

Living – not dying – with early Alzheimer's

We planned to meet at The Sunnyside restaurant on Main Street in Hyannis at 10:30 a.m. Wednesday. It was almost 10:40. I sipped my coffee, thinking to myself: *Maybe he forgot.*



**Sean
GONSALVES**

I replayed the opening scene of the 10-minute documentary on Greg O'Brien's memory-mauling battle I had seen the night before.

A former investigative reporter, newspaper editor and publisher now living in Brewster, O'Brien walks from his family's house to his backyard office – a converted barn he calls "a place of memory," its walls covered with family photos and framed copies of stories and people he had covered through the years.

The first voice the viewer hears is that of O'Brien, diagnosed with early-onset Alzheimer's in 2009. "The



GREG O'BRIEN

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Gonsalves: Writer details life with Alzheimer's

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mornings are always the same – in disarray. At first light, I must focus on the five W's before tossing the covers – the who, where, what, when, why and how of life – as if rebooting my faithful MacBook Pro," O'Brien begins.

The camera pans across the office where O'Brien, now 64, spent the better part of the last two years writing his soon-to-be-published investigative memoir, "On Pluto: Inside the Mind of Alzheimer's."

"On doctor's advice I've begun labeling," he continues.

Cut to O'Brien in the bathroom, brushing his teeth. The camera zooms in on the toothpaste and mouthwash on the sink counter. Small pieces of paper are taped over the brand names with hand-written reminders: "toothpaste" and "mouthwash."

"I've attempted often to brush my teeth with liquid soap and on two occasions I gargled, briefly, with rubbing alcohol," O'Brien explains in the opening of a moving, intimate portrait of the O'Brien family's struggle with the brain- and body-eating disease that claimed the lives of both his maternal grandfather and mother.

O'Brien is featured in "A Place Called Pluto," one of four short films. It was produced by Emmy Award-winning filmmaker Steve James, probably best-known for the movie "Hoop Dreams." The executive producer of the film series is David Shenk, author of the seminal book on Alzheimer's, "The Forgetting."

Commissioned by the Cure Alzheimer's Fund in Boston and the MetLife Foundation, the documentaries are now hitting the film festival circuit. Last week, they were shown at the Tribeca Film Festival in New York, where O'Brien was invited to be on a panel to discuss the disease 5 million Americans suffer every day. During the weekend, there were two screenings in Somerville.

It will likely be shown on Cape Cod this summer, around the time O'Brien's book is set to be released.

The opening sequence that I was replaying in my mind – a mental trick most of us take for granted – was cut short when O'Brien walked through the front door and immediately recognized me seated at a booth halfway across the restaurant. He was carrying his trusty laptop under his arm.

I soon learned that, because every 30 seconds 60 percent of his most recent memories vanish, he relies on iPhone calendar alerts and emails he sends himself every day to keep up with appointments and meetings – in addition to reminders from his wife and oldest son, Brendan.

He walked me through his daily routine, beginning with the milligrams of multiple medications he takes – Aricept, Namenda, Celexa and trazodone – to deal with everything from "restarting the brain" to helping him fall asleep at night.

He runs and walks each day, hitting the treadmill at Willy's Gym in Orleans, which, he said, helps him to "deal with the rage."

He told me about the "sundowner effect" – that time of day when it gets dark. "The light changes," he said, "and it impacts the brain. Confusion sets in."

He explained how Alzheimer's doesn't just ravage the brain; it also attacks the body. "I've had no feeling in parts of my hands and feet for several years now."

And he's not seeking treatment for his prostate cancer so that he can focus on fighting

A PLACE CALLED PLUTO

To see the four short documentaries on living with Alzheimer's disease, go to livingwithalz.org

For more information about the forthcoming memoir on the battle with the disease written by Greg O'Brien, featured in one of the films, go to onpluto.org.

Alzheimer's. If the cancer takes him sooner than Alzheimer's, O'Brien said, that would be a blessing of sorts, saving him from withering away in a nursing home as his mother did before his eyes.

"I'm not disparaging nursing homes," he said. "It's a personal choice I've made."

Another personal choice O'Brien made was to use the skills of his journalistic career to document what it's like to live with a disease experts say will surpass heart disease and cancer as a leading cause of death in the decades to come.

"As an investigative reporter, I'm trying to write as I can. There will be a time I can't. But people with Alzheimer's, on some level, know more about the disease than doctors," he said.

"My book is about living with Alzheimer's, not dying. That will come in time," he said, explaining how he relied on six years worth of copious notes he took when he first started to notice the symptoms.

Advance reviews of the book so far have been glowing. Lisa Genova, author of the best-selling novel "Still Alice," which is being made into a Hollywood movie, said, "If you're trying to understand what it feels like to live with Alzheimer's ... then you need to read this book."

"I'm telling the biggest story of my life" – that from a man who covered the Mafia for the Arizona Republic and was taught how to be a court reporter by retired Supreme Court Justice Sandra Day O'Connor back when she was a Maricopa County Superior Court judge.

Shenk, executive producer of the films, said he wanted to focus on families and caregivers living with the disease, not the medical science. For more than a year they searched for someone who would "especially articulate with insight about the disease and themselves."

"That's a tall order," Shenk told me. "We almost gave up looking. And that's when we found Greg."

"It's an honor to know him. I've been trying to educate people about Alzheimer's for about 13 years now. And meeting Greg has been an important thing in my life," said Shenk, who is writing an epilogue for O'Brien's book.

"I don't think I'm getting out of this," O'Brien told me before we left the restaurant. "It's like death in slow motion, like having a sliver of your brain shaved off each day. I made the decision to not be a guinea pig. My contribution is to write about it."

But it's not all sadness. "You can't live without faith, hope and a sense of humor," he said. "Everyone gets knocked down. But I believe the measure of a person is how and when you get back up."

One day, O'Brien is well aware, he won't get back up. But that is true for all of us as we journey toward our own Pluto, "where no one can hear what you are saying."

It's just some of us know in advance how we'll get there.

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