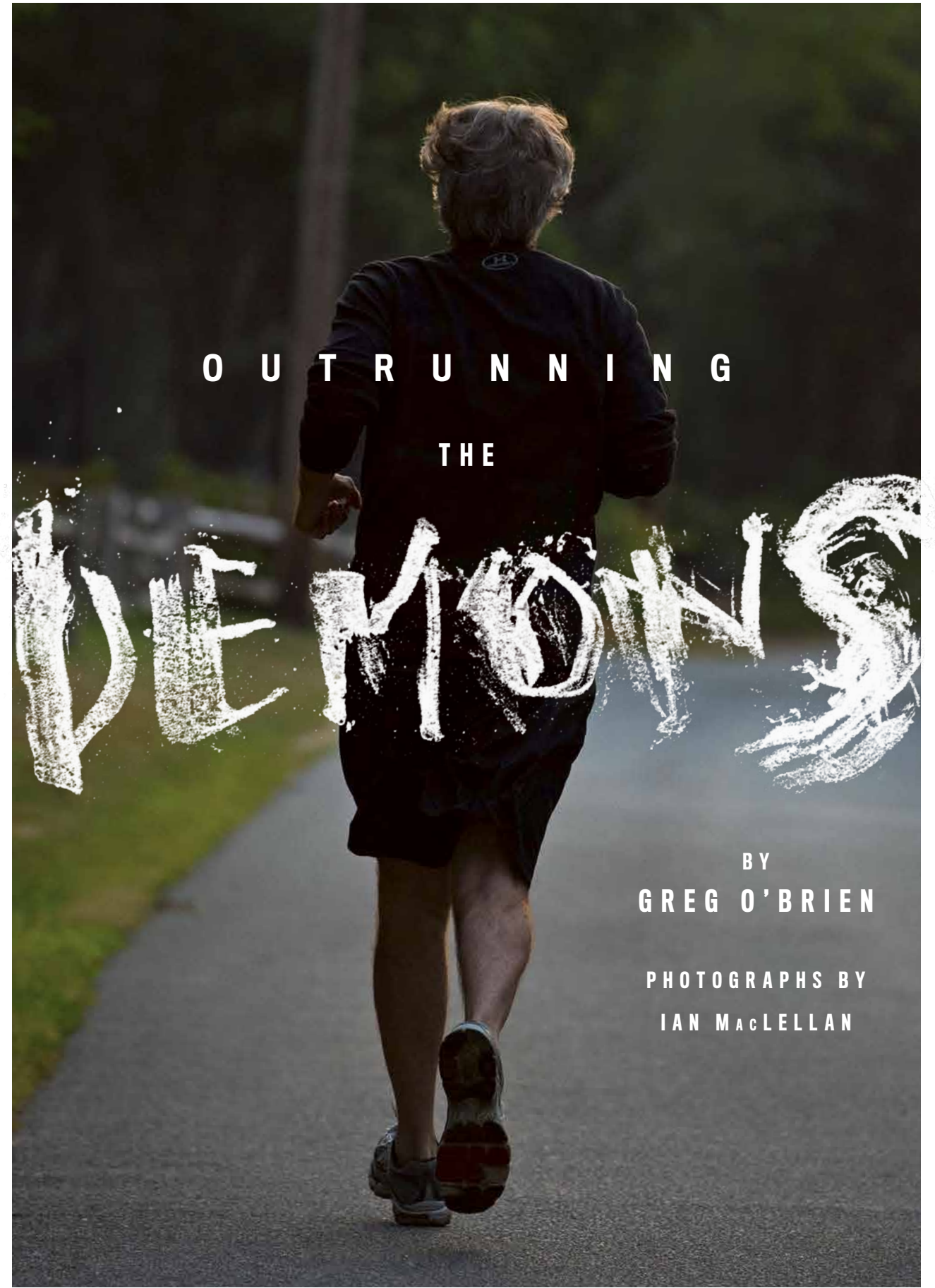


**IN MY BEWILDERING, TERRIFYING  
RACE AGAINST ALZHEIMER'S,  
QUITTING ISN'T AN OPTION.**



**O U T R U N N I N G  
T H E**

**D E M E N T I O N S**

**BY  
GREG O'BRIEN**

**PHOTOGRAPHS BY  
IAN MACLELLAN**



# THE DEMONS WERE CHASING ME.

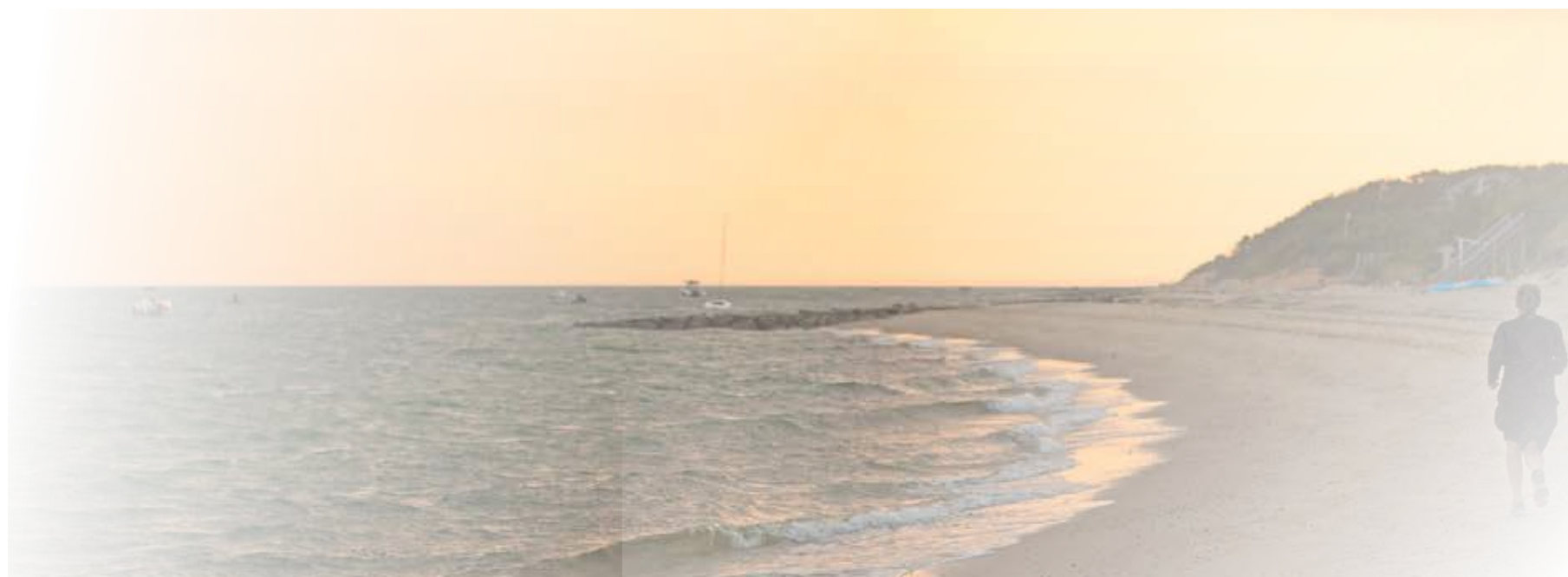
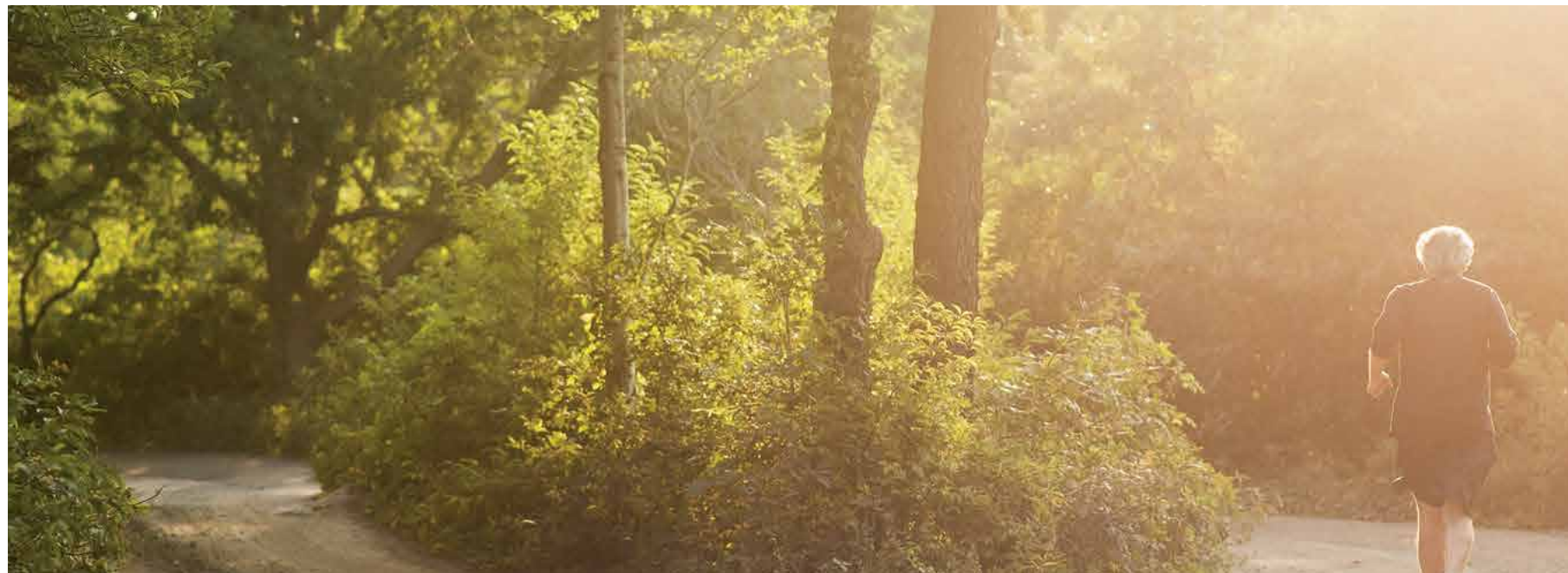
I could hear their screeching howls through the canopy of oak and red maple trees that enshroud Lower Road in Brewster, Massachusetts, on the Lower Cape. They were gaining, ready to pounce—I had to sprint to avoid capture at sundown. I felt them closing in as the spring afternoon gave way to dusk and a spectral fog crept over me, first in misty sprays that tingled, then in thick blankets that rose slowly from the base of my neck to my forehead, penetrating my mind and disorienting my senses. Alone, I was soon enveloped in fear and paranoia.

At full gait, I flew past Brewster's community gardens and its impenetrable stalks of corn, dashed by a forest of moss-covered locust trees bent in grim serpentine forms, and then sprinted in a panic past the ancient cemetery where baby Rhoda Mayo was buried in 1783, Dean Gray in 1796, and Reverend Otis Bacon—who "fell asleep in Jesus," as his gravestone declares—in 1849.

Where was Jesus now?



*Far left: O'Brien at work in his home office. Confusion and degeneration of his spine means he no longer runs alone, or for long, outside.*



The demons kept advancing as the blazing red sun sank into Cape Cod Bay, doused like a candle. Faster and faster they chased, and faster and faster I ran. I was 61 that day, two years into my diagnosis, and with every ounce of my will, I made it home. But I knew the demons would be back—with a vengeance.

My life, once a distance run, has become a race for survival. That's the way it is with early onset Alzheimer's. It's like a death in slow motion, like having a sliver of your brain shaved every day. Alzheimer's stole my maternal grandfather, my mother, and my paternal uncle. Now, at age 65, it's coming for me.

Before my diagnosis, I ran six miles a day along the back roads of Outer Cape Cod—running at least one of them at a six-minute-per-mile pace. Not bad for a guy then in his late 50s. I ran for the simple love of it; the solitude was soothing, and I enjoyed listening to the caw of herring gulls, the chirp of peepers, the cry of black-bellied whistling ducks.

After my diagnosis, the doctors told me that I had to ramp up my running. Physical activity—particularly in late afternoon—helps reduce the end-of-day confusion and restlessness common in dementia patients. Known as "sundowning," such symptoms are caused as light fades to black. This can also be a time of greater rage, agitation, and mood swings; like dandelions, we behave differently at night, our heads closing up tightly as the sun goes down. So every day before dusk, I ran from the demons of confusion, anger, and ongoing depression.

**T**HREE YEARS AGO, the demons finally chased me inside. Those country roads I loved eventually left me terribly lost in confusion and fear. My mind—afflicted by the amyloid plaques and tangles of Alzheimer's—could only focus on what it arbitrarily assigned as fearful, and all I could hear were the chilling hoots of a barred owl. My mind grew dead to the song of shorebirds.

I retreated to the treadmill at Willy's Gym in nearby Orleans, where I held the railings so I wouldn't lose balance. The monsters followed me there, too,

taunting me with loss of self, greater rage, and thoughts of suicide.

One damp fall evening, the rage was crushing. Determined to outrun the fiends, I defined survival that day as a personal record for a mile, and asked a young woman at the gym counter to clock my run.

"No one will believe this," I told her. She obliged.

I held the railings, looked straight ahead, and imagined the run of my life. I was going to beat the demons, kick their ass. At the half-mile mark, my timer—the slight, honey-blond coed— informed me my time was three minutes, five seconds. *Not fast enough*, I thought. My pursuers were gaining. *Not today*, I kept telling myself. *Not today!*

A minute later, the woman, concerned at my pace, asked, "Mr. O'Brien, should you be doing this?"

"My dear," I replied, panting, "You're asking me the wrong question. The question is: Could you be doing this when you're my age?"

She cheered me on. "You run like Superman," she said. At the stroke of a mile, my time was five minutes, 20 seconds, a PR. I beat the monsters that day, and impressed a young woman.

Faster than a speeding bullet, more powerful than a locomotive.

**YEARS AGO**, I thought I was Clark Kent. As an old salt news reporter, I coveted the role, even wore at times a trademark blue T-shirt with the iconic Superman shield under a Brooks Brothers dress shirt. But these days, I feel more like a baffled Jimmy Olsen, the fictional fledgling photojournalist for the *Daily Planet*. And on days of muddle, more like Mr. Magoo, the cartoon character created in 1949 who couldn't see for beans and was too obstinate to admit it.

These days, I get lost easily and don't recognize people I've known all my life, including, on two occasions, my wife. What was once familiar is now fleeting, and my memory is a progression of blanks analogous to someone shutting lights off in my brain. Close to 60 percent of my short-term memory can be gone in 30 seconds—names, numbers, places, thoughts—though the long-term

*From top: Large labels help O'Brien identify common products; in the beloved home he must soon sell; with son Conor.*



memory survives in part, as it does for most with early onset Alzheimer's. It is dispiriting to lose a thought in a second, 86,400 seconds a day.

My days all begin the same, in disarray. At first light, I must focus on the 5Ws: the who, what, where, when, and why of my life, and that's just on the way to the bathroom, where on doctor's advice I have begun labeling the toothpaste and rubbing alcohol in large, hand-scrawled letters. I have often attempted to brush my teeth with liquid soap, and

Some days are exceedingly terrifying, filled with hallucinations and delusions. These false impressions of objects, events, and sensory perceptions like smell, taste, or sound are caused by changes in the brain common in Alzheimer's and dementia patients. As they were for my mother, I find the hallucinations most troubling: those spidery and insect-like creatures that crawl along the ceiling—sometimes in sprays of blood, sometimes in a platoon—then inch a third of the way down the wall

back, but was not going to allow that to break a chain of 16 consecutive Brew Runs. Giving in, I thought, was akin to waving a white flag at Alzheimer's. *Screw that!* So for nearly two miles, I ran in pain, as if a knife were repeatedly cutting me from my lower back down my right leg to the ankle. I crossed the finish line "bloody, but unbowed," as William Ernest Henley wrote in *Invictus*. "I am the captain of my soul."

Recently, my personal physician, a close friend who cares for me like

## RUNNING FLICKS THE LIGHTS BACK ON SO I CAN DO WHAT I LOVE MOST—WRITE, THINK, AND FOCUS.

on two occasions gargled briefly with rubbing alcohol, which doesn't have a pleasant, minty taste.

After that, I go deep into my lists—my notes for every element of the day. I rely on my MacBook Pro laptop, replete with prompts and reminders—my portable brain, as I call it—and I continually email myself cues from my iPhone, as many as 40 to 50 a day, reminders of deadlines or the dates, times, and locations of appointments. (Sometimes I poke fun at myself, emailing: "You're doing pretty good, in spite of the fact you're such a dumb-ass!") My life has become a strategy of labeling, listing, confirming, and reconfirming. I have a playbook, a script, a backup for everything, because I have a formidable enemy—my mind. It used to be my best friend. Now, I don't see any chance of reconciliation. *Illegitimi non carborundum*, as I say: Don't let the bastards grind you down.

Still, I often fly into an inexorable rage, like when I hurled the phone across the room, a perfect strike to the sink, when I couldn't remember how to dial; or when I smashed the lawn sprinkler against an oak tree in the backyard because I couldn't recall how it works. I have pushed open the flaming hot glass door of the wood stove barehanded, melting my skin into second-degree burns, simply because I thought it was a good idea. I cry privately, the tears of a little boy, because I fear that I'm alone, that nobody cares, and that the innings are starting to fade.

before floating toward me. I brush them away almost in amusement, knowing, for now, that they are not real, yet fearful of their representation of cognitive decline. On a recent morning, I saw a bird in my bedroom circling above me in ever-tighter orbits, then precipitously it dove to my chest in a suicide mission. I screamed in horror. But there was no bird, no suicide mission, only my hallucination. And I was thankful for that.

**I'M NOW UNABLE TO RUN** as I did the day I set my personal record at Willy's Gym. Alzheimer's breaks down the mind, then the body. I haven't had feeling in the tops of my feet and hands for three years, and I sleep in my running shoes every night just so I can feel that I have feet. Recently, I was also diagnosed with acute spinal stenosis, scoliosis, and degeneration of the spine. So each afternoon now, I crank the treadmill at the gym to an elevation of 15 and to a speed of up to 6.2 mph, and run-walk four to five miles. The pain is still present, though there is less pounding on the spinal cord. I still consider it running. Running for my life.

In a moment of pluck, I took a Lazarus run, back from the dead, in September—the annual 5K Brew Run on the Cape. Mimicking Rosie Ruiz, who snuck from the sidelines into the 1980 Boston Marathon, I had my son drop me at the 2K mark—the difference being that I announced to everyone that I had a bad

family, took away my right to drive at night, and my lawyers told me to sell my cherished family home to reserve cash and simplify my life. As awful as this is, I would be more horrified if I couldn't run. For me, running restores mental as well as physical stamina. It flicks the lights back on. It reboots my mind, provides a reprieve, so I can do what I love most—write, think, and focus. It calms my rage, like letting steam out of a boiling teakettle. It's not just me: Researchers, too, have found that regular aerobic exercise benefits the brain and may slow the progression of cognitive decline.

Thus, if I'm not running, I'm slipping backward into Alzheimer's, into the hands of a pack of forbidding demons.

The Irish like to say, "Don't get mad, get even." And so I'm getting even every day with Alzheimer's. I'm pissed off that I won't win this race, and so is my family. There's not a damn thing we can do about it. But six years ago, I made the decision to make myself a moving target, and make these demons work for every piece of me. **EW**

*Greg O'Brien devotes his time to speaking and writing about living with Alzheimer's. He contributes regularly to NPR's special series, Inside Alzheimer's; his 2014 book, On Pluto: Inside the Mind of Alzheimer's, has won numerous awards; and he's the subject of the short film A Place Called Pluto (watch it at livingwithalz.org). For more from O'Brien and others on running with Alzheimer's, go to runnersworld.com/alzheimers.*