their families, are well aware of the need for research on the brain. What gets lost is that you can’t understand what’s abnormal without understanding what’s normal. So donations from people without brain disorder is just as important, if not more important.” This is an area where awareness falls short – the human brain is not one that is typically thought of when considering organ donation. With diseases like Alzheimer’s, Parkinson’s, and other dementia – not to mention traumatic brain injury – the study of both afflicted and unafflicted brains is of paramount importance.

November is National Alzheimer’s Disease Awareness Month, designated by President Ronald Reagan in 1983. As our discussion with Dr. Haroutunian shows, awareness is key to both understanding Alzheimer’s and continuing to push for a cure. To do our part, we’ve pulled together a list of essential reading on the subject of Alzheimer’s Disease.

*Before I Forget: Love, Hope, Help, and Acceptance in Our Fight Against Alzheimer’s* by B. Smith, Dan Gasby, and Michael Shnayerson

To slowly lose the one you love must be one of the hardest things to go through in life. In their book *Before I Forget*, with the help of coauthor Michael Shnayerson, B. Smith and Dan Gasby take us through B.’s initial symptoms and diagnosis, then offering an intimate look at what dealing with the initial degeneration and the emotional and physical stress that can put on people who love each other more than anything else. Ever optimistic, though, the authors also offer a glimmer of hope and resources for when times become especially challenging.
Still Alice by Lisa Genova

*Still Alice* is the fictional account of Alice Howland, a cognitive psychology professor and linguist, who is diagnosed with early onset Alzheimer’s at the age of fifty. It is a realistically tragic and oft-painful account of the impact of Alzheimer’s, not only on the victim, but also the family. Julianne Moore took home an Oscar for her portrayal of Alice in the 2014 adaptation.


Greg O’Brien, an investigative journalist, was diagnosed with early-onset Alzheimer’s in 2009 at the age of fifty-nine. He has since become a staunch Alzheimer’s advocate and an important figure in raising awareness of the disease. In this article for *The Washington Post*, Greg recounts his diagnosis and his ongoing efforts to document his progression with the disease. Greg O’Brien memoir, *On Pluto: Inside the Mind of Alzheimer’s*, is also a must-read.

We Are Not Ourselves by Matthew Thomas

Matthew Thomas’s debut novel is a beautifully written, emotionally resonant chronicle of
the lives of Ed and Eileen Leary. It follows the family through the decades after WWII and charts the devastating effects Alzheimer’s has on the life the couple has created.

“When Mom has Alzheimer’s, A Stranger Comes for Christmas,”
NPR, by Vanessa Rancano

The holidays can be particularly difficult for families dealing with Alzheimer’s. Between the memories invariably invoked to the difficulties of celebrating, it can be a complex and trying time. This article from Vanessa Rancano follows the Downs family, including matriarch Helen Downs, who is suffering from Alzheimer’s, as they grapple with the impact Helen’s diagnosis has had on their family.

Alzheimer’s: Answers to Hard Questions for Families by James Lindemann Nelson and Hilde Lindemann Nelson

As of 2015, there were more than fifteen million caregivers providing care for Alzheimer’s patients, many of the them family of the afflicted. As the number of Alzheimer’s victims rises, so too will the number of caregivers and families affected. They are faced with incredibly difficult decisions, particularly those on end-of-life issues. Alzheimer’s: Answers to Hard Questions for Families provides not only advice on how to approach difficult topics, but also state-by-state and city-by-city directories of agencies and resources for caregivers.
The Worst Day of My Life So Far by M.A. Harper

As a growing number of Americans find themselves caring for a family member with Alzheimer’s, it is increasingly important for us all to understand and sympathize with their trials and difficulties. In this sometimes-unexpectedly hilarious novel, M.A. Harper helps us do so with the story of a woman who must return home to look after her ill mother.


In this article from The New York Times, N.R. Kleinfield touches on the pain of the early days of an Alzheimer’s diagnosis when one begins experiencing symptoms but is largely cognizant and left with the knowledge of the disease’s implacable onslaught. It follows Geri Taylor, a health-care executive diagnosed with Alzheimer’s at the age of sixty-nine.

All Gone: A Memoir of My Mother’s Dementia. With Refreshments by Alex Witchel

“All Gone: A Memoir of My Mother’s Dementia. With Refreshments by Alex Witchel

“Is there any contract tighter than a family recipe?” Alex Witchel asks as she recounts the experience of watching her mother lose her fight with dementia. To cope with the pain of
witnessing her once vivacious mother dwindle away, Witchel retreats to the comforting recipes of her childhood as a way to hang on to the woman who meant so much to her.

Losing my Mind: An Intimate Look at Life with Alzheimer’s by Thomas DeBaggio

Diagnosed with early on-set Alzheimer’s (a viciously aggressive form of the disease), renowned herb grower and owner of DeBaggio Herbs Thomas DeBaggio began to chart — in his words — “the mechanics and musings of my failing mind.” It is at turns poignant, painful, and inspiring.

When Someone You Love Has Alzheimer’s by Earl A. Grollman and Kenneth S. Kosik

When Someone You Love Has Alzheimer’s provides advice and guidance alongside practical information on what an Alzheimer’s diagnosis actually means: how the disease is diagnosed, what course it takes, how memory and cognitive function are affected, and beyond.
“Inside Alzheimer’s,” NPR, Rebecca Hersher

In this NPR series, Rebecca Hersher talks to Greg O’Brien on a variety of issues and topics related to his Alzheimer’s diagnosis and its impact his life and family.

As a final note, The Alzheimer’s Association is an excellent resource for information for Alzheimer’s and Dementia. Their website can be found here.