



*Finding the Right Words: A
Memoir about Alzheimer's,
Literature, and Neurology*

Special thanks to: USC Verdugo Hills Hospital, California Alzheimer's Disease Centers at USC and Rancho Los Amigos, USC Alzheimer's Disease Research Center, John Danner, Deborah Weirick, Caltech, the Alzheimer's Association, GBHI, and Sarah Weinstein



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

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.

Project Goals

- Cindy:
 - Interdisciplinary crossover
 - Helping others
 - Making the science and clinician accessible
 - Finding the humor in the tragedy
 - Sharing my story
 - Recovering my own memories



- 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 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

- Cindy:
 - The act of remembering
 - Co-authorship
 - The book's structure



Dr. Rita Charon, “Narrative Medicine,” JAMA October, 2001

“The effective practice of medicine requires narrative competence, that is, the ability to acknowledge, absorb, interpret, and act on the stories and plights of others. Medicine practiced with narrative competence, called *narrative medicine*, is proposed as a model for humane and effective medical practice. Adopting methods such as close reading of literature and reflective writing allows narrative medicine to examine and illuminate 4 of medicine’s central narrative situations: physician and patient, physician and self, physician and colleagues, and physicians and society. With narrative competence, physicians can reach and join their patients in illness, recognize their own personal journeys through medicine, acknowledge kinship with and duties toward other health care professionals, and inaugurate consequential discourse with the public about health care. By bridging the divides that separate physicians from patients, themselves, colleagues, and society, narrative medicine offers fresh opportunities for respectful, empathic, and nourishing medical care.”

The “narrative” of dementia

- 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.
- 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.
- 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.
- Dementia as a disease that undoes narrative, or one that calls into questions assumptions about narrative.



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

Drawing by Caroline Prioleau

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

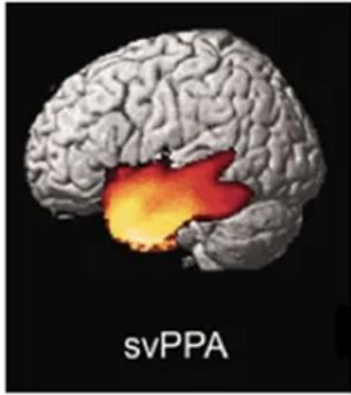
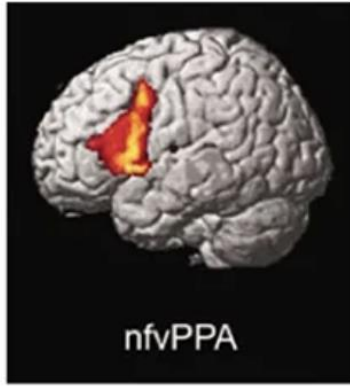
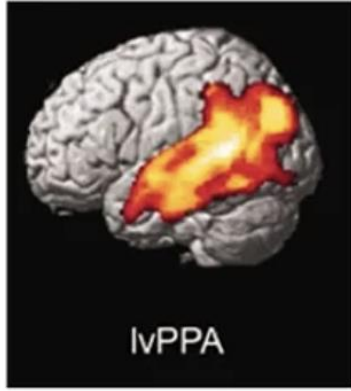
Frontal Lobe

Amygdala
emotion, memory

Hippocampus
memory, learning

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

**Main Differences among the Three Variants
of Primary Progressive Aphasia**

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



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, language**

Modifiable Risk Factors

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



Caregiver Burden

1. Data show caregivers suffer health problems
2. The emotional effects of stigma on person with dementia and caregiver
3. Economic challenges of caregiving



Ideas for Caregivers

- Keep a journal.
- Join a support group.
- Ask for help.
- When talking to your loved one with dementia, there is no need to correct them unless it's a matter of safety.
- Try to be patient but know no one is perfect.
- Try to find out how your loved one thinks about their quality of life. This information can help going forward.
- <https://ncoa.org/article/8-tips-for-alzheimers-and-dementia-caregivers>

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Excerpt from *Finding the Right Words*

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?

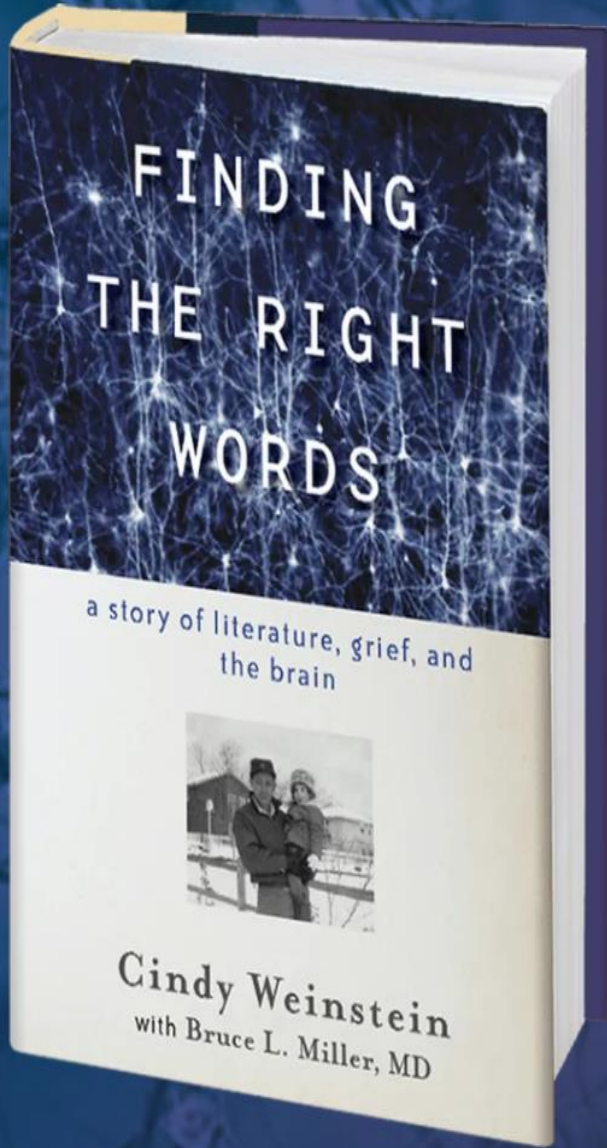
The two of us began a frantic search through the aisles. With fear and hope, I watched my dad looking at the various cans and boxes of stuff on the shelves, his expression turning from hope to disappointment to sadness and back again with each swift rejection of not seeing the thing he could not name. 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 facily 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?

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