

# In winter of life, memories fade

## 'Monsters' of disease must be kept at bay

By GREG O'BRIEN

Since I was a child, I started counting daylight minutes beginning with the winter solstice, when the sun is lowest in the sky. On that day, the start of new tilt of the planet's semi-axis, we enjoy a scant nine hours and 32 minutes of daylight. Day by day, a minute is added to the sun's purposeful journey to the horizon; about the time it takes for a genuine hug. At last comes the June solstice, heralding summer, the longest day of the year.

Today, at age 64, the longest day has new meaning for me as I battle these monsters of Alzheimer's disease. For those afflicted with Alzheimer's and for their caregivers, each day brings new trials from sun-

rise to sunset; every day is the Longest Day.

My maternal grandfather and my mother both died of Alzheimer's. Now it has come for me. I was diagnosed with Early Onset Alzheimer's in 2009 after a serious head injury unmasked a disease in the making. I also carry a marker gene. As one of 10 kids in an Irish Catholic family raised in Westchester County, I learned early on that you never get mad; you get even. I seek now to get even with Alzheimer's.

Since the day I sensed something was terribly wrong, my investigative reporting instincts have compelled me to document my experience, to compile a blueprint of strategies, faith, and humor, a day-to-day focus on living with Alzheimer's, not dying with it — a hope that all is not lost when it appears to be.

For me, the mornings are always the same. It's Groundhog Day. In disarray at first light, I must refocus on the five Ws: the Who, What, Where, When, and Why of life, before tossing the covers and organizing

the scattered files of my mind. I do this out of instinct, but there's always the depression, fear, and angst to walk through — and that's just on the way to the bathroom where, on doctors' advice, I've begun labeling the toiletries. I have attempted often to brush my teeth with liquid soap, and on two occasions gargled briefly with rubbing alcohol.

Then, I go deep into my lists — notes for everything, printed and on a digital calendar with repeat advisories. My life has become a constant strategy. I have a playbook, a script, a backup for everything. I think of my brain today as more like a smart-phone: still a sophisticated device, but one

that constantly freezes up, shuts down without notice, drops calls, pocket dials with random or inappropriate conversation, and has a small battery that takes forever to charge.

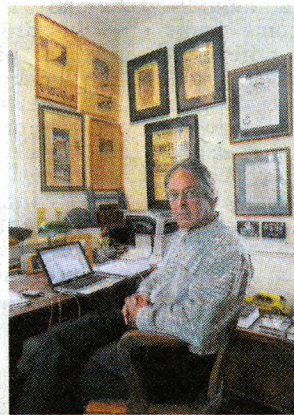


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**GREG O'BRIEN: Uses pen to tackle Alzheimer's.**

Doctors tell me I'm working off a "cognitive reserve," a backup tank of inherited intellect that will carry me in cycles for years to come. They tell me to slow down, conserve the tank. It's lights out, they warn, when the tank goes dry, just as it was for my mother. In

laymen's terms, the "right side" of my brain — the creative, sweet spot — is intact, for the most part, although the writing and communication process now takes exponentially longer. The left side, the area of the

brain reserved for executive functions, judgment, balance, continence, short-term memory, financial analysis, and recognition of friends and colleagues, is at times, in a free fall as I brace for a crash landing.

Years ago as a cub court reporter for The Arizona Republic, I befriended a Maricopa County Superior Court judge who instilled in me a firm resolve for asking questions. "Keep at it until you get the answers," counseled Judge Sandra Day O'Connor, whose perseverance led her to become the first woman justice of the U.S. Supreme Court. She subsequently retired to care for her husband, John, who eventually died of complications from Alzheimer's.

So I ask questions every day to stay in the moment, as our nation's millions of caregivers ask hard questions about why there are not enough resources for better care and research for a cure.

At twilight, I'm back on the mat with the monster. The journey through Alzheimer's is a marathon.

That's why I run several miles each night to increase the cerebral flow as the sun begins to set and more confusion takes over. I run until my legs give out. My daily physical routine helps reduce end-of-day confusion and restlessness, common in dementia patients, a period known as "sundowning," caused as light fades to black — a time of greater rage, agitation, and mood swings.

As the sun sets on the longest day, I will be back on my treadmill, at the gym and in the mind, as individuals around the world engage in a faithful uphill climb to halt this tsunami of a disease about to swamp a generation.

*Greg O'Brien is a former Boston Herald reporter. His latest book, "On Pluto: Inside the Mind of Alzheimer's," will be published this summer. He is also the subject of the short film, "A Place Called Pluto," directed by award-winning filmmaker Steve James, online at [livingwithalz.org](http://livingwithalz.org). He lives on Cape Cod.*