

*(Alzheimer's) Finding the Right  
Words: A Story of Literature,  
Grief, and the Brain*

Special thanks to: Dr. Maya Maxym, Summer Mochida-Meek, Dr. Kelley Withy, Gregg Kishaba, ECHO, Caltech, the Alzheimer's Association, Global Brain Health Institute, Dr. Bruce Miller, and Sarah Weinstein

# Excerpt from *Finding the Right Words*

My dad worked incredibly hard. When I was little, he went to the office six days a week, and then as Apex Electrical Supply took off, the business he owned with my mother's brother, he worked five days a week and then four-and-a-half so he could golf on Friday afternoons. I used to love going with him to the office and typing on the wide-girthed Selectric typewriter or answering the phone, "Apex Electrical Supply, may I help you?" Best of all, though, was getting to ride in the grimy van with him when he was delivering cables, wires, whatever. In those days, there weren't minivans or SUVs, so being in an elevated seat high up on the road counted as a novel experience, as fun. He liked to bowl and dance. His bowling day was Thursday; my mom's Monday. They liked to go dancing at the Meadowbrook Ballroom in Cedar Grove, the town next to Verona. At every bar or bat mitzvah, he would try to teach me how to dance. He liked Robert Goulet who starred in a 1960s Broadway show called *The Fantastiks* and sang Dad's favorite song, which was "Try to Remember." Talk about foreshadowing. He also loved Cat Stevens's album *Tea for the Tillerman* and Roberta Flack's "The First Time Ever I Saw Your Face." He wasn't materialistic, but he loved his Movado watch, a birthday present from my mother—no numbers, black face, and a diamond where the 12 would have been.

He used to tell me I was afraid of my own shadow, and he was right. Drying to death in a Maytag machine wasn't the only example. Here's a list: the dark, clowns, dolls coming to life (a *Twilight Zone* episode that I saw in Florida that scared the shit out of me for life), the Wicked Witch of the West (her skin, her laugh, the monkeys), my third-grade teacher, who was mean and sent me home from school because she said the gray and beige checked hot pants I was wearing, which my mother had bought me as a birthday present, were too short. The first time I saw my nana without her dentures (I didn't know she wore dentures) terrified me. Her face was disfigured, wizened, collapsed in on itself. Speaking of teeth, I recall my father going to the dentist and consistently refusing Novocaine. The dentist would try to change my dad's mind by telling him how much the procedure was going to hurt, but Dad wouldn't be swayed. I don't think it was entirely about being macho, though he definitely relished narrating the pain and the sound of the drill all while not under the influence. He would say that he preferred the pain to the numbness.

Here's more. He had an aqua Dodge Dart, and he loved it because it lasted forever. Years later, he bought a Dodge Swinger (brown body, cream-colored roof) and hated it. That's when I first learned that the word "lemon" could be applied to cars. He also hated raisins, which upset my Grandma Sarah because she liked to make rugelach, a bite-sized Jewish dessert, with them. He loved Grandma Sarah so much that when he went on a golfing vacation with some of his friends to Bermuda, he took time out of the short trip to visit her in Miami. I remember him saying how happy he was that he had done this because it was the last time he saw her before she died. Dad was like this—he took care of people. He made sure my brother knew how much he was loved even while he was becoming a Buddhist. He made sure that my sister got a dog after my uncle retracted on a promise to give her one from his friend's litter. I think he bought Tocca and brought him home the day of my uncle's betrayal or the next. The first time I saw my father cry was when he came home from the veterinarian having put down Tocca, our beloved dog of thirteen years. I don't think I ever saw him cry about having Alzheimer's, at least I don't remember. But maybe I'm blocking it out. He loved my mother so much that when he got sick, she loved him back with all she had. And he loved me in ways big and small, in ways that make it necessary for me to write this book for him.



# Dr. Bruce Miller and the Global Brain Health Institute

- Born in Indianapolis, Indiana
- Professor of Neurology at UCSF since 1998
- Member of the National Academy of Medicine since 2016
- Director of Memory and Aging Center at UCSF (MAC)
- Co-Director of Global Brain Health Institute (GBHI)



## What is GBHI?

- An interdisciplinary cohort of artists, doctors, and professors seeking to understand dementia and bring an equity-based approach to medical care



# Project Goals: Cindy

- Interdisciplinary crossover
- Helping others
  - Making the science and clinician accessible
  - Finding the humor in the tragedy
  - Sharing my story
  - Breaking down stigma
  - Giving readers state-of-the-art information about dementia
- Recovering my own memories





# Project Goals: Bruce



- Reach a general audience
- Pursue creative writing
- Share history of dementia research
- Bring the arts and sciences together
- Highlight the importance of empathy in doctor-patient interactions
- Make neurological language accessible

# The “narrative” of dementia

1. Importance of narrative from a medical point of view. What is the first clinical presentation? What comes next? and then what's next? This chronological narrative helps the doctor deliver a “precision diagnosis.” Also, presentations are linked to specific places in the brain. Knowing this will help, one hopes, with scientific discovery and intervention.
2. Through conversation (and profound empathy) Bruce and I eventually identified the first symptoms of my father's dementia: depression/word-finding. A diagnosis, in the absence of PET scans and MRIs, was given. Early-onset Alzheimer's with the logopenic variant.
3. Grief, though, is not chronological, and my memories were anecdotally organized, not temporally. That said, we did create a narrative that started with diagnosis and ended with memory. Within that structure, the narrative goes back and forth in time.
4. Dementia as a disease that undoes narrative, or one that calls into question assumptions about narrative.



# Excerpt from “Two Kinds of Space”

*Pals from a lifetime of golfing together abandon Jerry the moment that he turns the wrong direction to drive a golf ball. Alzheimer's disease is often a litmus test for our humanity, a test that Jerry's friends in his golfing fraternity badly failed, scoring an F in empathy, friendship, helping, courage, and inner strength. If Jerry is going to recapture the fun that he had golfing or gambling, Cindy is the only hope. Yet, the very idea of golf or gambling is alien to her. Cindy's "space" is quite different from Jerry's. Worse, for her, the casinos and golf courses, where these activities need to happen, smell of decay. Las Vegas, Atlantic City, and the golf courses of New Jersey, glittery places of hope and play for new American immigrants in the 1930s, '40s, and '50s, seem old and stale to the children of these immigrants. These children, like Cindy, need new dreams and playgrounds, not places where their parents and grandparents are dying. Spaces of hope for one generation become reminders of the inevitability of death for another.*

*Dementia, with its relentless erasing of what we do well and not so well, is often a reckoning for a patient's loved ones. This is who my dad was, this is what I knew about our relationship, and this is me in comparison. Alzheimer's disease challenges concepts around our own "space" and chips away at our confidence. No longer is our parent a steady rock that supports our life, a support that consciously and unconsciously buoys us up. Self-reflections, and reflections about who our loved one is and is becoming, emerge like scenes in a sad novel. In this book, every month, the loved one is different. It happens fast, and the accounting must be repeated over and over again. Alzheimer's disease, and really any serious chronic illness in a person we love, forces us to know that our time is short. We too will pass, maybe in the same sad way. Our "space" will disappear.*

*it seems insensitive to say that there is something good that happens as Jerry loses his personal space and comfort zone while simultaneously losing his ability to navigate. The pain for Cindy and Jerry is excruciating, almost impossible to measure. It is also a time when loved ones try to understand, reach out, learn and develop new skills. Jerry's fast friends who abandon him at his first moment of vulnerability are the biggest losers in this story. Their own brain systems for caring, learning about Alzheimer's disease, and deepening their own altruism suffer, and they become forever less, much less. Cindy's act of engagement broadens her vision. She taps an inner strength, a circuitry required for our survival, bringing a new and stronger self for future crises.*

# The Challenges: Cindy

- Co-authorship: finding Bruce
- The book's structure
- Finding a publisher





# The Challenges: Bruce

- Finding time to write in between seeing patients, supervising research
- Writing in a personal way
- Getting to know Jerry only through Cindy's memories



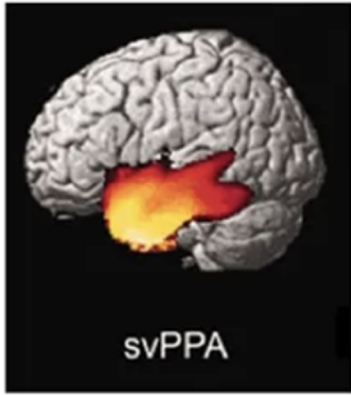






**Pg 24:** Different brain disorders that lead to the symptoms of dementia.

Drawing by Caroline Prioleau

Main Differences among the Three Variants of Primary Progressive Aphasia

	<b>Semantic Variant Primary Progressive Aphasia</b>	<b>Nonfluent Variant Primary Progressive Aphasia</b>	<b>Logopenic Variant Primary Progressive Aphasia</b>
<b>Clinical Diagnosis</b>	<ul style="list-style-type: none"> <li>• Impaired naming</li> <li>• Impaired single-word meaning: "Bird, what is a bird?"</li> <li>• Surface dyslexia or dysgraphia: "Yacht" is spelled "Yot"</li> <li>• Spared speech production (grammar is normal)</li> </ul>	<ul style="list-style-type: none"> <li>• Fewer words</li> <li>• Agrammatism: "I there goed"</li> <li>• Effortful, halting speech with gesticulations and hand movement</li> <li>• Spared single-word comprehension</li> <li>• Normal comprehension</li> </ul>	<ul style="list-style-type: none"> <li>• Word-finding pauses in spontaneous speech: "I was looking for my . . . my . . . um keys"</li> <li>• Impaired repetition of sentences and phrases</li> <li>• Spared single-word comprehension</li> <li>• Spared motor speech (no distortions)</li> <li>• Absence of frank agrammatism</li> </ul>
<b>Atrophy on MRI</b>	 <p>svPPA</p> <p>Predominant anterior temporal lobe</p>	 <p>nvPPA</p> <p>Predominant left posterior-fronto-insular</p>	 <p>lvPPA</p> <p>Predominant left posterior perisylvian or parietal</p>





**Left outside (lateral)**

**Right outside (lateral)**

**Parietal Lobe**

**Temporal Lobe**

**Broca's Area**  
speech production

**Wernicke's Area**  
understanding  
language

**Front**

**Right midline (medial)**

**Back**

**Underside (ventral)**

**Front**

**Occipital Lobe**

**Frontal Lobe**

**Amygdala**  
emotion, memory

**Hippocampus**  
memory, learning

**Pg VI: Key parts of the cerebral cortex. Drawing by Caroline Prioleau**



# Impactful Science

- Support readers with information:
  - Prodromal stage: hearing and sleeping
  - Mood changes and depression
  - Medication
  - Brain-body connection
  - Cognitive Reserve
- The empowering effect of possessing information and some of the language used by neurologists

# Caregiving

“There are only four kinds of people in the world—those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers.”

Rosalynn Carter

Former First Lady of the United States

## Am I A Caregiver?

Although caregiving will likely affect all of us at some point in our lives, many caregivers do not identify as a caregiver. Too often we hear caregivers describe themselves as “just” a daughter, husband, friend, or neighbor. If you provide support such as errands and grocery shopping, wound care and prescription management, or cooking, cleaning, and personal care at home – you are a caregiver, and you deserve to be seen and supported. (The Rosalynn Carter Institute for Caregivers)



# Caregiving for your loved one with dementia (part 1)

- Hearing is often an issue. Hearing aids are now available over the counter. This can help not only with actual hearing but with the social isolation that can accompany hearing difficulties.
- Sleeping is often an issue. If sleep apnea is part of the problem, see about getting a cpap machine. Also, reduce caffeine intake.
- Simplify when possible. Choose clothes that are easy to put on. Keep the space as uncluttered as possible, especially if falling is a concern. Try to limit the challenges the person with dementia faces. There are challenges enough.
- Wordfinding can be especially hard. If your loved one is search for a word and can't find it, you can see if you can guess it but that sometimes leads to frustration, especially if you can't find it either! You can try and move the conversation in another direction. Or you can let the person know how hard this is and you understand. If you are able, you can use this difficulty as an opportunity to hear the emotions your loved one is experiencing and perhaps share yours.
- Difficult conversations:

Quality of Life discussions

Do Not Resuscitate orders/Advanced directives

Anosognosia is when a person doesn't recognize their health issues. This is especially an issue in mental health. But what if your loved one DOES know they are ill? And what if they ask you directly about that. How might you handle that?

# Caregiving for your loved one with dementia (part 2)

- The power of music! If possible, make a playlist of your loved one's favorite songs. People with dementia can remember music, as we know from Tony Bennett and Glen Campbell.
- Intergenerational relations. If possible, bring children and teenagers into the life of the person with dementia. Studies show these kinds of relations can be quite beneficial.
- It's okay to inhabit the world of the person with dementia by which I mean it's okay to "lie." If your loved one's mother, for example, has died and they want to see their mother, you don't have to tell them she has died because that might lead to them experiencing their grief all over again, which they met forget and have do all over again. Other options include, "we can't see her today," but why don't we look at some pictures? Or "we can't see her today," so why don't we tell some of our favorite stories about her. Not everyone feels this way, though.
- The importance of touch to calm the person. This gets back to the wordfinding issue. Sometimes instead of playing a guessing game or having your loved one spiral because they can't remember the word, you might say, this really stinks doesn't it and hold them/hug them.
- If the person with dementia loves dogs or other animals, keep those present in their life, as much as possible. Communication with animals doesn't (usually!) require language so there can be a calming effect.
- According to many of the neurologists with whom I studied, anti-psychotics (Haldol, for example) should be the last intervention one tries.



# Caring for yourself: Breaking the Stigma

- Make sure you go to the doctor!
- And when you do and you fill out the intake form, there is typically a place for “other.” Write that you are a caregiver. What you are doing is a(nother) full-time job, which comes with physical and emotional consequences.
- Caring for yourself can look different for different people.
- Writing/Journaling: A way of releasing your emotions and, maybe even more importantly, undercutting denial. If you write it down, it is real.
- Sharing your experience as a caregiver with others: support groups, outreach events, therapy, friends, houses of worship, social media (though this can have some unintended consequences).
- Ask for help. Be specific. I am too tired to make dinner, would you be able to help me? I need to go for a walk, would you watch tv with my loved one while I do that.
- When you go the doctor/neurologist, bring questions. No question is too elementary. Also, if you have the strength, and this can be difficult, see if the doctor will listen to a story or stories, told by you and/or the person with dementia. You can say, we’re here because this happened or these things happened, and I’m concerned. Sometimes a story will illuminate something that bloodwork or a brain scan won’t. Also, it gives you a voice in the doctor’s office.
- Try to be patient but know that no one is perfect.

# Modifiable Risk Factors

- Eat Right! – Mediterranean Diet
- Get Sleep!
- Get Hearing Aids!
- Get Exercise!





# Table of Contents

*A Note to the Reader*

*Preface*

## **Diagnosis**

Hitting the Fan

The Detective Story

## **Word Finding**

Call Me Ahab

Where Dementia Decides to Dance

## **Space**

Lost in Space

Two Kinds of Space

## **Behavior**

Turning Right

The Neglected and Poorly Understood

## **Memory**

In Memoriam: Jerry Weinstein

A Tragic Juxtaposition

Afterword

*Acknowledgments*

*Glossary*

*Works Cited*

*Index*



# Excerpt from *Finding the Right Words: A Story of Literature, Grief, and the Brain*

It was a beautiful spring day in Berkeley, and that evening, we were going to make dinner at my house. Dad wanted a salad with his chicken. This seemed like a rather straightforward proposition until we got closer to the market, and Dad realized he wanted something very specific in his salad but couldn't remember what it was. I was always good with words, having been trained in the arts of playing Scrabble at a very young age with a very competitive mother, and then spending hours on the New York Times crossword puzzle as a college student (pre-Google). I was therefore confident that I could help Dad get to the right word with little fuss. Cocky, rational me went into problem-solving mode. Initially, I thought he wanted a certain kind of lettuce and not just iceberg. We were in Berkeley after all, and Dad had succumbed to the charms of the gourmet ghetto with its gorgeous produce and cheese varieties. Arugula? No. Red Leaf? No. He made it clear that it wasn't lettuce that he wanted, but it was something in the salad. Goat cheese? No. Tomatoes? No. Chickpeas? No. Sprouts? No.

I was starting to get a little antsy myself as I realized I wasn't hitting my mark. Dad picked up his pace as if speed would help him find the word more quickly, as if the word were running away from him and walking faster would help him catch it. I suggested that we might be able to figure out what it was that he wanted once we got to the market, and we could go through the aisles.... For some reason, I was set on the idea that it was chickpeas that he wanted, but he just wasn't connecting the word to the thing. Thus, I gently directed us toward the beans. Bad move. He got angry not only because he didn't want chickpeas, but also because he realized that I was behaving as if I thought he didn't know what the word "chickpea" referred to. He was right to be angry, and I was right to treat him like a child because he was one, sort of. I now see his anger as a good thing—he was angry that I was treating him like a child, and he was healthy enough to know it. As the disease progressed, I came to miss that anger because it had confirmed for me that some structures remained in place. He was still my father and I his child. Absent the anger, that was gone. He was gone, too, and so was I.



# Excerpt continued

I regrouped us, and we walked toward the produce aisle. He told me it wasn't anything like that, as in nothing refrigerated. What the fuck was it? Capers? I didn't think he liked capers, but the past was pretty irrelevant as I also thought he knew the woman to whom he had been married for over thirty years. At a certain point, my dad's desperation became my own. No longer were we walking through the various aisles, which was another one of my initial strategies (saunter through the aisle and maybe he'll see what he wants and that will be that), considering other things we might have wanted with dinner. It was all about finding whatever it was that we were looking for. Our white whale. Who knew it was croutons?

The two of us began a frantic search through the aisles. With fear and hope, I watched my dad looking at the various cans and boxes of stuff on the shelves, his expression turning from hope to disappointment to sadness and back again with each swift rejection of not seeing the thing he could not name. I decided it would be worse for me to keep guessing, so I shut my mouth and just kept him company on his heartbreaking journey through the supermarket. Eventually, we found the croutons. Dad's face lit up. He was so incredibly happy; I could have cried for joy myself. It was over. The relief was physical. Our hunt through the oceans of salad paraphernalia was over. We could go home, make the damned salad, and eat.

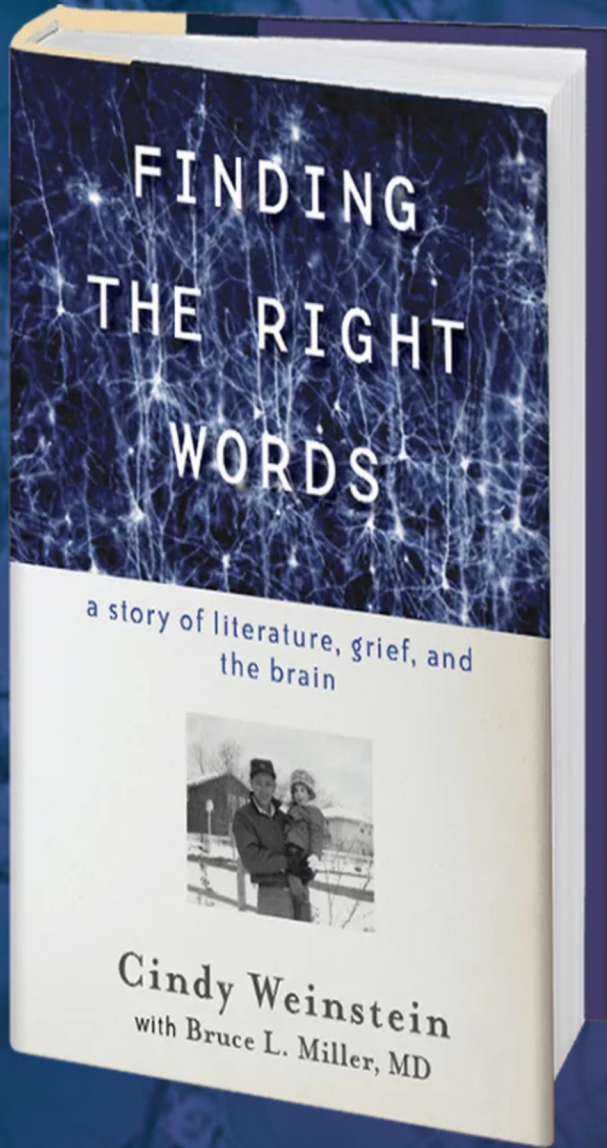
Until my dad decided that he wanted to rent a movie. I'll cut to the chase and tell you it was Ferris Bueller's Day Off. But my dad didn't, couldn't find the words. And so we started all over again.

# Excerpt continued

A crouton is a small, square-shaped piece of fried bread that is placed into soups or salads. The crouton originated in France in the 1800s, where a rich and complex food culture was emerging, and humans were creating a new way of cooking and eating. Croutons are an acquired taste, rarely appreciated by young children, but by early adulthood many of us begin to enjoy the aesthetic of eating a soft and chewy green salad with dressing that is dotted with hard and crunchy croutons. The actual origin of “crouton” is from the Latin word *crout*, which signifies crust. As is often the case with the English language, simply following phonetic rules does not help us to spell “crouton.” Rather, we associate the orthograph—the written constellation of letters—with the meaning for the word, which allows us to remember the correct pronunciation. Most of us infrequently eat, speak about, or write, the word “crouton.” It is a word that is used with low frequency by most people. Unless, of course, we are cooks and place croutons in salads every day or fanatically eat salads with croutons on a daily basis.

Ordinarily, words that we use frequently, like mother, father, shirt, cup, table, or house, are more facilely produced than a word like crouton. Therefore, it is not surprising that Jerry Weinstein, as part of his inability to name items (anomia) had difficulty generating “crouton” during a conversation with his daughter. Jerry’s struggle to remember “crouton” is the first moment that Cindy becomes aware that he is having cognitive issues. Anomia is one of the earliest manifestations of Jerry’s Alzheimer’s disease. Soon afterward, Cindy realizes that there are other signs of trouble. Jerry was never much of a reader, but now his spelling is off, and his writing is shaky. How disturbing for Cindy, a voracious reader, writer, and emerging literary critic, to see her father struggle to name, spell, or write. A steady cascade of losses soon follows, and, like many, Cindy watches her beloved parent descend into the dementia of Alzheimer’s disease.





# Any questions?

For more information, including upcoming events, early praise, and purchase options, visit: [www.weinsteinandmiller.com](http://www.weinsteinandmiller.com)

