

Living With Alzheimer's Disease: An Interview With Greg O'Brien



Greg O'Brien

BY MICHAEL DREGNI

“Alzheimer’s is death in slow motion,” says Greg O’Brien. An award-winning, nationally recognized journalist, he was diagnosed in 2009 with early-onset Alzheimer’s at age 59. Now 66, he is chronicling how dementia is affecting his life and his family as a way of raising public awareness of the disease.

He published a memoir in 2014, *On Pluto: Inside the Mind of Alzheimer’s*, detailing his ongoing battle with the disease as a means of providing others with “a blueprint of how to fight” the disease. O’Brien and his family were also

the subjects of the short film *A Place Called Pluto*.

“There’s only so many things I can do now, but the one thing I’m going to do until I can’t anymore is be a reporter,” Greg says. He calls himself “an embedded reporter inside the mind of Alzheimer’s,” and he’s chronicling how dementia is effecting his life and that of his family as a way of raising public awareness of the disease.

In this exclusive interview, O’Brien discusses how he is fighting Alzheimer’s by living with the disease and not dying from it.

Q&A

Experience Life | I just finished reading your book; it’s powerful.

Greg O’Brien | Thanks. I’m working on a revised, expanded edition that will be out soon that takes the story from the time I finished the first edition up to today. It doesn’t change the focus of the book; it adds to it.

EL | You explain in detail many of the coping mechanisms you use to deal with Alzheimer’s on a daily basis. Where and how did you learn this?

GO | I learned a lot from my maternal grandfather and my

mother and later from my paternal uncle — all of whom died from Alzheimer’s. And also from my father, who died of cancer, but before he passed away he, too, was diagnosed with dementia.

My mother in particular taught me a lot, because I was the family caregiver for her here on Cape Cod and I learned strategies early on. My mother was a role model; she taught me how to live with the disease. I was in the very early stages when she was going through her final stages, and we talked about the disease, we even took our medication together.

As I note in my book, lying down in football is a position of defeat, and you’ve got to fight Alzheimer’s 24/7 — and it beats the hell out of you. As a journalist, I had — I don’t want to say it’s a leg up — but I learned early on how to take copious notes, how to work through problems, how to problem-solve, how to multitask when it was very difficult, and those were lifelong skills that have helped me in the years of dealing with Alzheimer’s.

You’ll never see me without my Apple laptop, because I write everything down. And my iPhone: I send myself 50 emails

or more a day to remind myself of things — I'll interrupt people and say, "I've got to send myself an email." Sometimes I forget that I've sent myself all those emails, and then at the end of the day I'll look at my inbox and there's 57 new emails and I realize that 37 are from me. It's like a record I keep. God bless Steve Jobs.

There are times when the light [in my brain] will go off and I'll pick up the phone and not remember how to dial, or a lawn sprinkler and not remember how it works. Or once, with the family's wood stove in the wintertime, I opened the door with my bare hand and got a second-degree burn.

EL | You describe in your book how you put labels on things as reminders — including labeling your mouthwash to differentiate it from a bottle of isopropyl alcohol so you don't gargle with the alcohol, as you did on a recent morning.

GO I didn't want to do it [label everything] because I felt like a freaking child. I talked to my doctors and counselors, and they said, "No, Greg, it's OK. It's your bathroom and no one else is going in your bathroom but you and your family."

I can look at something — and this is what's happening to my brain now: It's not telling me things. I will look for my laptop, I'll be staring at it and my brain will not tell that that's my laptop. This happens on a regular basis. So what you do is identify things and write it down so you'll know what it is.

And yes, I gargled once — I looked at this thing and my mind said it was mouthwash and it was freaking rubbing alcohol and it was just like, *Oh my god!*

It's a progression and some days are better than others.

My mind today is like an iPhone: It's still a sophisticated device, but it has a short-term battery, it pocket dials, it locks up, and it gets lost very easily.

It's like having a sliver of your brain shaved away, a death in slow motion, and you wonder when you get up the next day who's going to show up in your brain.

EL | Can you explain your perception of the image the world has of Alzheimer's?

GO I speak a lot across the country about the disease and I start out by saying there's a stereotype of Alzheimer's: You're 85 years old, you're in a nursing home, and you don't know who you are or where you are. But that just isn't a true picture of the disease.

Alzheimer's is a disease that can take 20 to 25 years to run its course. Research has shown that the process of the disease begins even before you notice any symptoms — it can start as early as in your 40s.

It's like having a sliver of your brain shaved away, a death in slow motion, and you wonder when you get up the next day

who's going to show up in your brain.

Alzheimer's in the early stage is like a light that goes out in your brain. Have you ever lived in a house with a basement? Have you ever done the laundry in the basement when someone up in the kitchen didn't realize you were there and shut the light off? In Alzheimer's, when that light goes out, you go into a rage — you yell and you scream to try to restart your brain. And often it does. It's on, it's off, it's on — it's like a light flickering, a loose plug in a socket. I know firsthand thanks to my family history that someday there's not going to be someone up in the kitchen to turn the light back on. It's going to go dark forever.

Today at times, the light's going on and off in my brain. Sixty percent of my short-term memory can be gone in 30 seconds. It's not like someone just forgetting something; it's like *Boom, boom, boom, boom, gone, gone, gone, gone*. I get lost in places I've known all my life. I didn't recognize my wife on two occasions. I have incredible rages. At times, as my mother did, I have hallucinations.

And people don't want to talk about this! And I say, "You know, dammit, unless we work to try to make this disease as well known as they did with cancer and as they should have done with AIDs, and now they're trying to do with ALS and autism, no one's going to talk about it. There are people who are dealing with these freaking symptoms every day and they're afraid to talk about it.

I find that among people with Alzheimer's, everyone's different: It's like snowflakes — there's no two people with Alzheimer's that are the same.

EL | The title of your book — *On Pluto* — is based on the vivid analogy between the planet Pluto and Alzheimer's. Can you describe the connection?

GO | The environment of Pluto is a great description of Alzheimer's: Isolation, the starkness, the darkness — and the fact that Pluto is now known as a dwarf planet; it's not a real planet anymore, and you're less of a person.

What happens in this disease is that you drift out, and I'm always fighting against the urge to drift out. Like I said, lying down in football is a position of defeat, and

so I fight while I can, but every once in a while I let myself go, and I had to invent a place that I was comfortable with, and so I called it Pluto. My family's been out there — my mom, my grandfather, my paternal uncle, my father. I've been out there and someday I'm not going to return from Pluto and I want people to know where I am.

EL | You write in your book that your goal now is "living with Alzheimer's, not dying with it." Can you explain?

GO | My feeling is that if you give up — and I've got to tell you

there's days when I want to give up — you let go, and I try to stay focused because if I don't, I will drift away.

When your mind fails, you reach for your heart. My mind used to be my best friend, but I don't see any chance for reconciliation. You have to raise the question, Is memory all that it's cracked up to be? How big was that home run you hit in high school? How big was that fish you caught? And we remember what we want.

But the heart is really the place of the soul that I believe survives forever. And when you learn to write and speak from the heart, you're speaking from that place inside you. I believe the spirit survives.

I've committed probably every sin a man could commit in life other than murder and adultery — and I've been tested in both. I'm just a regular guy who's trying on his way out to do something good by spreading the word about Alzheimer's.

And when you learn to write
and speak from the heart,
you're speaking from that
place inside you. I believe
the spirit survives.