Alzheimer's Talks
with Greg O'Brien
April 28, 2017

Note: This transcript has been edited for content and clarity.

Meryl Comer: Welcome to Alzheimer's Talks, a free monthly teleconference presented by UsAgainstAlzheimer's. I'm Meryl Comer and joining us today is journalist and author Greg O'Brien.

Before we begin, UsAgainstAlzheimer's has suffered a personal loss to our family. Our beloved co-founder, Trish Vradenburg, passed away last week from a heart attack. We are devastated by the loss, it makes us strive to fight harder but the outpouring from so many of you has been stunning, in your respect and support for her husband, George, our other co-founder. They were at a point in their lives where they could have really led the good life, but they've devoted the last two decades because of a personal family experience to fighting this disease and we do feel like a family.

I want to flag a remark by Senator Ed Markey, since we have so many advocates on the line. He delivered this from the Senate floor and he talked about Trish's powers as an advocate, and because so many of us like to think we're advocates or we try very hard, he said that: "Simply put, you never wanted to tell Trish "Maybe" or "No," particularly when the issue was Alzheimer's disease. This was compounded by the fact that Trish was a master communicator and humorist. She did not mince words and knew how to convey a message, often delivered with memorable one-liners. A gifted writer, she authored novels, sitcoms, and op-eds, with many of her most recent pieces calling attention to the great threat of Alzheimer's disease…In closing, it is difficult for me to comprehend that Trish has passed away and that we will no longer hear her powerful voice, her luminous laughter, her one-liners, experience her creativity, and benefit from her passionate conviction that we must keep fighting to defeat Alzheimer's. The indomitable memory of Trish Vradenburg – an amazing, creative, and pioneering woman – motivates us all to live to the fullest and to accelerate our work so that we can soon reach the day when Alzheimer's disease is found only in the history books. In these ways, her inspirational legacy lives on as George continues their important work with Trish in his hear, in her family's love, and in her friends' and colleagues' admiration." Those are the words from Senator Ed Markey on the floor of the Senate.

In introducing Greg O'Brien, I'd like to actually quote from Trish who wrote a blog post about Greg. What she said was that in 2009, at age 59, Greg was diagnosed with early onset Alzheimer's. It wasn't surprising since his family was laced with the disease. His grandfather, his uncle, and his mother had all succumbed to this merciless killer. Now it's Greg O'Brien's turn. But he isn't going down without a fight. An investigative reporter by profession, he began taking copious notes about his arduous trek into his mind, riddled with Alzheimer's. Thus began O'Brien's chronicle, which resulted in his heartbreaking, defiant, and profound book, On Pluto: Inside the Mind of Alzheimer's.

Greg, we are honored and thrilled to have you with us today, as an advocate who also mourns the loss of Trish along with us. Thank you.

Greg O'Brien: It's an honor to be here. George and Trish are like family to me. Senator Markey is also a close friend and it's soldiers like that, that are going to get us to the point where we're within reach of a cure someday. That's a heavy lift but if we all lift together, maybe we can do it.

Meryl Comer: Greg, let me ask you, because we're talking about the power of advocacy. What has that done for you personally? I say it saved my life, because it permitted me to sort of flip my pain and fight it at a different level. What has it done for you?

Greg O'Brien: Well, interesting that you use those words because it saved my life as well. In fact, when I was diagnosed, my neurologist knew my background as a career journalist and he looked up and said, "Greg, you need to write about this. People need to hear the story and you need to get it out for them as well as for you." And so, rather than go into a pity party, because I had a front row seat with my mother, my paternal grandfather, my uncle, and also my father before he died, of dementia, I could have gone into a pity party but you know, if you do that, Meryl, and anyone who's listening and thinking about it, if you do that, it's really a party of one. And I get tired of that damn quick, and as a journalist and political investigative reporter, my gut instinct was to report about a story that was unreported. And I said, shame on me if I don't, shame on me. And I talked to my doctor and I said, but you know I'm kind of concerned about pulling my pants down in public, maybe not so much when I was twenty-five, but I'm in my sixties now—that's an Irish joke, you can laugh, if anyone wants to, you gotta laugh in this disease—and I'm afraid what people will say or what they'll think of me, or will they keep their distance? The doctor said, you know, in this fight, Greg, there are more people who are going to move towards you than away. Don't pay any attention or waste any time on the people who turn away because you're going to forget who they are some day anyway. He had a sense of humor, too.

Meryl Comer: I think everyone has been touched by your book because of your ability to communicate. We talked to you two years ago. Do you remember where you were in the disease two years ago? And can you contrast it with where you are now? Back then you were complaining because you were throwing the phone against the wall, the lawnmower was an episode, you were angry, you were frustrated. Can you describe the difference now?

Greg O'Brien: Yeah, there's more progression. One of the things that's probably a good place to jump off—and Meryl, you're a good director so I need direction, so if I go long, you pull me back in—there's a stereotype about this disease that a lot of people don't understand, and just like my mother was just like me, I was given a God-given ability to write and communicate and was given a good intellect, and I'm not stupid, I just have a disease, but I will tell you a good example and I wrote about it; I write often on the Huffington Post. Two weeks ago, I reached for a razor blade to brush my teeth because I thought it was a good idea, and I'm afraid about the day when I don't. More and more, it's the short-term memory; sixty percent of it gone in seconds just like: Click, click, click, click, gone. If I see anyone now, outside where I would expect to see them, I don't know them. But you know what's so cool—and maybe we could talk about it—the whole concept of dementia-friendly; in my small town on Cape Cod, they all know, and they come up and they re-introduce themselves, and God bless them.

I see things that aren't there. George had me over in Switzerland speaking, and I had a couple of out-of-body experiences in Switzerland where the hallucinations were crazy, I didn't know where I was, and a lot of people came to my aid. And then there's the tremendous rage, when the light goes off in your head, and that's increasing more. And you can't do what you used to do. I think you know, I also have cancer and clinical depression. And the family, my wife is scared. There was a time, not long ago, I don't know if I told you, Meryl, because I don't remember, but God damn it —am I supposed to say that word? I'm not supposed to say that word. I should watch my language—I lose my phone all the time, and I'm putting it, now, in the refrigerator, and I'm putting sometimes my laptop in the stove. I may have told you; recently my wife opened the dishwasher in the morning and found my business cards. My brain had told me that I had spilled coffee on my business cards and I needed to wash them. And you gotta laugh at that.

But then, later, I lost my phone and there was tremendous rage, tremendous rage. And it's funny, a big part of it is, in this disease, and anyone who is a caregiver like you and others will know, that other than a small circle of people, really don't understand this disease because it's like snowflakes, no two patterns are the same.
I was very angry at God the other day, and I'm not here to preach who God is, that's for everyone else to find, the universe, whatever you want to call it, and I yelled out, 'cause I was really upset, I said, "Do you know who I am? Do you have a clue, who I am?" And I said, you gave me cancer; you've given me depression; you've given me spinal stenosis and scoliosis, the brain signals aren't going down from my feet up to my knees now. I said, "You got a clue who I am?"

I've always told people that I want a God or the universe like a—and I don't want to offend anyone with the Patriot thing, but—like the coach Bill Belichick and I heard back in my heart, which I believe was God or the universe and a word I always use, I heard back, "Yes, dumb ass, I made you and I have you right where I want you."

So, to answer your question, there are days, Meryl, more and more now, you say, what's different? I've talked to some counselors recently. I want to go home, and I think people know what I'm saying, but I'm hearing, no, that's not your time, what you're supposed to do is open the door for others.

Meryl Comer: You have, and you're giving us a glimpse into your journey.

I would like to say to our audience, if you have a question for Greg during the call, please press *3 on your phone; you'll be placed in a question queue. Have your questions ready so we can line them up.

Greg, we have a question that's come in online from Cynthia Taylor. The need for some kind of control—what tools or strategies do you use right now to deal with day-to-day life? You mentioned humor, but do you write things down? What are the techniques?

Greg O'Brien: Okay, so, this is where maybe I have an advantage over others, as a trained journalist. I journal probably every four minutes. You'll never see me without my laptop, because of all these things I know that I'm going to forget. I have an expanded edition to *On Pluto* that's coming out in June; I'm working on 8,000 pages of notes, of things that happened the moment that I write it down, and when I do, if anyone's listening, as a strategy, I say, okay, I'm not going to get upset if I forget because I've got it written down.

I learned, with my son who helps me, to back it up on a hard drive, is that what they call it, and then I'll send myself emails in the moment. I'll email myself forty times a day. I think, Meryl, you've heard me say this before, I forget I did it, and at the end of the day, when I'm really tired, I go, Oh my God, I've got fifty emails to go through and then I realize forty are from me. But it's those kinds of strategies that I've learned. And then asking questions. I have a great anecdote about asking questions. If I keep it short, can I tell it? Because I think it's very helpful. It's a good one.

Meryl Comer: Go right ahead.

Greg O'Brien: When I was a young reporter—I was raised in the east, live on Cape Cod now—but when I was a young reporter, my first job was at the *Arizona Republic* in Phoenix, and I was a court reporter. I've written about this in my book. I was assigned to superior court, and I went there, there was this woman judge, she was really tough. She started screaming at the prosecutors and defense and hit the gavel and said "We're done" and she stormed into her office and she was scary, like the Wizard of Oz.

I sheepishly knocked on her door. I said Judge, this is my first story, I gotta write what happened. She, right away, changed her attitude and said come in. She said, keep coming back and we'll talk more. And we'll talk more, and talk more, and she kept saying, keep asking questions, Greg, until you get the answers, keep asking questions until you get the answers.

Well, 18 months later, she was promoted out to the Arizona Court of Appeals, and I'd see her out there and she'd kept saying, keep asking questions until you get the answers. Well, maybe you know where this story is going. President Ronald Reagan appointed Sandra Day O'Connor, the first woman Chief Justice to the Supreme Court, who taught me court reporting, and we stayed in touch. She lost her husband to Alzheimer's, and we're on parallel tracks. So anyone who's listening, that's another strategy. Don't be afraid to ask questions when you don't know when you forget, because I've had to let that go.

Another part of the strategy, then I'll be done with the answer, which I think is important: you're told not to withdraw in Alzheimer's, and you got to fight against that every day and Meryl, I'm in the process of withdrawing now, but I find myself withdrawing from people who I love, who I try with, who just won't get it. They're afraid of the disease, they don't understand it, and so I don't bang my head against the wall with them, I just withdraw from them. I don't know if that's right or wrong, but maybe that's helpful to someone on the phone.

Meryl Comer: It's how you use your energy and your time; it's a lesson for all of us. In your revised edition of *On Pluto*, there's a voice that wasn't heard in the first edition: Mary Catherine, your wife. Can you describe the family dynamic? Why it was important for you to use your valuable time, which is so precious, to add on to the book, to revise it, to add additional stories, and comments from her vantage point?

Greg O'Brien: I had heard, from a lot of friends and editors, that I should include what the family has to say in this. So I asked them, and to my surprise, they wanted to talk. They're the ones that have to deal with this day in and day out. There are so many people who will do a drive-by. You know what that is. Where they don't really spend any time, they just kind of drive by and go on their way in life. You don't have to be in a car to do a drive-by. But my wife, she's in tears. She's scared. She said, "It's just difficult, people don't understand."

And this is where, Meryl, you're such a hero, what someone like you goes through. We're going to forget that stuff, but that's going to live with you forever. It's very upsetting to her, and she's groping. It's a difficult time for her and the family. She writes here, "There was a time recently when Greg misplaced his phone for the fortieth time; he began yelling and screaming at Conor and me. Though I understand he's upset about losing memory, I worry sometimes about his anger, that he will hurt himself." And that's just part of what you have to deal with.

She's a hero. She writes in the end that she cringes for the future and what happens, and you know, likewise with Brendan and Colleen and Conor. But this disease has brought us closer together, and I think it brings families closer together as it did with the Vradenburgs.

Meryl Comer: It either brings families closer together or it tears them apart, I think, from experience. Conor travels with you. Here's a young man, watching his father travel this journey. What are the dynamics between father and son, and what would you advise people in how they manage the conversation with their children? Conor is what, twenty-four now?

Greg O'Brien: Twenty-seven. And Conor is an all star. He drives me; he is my caregiver during the day. If I give a speech, he is my associate; very helpful too as a researcher, he's got a touch of a writer. It was so important that my neurologist said, two things: first of all, you've got to talk to a lawyer and an estate attorney, not that a journalist has much money 'cause I don't, but you've got to turn everything over to your wife, you can't own anything, there's a five year look back if you go to the nursing home; and then you've got to tell your kids. And that was so hard, but after I told them, my son Brendan, who's thirty-one, he's a writer-producer in Boston now, he said, well, Dad, that explains a lot. And then I heard from all of them that they were really worried and they were talking privately about what was happening to me, and you know, he said, that explains a lot.

Meryl Comer: Greg, we have a lot of people lined up on the phone and emailing us. I'd like to go to Annette Guidry from Boise, Idaho. Annette, you're on the air.

Caller: Hi. What's the best thing for a caregiver to do when their loved one, who is experiencing dementia, is in the midst of rage whether it be rage just at the situation or rage at them? What would the person with dementia best appreciate? What's the best way to calm things down, or to allow the anger, and what can we do when we're dealing with rage? I need to know, what's the best thing to do?

Meryl Comer: That's a great question. Greg from your perspective, as the person living with the rage, what would you say?

Greg O'Brien: The rage is incredible. Meryl, you deal with this, so I'd like to hear what you think, but I think body language is so important. It's not so much what you say, because in rage you can't process it. It's how you say it, or how your body appears and if you're stiff or if you're relaxed, because that can calm you down more. And then knowing that people around you care, and using the collective, "We'll fix it," "We'll find it," so it's not like, "I lost my phone sixty times a day," and then "You'll find it." No, 'cause I lost it sixty times today. So, "We'll find it."

This is just my thought, Meryl, you don't get there by changing your body language in an instant. That's over time, so the person realizes that when they've lost it, that *you're* not losing it. And we don't want people around us losing it, and often in rage, I find myself halfway through it, because it's blind rage, realizing what I just did. And it's angered me even more. But if I see people calm around me, that can start to bring me back. Meryl, you've dealt with some horrific situations; what do you think, to answer the question?

Meryl Comer: Annette, I've been a caregiver for twenty-one years, I'm still a caregiver for my husband with early onset, and he was deemed too dangerous to come home and no one would take us so I've had him at home. How I handle the rage is, I always approached him, and protected anyone who was trying to help me with him, with great care. I would always, again as Greg suggested, say, "We'll look for the phone," "We'll find it together," and I always answered the questions. Part of the rage is the frustration of not remembering, and confrontation if they don't remember something, it's irrelevant. You have to go with them in the disease. So we would hunt for something, or I'd give him another set of keys, because you know what, the door's not going to open with any set that he has, because I've secured the house so he can't wander. But again, it's the spirit of how you do it.

Now, there is an issue when rage becomes dangerous. And this is important for all caregivers. I literally went out and bought one of those mirrors where you can see around the door, so that I could see if he was in rage, where he was coming. If he was in rage, I walked out of the room and came back in and said, "Hi honey, I'm home," just to change the conversation, to refocus it. These are strategies we all learn over time. As caregivers, though, you need to protect yourself. You don't want to be hit by the phone. I put away all dangerous items like knives, anything that can be used potentially as a weapon, including a golf club or a baseball bat. Anything that is a potential weapon disappears and it's never part of a conversation, that you have to take it away from a loved one. But rage is very tricky; doctors told me to call 911 if my husband got too dangerous. Tell us, how many of us are quick to call 911 on a loved one? We're protecting their dignity and we're trying to handle them, so that's a whole other conversation. The value of Greg's conversation is that he can give us perspective of the person living with the disease.

Greg O'Brien: Just a final point, Meryl, which might be helpful. I don't know, Idaho is a gorgeous place, but like Cape Cod is, it may be rural. One of my best friends is the police chief in Brewster, in the town I live in on Cape Cod. And we're brothers. And he's had talks with both of us, and he has made Mary Catherine very relaxed about calling him. All the police know me. And he said, if you have a problem, you call me. But another point, and then we can move on, is—maybe, Meryl, you want to comment on this—the reality is that there is anger in the person in rage but you have to accept or try to accept, which we can't always process, the anger in the caregiver who's getting beat up.

I'm going to read a paragraph from my wife's reflection in the new edition coming out, this is a quote from her: "I'm heading into the worst part now. We're going on forty years of marriage and memories together and they are slowly fading for Greg. I spent forty years of my sixty-plus years of life with someone who won't remember that we honeymooned in Hawaii or met in college or traveled to Ireland. I will be left alone with those memories as I grow old. That is scary sad for any caregiver. Sure, there are memories that I want to forget and we've discussed that, so I have to be grateful to some extent. But to grow old and not share the most significant part of your life is more than disconcerting. I ask more and more to Greg, 'Do you remember?' questions and he doesn't. It gets increasingly sad. The anger, now, with both of us, escalates."

And I think part of it, in dealing with the situation, is to appreciate the anger that's got to be inside caregivers. You can't put up with that stuff without feeling anger, and so, talk about it just as you heard Meryl do.

Meryl Comer: We'd like to go to Mike Belleville. Mike says he is living with the disease as well. This is an online question. This is to you, Greg. As someone who is living with the disease as well —this is going to be a hard one for you, Greg—how did you learn to relinquish control of things to your spouse?

Greg O'Brien: That's a tough one for me. You're talking to an Irish mick who has always been a loner and I'm kinda the guy who'd go out and tie myself to a tree before I'd have someone take care of me. I'm working on that. Those who have gotten there before me, I have nothing but applause for them. I don't even have a gentleman's C in that course right now, and I'm just being honest with myself. I need to work harder on that. I need to relinquish more.

Meryl Comer: We have a question from Noah: You mentioned that you have hallucinations from time to time, like seeing people that are not there. How long do they last? Do you have any strategies right now for breaking that or did they just seem to dissolve? Are you distracted? What happened?

Greg O'Brien: Well, my mother used to have hallucinations. I've also been in the unusual position too of being family caregiver, I was the family caregiver for my mother when I was starting my symptoms, and for those who are listening, what the doctors had said had accelerated it were two serious head injuries—and we don't need to spend a lot of time, people could look that up about how that will accelerate—but my mom would talk about things that she'd see, and she'd be in tears, holding my hand, and then when she would calm down, she would say, I just kind of brush them away after a while and know that they're not real.

So when these things come on, a hundred percent of the time, I have to put my hand up in front of me and brush them away, so I know they're not real. A small case in point: I was honored to give a speech to a thousand people in Hollywood. They put us up—which was wonderful—at the Beverly Hilton, and I'm getting dressed up for the event, it was a formal event, and my wife says, "Greg, put your shoes on." And I turned to her and I said, "I can't," and she said "Why?" And I said, "Because there's someone standing in them." And that's what this disease is. You don't know when or where, it just, there was someone in my shoes, in the moment.

You have to try to stay within yourself then, but maybe the end of my answer here, this disease is such, I want to encourage here and not discourage, but I want to be honest, brutally honest with people. This disease sucks the living life out of you, to the point where there are times when you want to give up. However, however, however, it is through the work of organizations like UsAgainstAlzheimer's, it is through the work of people who support those efforts that keep me and millions of others in this game, so please do not ever underestimate the impact that you can have.

Meryl Comer: Never underestimate the power of those living with the disease, to share their voice, side by side with their families, because this impacts all of us.

Here's another question, Greg, from Eleanor Cory from New York. She has Alzheimer's and she says, why does my Alzheimer's affect some of my memory issues and not others? I can write music but I can't negotiate directions to destinations. Now, you're not a doctor so it's hard to answer that question but can you take it from your point of view?

Greg O'Brien: But I did sleep once in Holiday Inn and I cut up a frog in high school.

Meryl Comer: That doesn't count, Greg. But tell us what you can do, what's still very strong for you and what are weaknesses that you have to let go? Or are you aware of them?

Greg O'Brien: Okay. Now, because I was such a wise guy a moment ago, took my focus off, and I'm kind of embarrassed, but, give me the lead into that question again? I had the answer, and then I had to be a stupid wise ass about cutting up a frog and then I got my attention off, and I forgot the question.

Meryl Comer: That happens to all of us, Greg, not just you.

Greg O'Brien: This is the Irish in me; I need to stop being such a smartass.

Meryl Comer: The point is, the woman, Eleanor, has Alzheimer's and she said, it affects some of my memory issues and not others. She can write music but can't negotiate directions to destinations. So, what can you do, and what have you really had to give up? What can't you do now?

Greg O'Brien: Ok. That's may be one of the best questions of the day. I could just answer in layman's terms, but in talking to people like Dr. Rudy Tanzi (Mass General, Harvard, Cure Alzheimer's Fund, people could look him up, one of the top experts in the world), they don't know why but in this disease, and this is a simplification, the right side of the brain, the creative sweet spot, seems to be affected much later than the left side of the brain, that requires executive functions. So, someone like me, who was always able to write, was always creative, and that's the essence of who I am, as my neurologist has said, that's the last thing that's going to go. So I appreciate what this person is saying. I get lost. I can't figure out directions, I can't. So I would say, maybe in answer to the other question, that part of me, I've let go, the control thing. I used to tell people, I thought of my brain, early on, as a big garbage pail, think of those big green plastic garbage pails and I would throw all sorts of stuff into my brain, stuff that people care about, don't care about, sports trivia, stupid stuff, important stuff, and in Alzheimer's, the brain's ability to process diminishes —and maybe Meryl, you might want to comment—you go into a lot of these Alzheimer's programs and you go into some of the homes, and they are encouraging people to write and paint, and turn on the right side of the brain. And if I knew why that worked that way, I could tell you how many angels dance on the head of a pin, but I can tell you what works, so I've tried to let as much of the other side go, the executive function side. I have lost—I don't want to gross anyone out but—I have lost continence now so you'll never see me with white pants and you can get the picture. But you focus on what you can do.

Meryl Comer: I think that is, Greg, one of the most important points; you have to go with the disease and have to be willing to let go of certain things and play to whatever strengths you have. If Eleanor can still write music, the advantage of music is that it infuses the brain, it's not just in one part of the brain and that's why, not unlike your creative skill, it's one of the last skills to go.

Greg O'Brien: Write music every day, Eleanor. Don't give up on that.

Meryl Comer: Yeah, don't give up on that. Now, that really prompts another question that's come in from Del Muzzillo. He's out in California. Having dementia, tell us how you live your lifestyle in nutrition. What are you trying to preserve and do you eat a special way? Are you eating brain food? What are you doing?

Greg O'Brien: Okay. Well, remember how I told you I flunked the other test about learning to give up more control? I can talk to you about what this gentleman should eat, and Rudy Tanzi will tell you things like the Mediterranean diet, a lot of fruits and nuts, so look up the Mediterranean diet

Meryl Comer: Are you doing it, though? I want to know if you're doing these things.

Greg O'Brien: I'm doing it more and more. But I'll get to what I'm doing though. That's right, you're the host and I'm answering the questions. I need to work harder on that. What I am doing, which is helpful, and Rudy Tanzi will say, it's just as helpful as a diet and probably more helpful. So if you only can do one of these things, you might want to consider this: exercise. It reboots the brain. And every day, when I'm done with this, 'cause this will sap me, my son will take me to the gym and I'll work out for an hour, and then I'll go write for an hour. And it restarts the brain in physical ways and in creative ways. In the old days, I'd sprint. I was a pretty good runner; I could do a six-minute mile. Now with spinal stenosis and scoliosis, I have trouble walking sometimes but I won't lie down. I push the treadmill up to 15, the elevation, and crank it up to 6.2 and do my miles that way. And that's a big help. But I do need to eat better and look at the Mediterranean diet; I'm doing more of that, salads and things like that, I don't eat a lot of meat, by the way, but maybe that's good for you, I don't know.

Meryl Comer: So we have lots of questions coming in. So we're going to do it like television time. You get thirty seconds on an answer. Can you do that?

Greg O'Brien: Just go *Beep, beep, beep*.

Meryl Comer: Here's a question online from Noah, is losing a sense of time part of the disease? Not understanding whether it's night or day?

Greg O'Brien: Well, losing a sense of time, yes. Not knowing—this is my experience—not knowing the day, often not knowing the month. People, pretty much, at the stage I'm in, know the difference from day and night. However, what is happening, and you asked me this question early on, nighttime is called sundown, so people can look that up. It's becoming more and more problematic for me when the light changes. There's greater confusion. My wife has known this, knows about it, and has talked to doctors about it, about additional medications, and that's a time of incredible confusion. So it's more the sun setting and going to darkness that creates greater problems.

Meryl Comer: Can I just make a point about that?

Greg O'Brien: You're the host, you can say whatever you want!

Meryl Comer: As our listeners can tell, we're old friends. When you talked about exercise and how important it is to reboot the brain, I used to walk my husband six miles a day to slow that sundowning. It was a form of exercise but I did it in the early afternoon to again, try to get ahead of the sundowning that I knew would be coming, to sort of moderate it, so that was a strategy to use, that seemed to help. So it goes back to your point that, right now, exercise is about all we have to really use and try to stay as healthy as possible. I mean, one of the strategies, whether, and I consider myself at high risk because my mother has the disease, you are trying to stay well and healthy and use whatever alternative strategies there are until the science catches up. Not unlike what they had to do with HIV/AIDS.

Greg O'Brien: Can I just say one thing?

Meryl Comer: Sure.

Greg O'Brien: I'm more concerned about my family. I don't think the science is catching up with me, and I have to tell you, I have a lot of friends in this disease, who are at stages like I am, we'll have conversations, like me, who will tell you the same. I think I'm just being candid because I think that's what people want from me. I'm concerned about the next generation. I want to encourage others in strategies in how to ride this one out, but that's just my thought.

Meryl Comer: Can I ask you a personal question?

Greg O'Brien: Mm-hmm.

Meryl Comer: What are the most insulting comments or questions you've gotten? You speak all over the country. Are there any that just really stay with you because they're so insulting?

Greg O'Brien: Well, there was one . . . when I gave a speech out in Phoenix at the Cronkite Center at Arizona State University and my family was there, my kids were there, my wife was there, and the first guy who stood up, the first question was just this blunt: Have you ever thought of suicide? I gotta tell you, you could hear people breathing in the room. And, as a journalist, I was kind of trained that when you get those crazy questions, you kind of stand back and say something stupid like, well, that's a good question, while you're trying to figure out how to answer it. As it turned out, I had tried to commit suicide. It's a longer story and it's in the book if someone's interested. Let's just say I had a bleed out, I had lost eight pints of blood and I wouldn't tell anyone until I got to that moment where either I was going to go, or I had to tell someone, so I told that story about fighting and realizing I didn't have the right to take my life.

The other things that I'm hearing from other people in this disease which I think is so important, and in the book I'm dealing with people all over the country in this disease, and they say they are so, so upset about people coming by and saying, "You look good." You look good. Or, "you completed a sentence, you look good." And as I wrote in the book, it's almost like a mute saying, "Do I look like I'm deaf?" Go up to a deaf person. Do they look deaf? If you saw me, do I look like I have cancer? Course not.

Meryl Comer: No, you look like central casting.

Greg O'Brien: Why can't I look like I don't have Alzheimer's? That's insulting. That's totally insulting. I'm sorry, you got me going.

Meryl Comer: Keep going. You just got a piece of fan mail that came in. Just want to express their deep gratitude to Mr. O'Brien. "I've learned so much reading his book, he's brave and brilliant," and that comes from Jeff Wallace from New York.

Greg O'Brien: Well, thank you. I think any attributes I have are a gift, and Meryl, you and I have had that discussion before, it's a gift from God and the universe, I deserve no credit. Think of me as the container, maybe a cereal box? I want to get your audience laughing, because I want to tell them, if you can't laugh at a disease and if you can't laugh at Alzheimer's, then these demons are going to own you. You have to take it seriously, you've got to fight, but you've got to laugh.

Meryl Comer: More and more, Greg, there is an interest from regulators like the FDA on issues of what matters most to those living with the disease. Can you describe what matters most to you at this point in time, in your journey?

Greg O'Brien: That's a great question. I told you that I was with George in Switzerland, I was asked that question by some of the pharmaceuticals, and I said, look, try, for people like me, to come up with medications or strategies that help us run this out. But when you're talking about progressions, because there's only so much time, there's only so much money and we're worried about our kids, our grandkids, the next generation, put your resources into finding ways to turn the switch off in someone's head who may have all the symptoms. Rudy Tanzi will tell you that; there's a word for it and I can't think of it now, but before the onset of symptoms, the disease will start in your brain when you're in your forties and there's a word for it, Meryl, you're a lot smarter than me but I can't think of it right now. So find a way to turn that button off. Maybe the progression starts far later. And there's a guy in my book that I'm quoting, he said, look, do you think I want these symptoms for another twenty years? I don't think so. And I looked at this woman and I said, look, let me tell you something, people in this disease will probably tell you the same thing. Do I want a life prison term? Or do I want a ten or fifteen year term? Don't expand the progression for me; find a way to help me get through it, and then go cure this disease before the button turns on.

Meryl Comer: Greg, here's a question from Robin Smollar of Delray Beach, Florida. This is one that we all wrestle with. Am I wrong to not be tested when Alzheimer's is prevalent in my family and there's no cure?

Greg O'Brien: That's another excellent question. I've switched over on that. I was tested, because the doctors made me, given my family history. I have, and you can look this up, the gene APOE-4 copies on both sides of the family so that makes me a marked man at that point. Because they, early on, didn't have as much information as they do now, what they're trying to do is isolate people which is the A-List work and the clinical work that, Meryl, we're all doing, working with you to identify this earlier. I think it's so important because I think it's important to be identified; there are so many tools out there that can help you, so many strategies. As the great Bugs Bunny said, don't take life too seriously because nobody gets out alive, so understand that premise. And then say, okay, I gotta deal with this.

And maybe this is a good jumping off part for you to talk about the A List and the need for clinical trials and things along those lines, and get involved. I think if you talk about it, and pull this out of the closet, you're going to realize that you're not alone. If you're having these symptoms and you're scared, that fear is only going to get worse. When you realize that you are surrounded by people who care, and there are strategies and medications, and that we've taken the taboo off, which is part of my journey, and I promised this on my mother's death bed, I said we're going to start to talk about this, and I don't care what it takes, we're going to talk about it from inside the mind of Alzheimer's. We've got great doctors and researchers on the outside but we're going to talk about it from inside. And I think that's necessary.

Meryl Comer: You know, when there is the disease-modifying therapy and there are a number of therapies in the pipeline, to be tested now means you're right at the top. I'm really concerned, Greg, that we don't have the infrastructure in this country because people will now come out of the woodwork and want to be assessed and right now assessments are running a long time and if you look at genetic testing and what it's meant in other diseases, like cancer, knowing your genetics just gives you more specificity about you. So I think it's, put your life in order. I'm a big proponent, I did it myself and I've got a 3/4. My son called me and said, "Mom, what the hell did you just do?" But I felt it was important to know, because you behave differently, you pay attention, you decide what's important in your life and it's empowering and you can get things in order for your family. You mentioned how much you care about your family and their quality of life. That's where you'll have the incentive to start making your advance directives, so that your spouse or your family don't have to make the decisions for you.

Greg O'Brien: I know people listening will go, "Whoa, what is this guy saying," the disease steals, but diagnosis gives you time, along with what you just said, Meryl, you have time to get things in order, you have time to think about what's important, you have time to learn what love really is, you have time to realize that there really aren't different colors out there, we have the same souls, you know? We're all born united then we are divided even though we say things sometimes that can be hurtful and things like that. And you become more forgiving, less judgmental. Maybe that's the upside of this disease, and the upside of an early diagnosis, getting back to what you had asked before.

Meryl Comer: Greg, you have launched a new podcast series with us, thanks to the work with Virginia Biggar who has done a great job, around your book, *On Pluto*. And we have the first episode, it's the first in a series of podcasts and at the end of the podcast, we'd like our listeners to share their experiences, because the more we hear from everyone, we begin to paint a picture, a collective voice that will resonate in advocacy. Right now, quite frankly, everything we do is treated as anecdotal, your story, Greg, my story, somebody else's story, but look at the power when we begin to combine our stories so that we really paint the picture of what this disease is about. You have done so much in that space and I just want to flag it.

Greg, your new book coming out: a waste of time, great time, important time for you?

Greg O'Brien: Well, yeah, it's an expanded edition. The first book that came out was because I'm on a timeline, so it was, okay, early symptoms, the diagnosis, and the aftermath. The expanded version goes into Part Two or Part Three which is, okay, what next? What are the ongoing symptoms? How do you deal with it? How do others deal with it? What is the science? I have tremendous friends in this disease around the country who have opened their minds and their hearts to me and I tell their stories, and then at the end, my family, from a family perspective speaks to that. So I think it opens new doors in this conversation. It's been very difficult for me to write because it's painful and the writing process takes so much more out of me, but it's a labor of love and the book will be distributed by Viking Penguin Random House. You can get it through Amazon but it's probably not going to be available until mid or late June and *On Pluto* is available now. Now I sound like Fox News or something where they all sell their books. I don't mean to be political here.

Meryl Comer: Well, we've already sold some!

We don't have much time; we're up against the clock with two minutes left. I'd like to circle back because you knew Trish Vradenburg, you loved her the way we loved her and you sent a note to George and there was a part, if you can pull it up, that I'd love, rather than read it to our audience, have you read it, where you begin, "We can't even imagine your grief and loss." Would you mind reading that part of your tribute?

Greg O'Brien: "George, we can't even imagine your grief and loss. All we can do is to take our pain and multiply it exponentially to even begin to understand. We've lost a hero in Trish. A fighter, a crusader, a saint, a poet of a writer, one extraordinarily brilliant woman. They don't make such champions any more, the patent has now expired. To honor Trish's incredible life, we must all keep up the good work of UsAgainstAlzheimer's. We must redouble our efforts. Can I hear an Amen to that?"

Meryl Comer: Amen. For those who would like to leave a message, to George, on the passing of his wife, Trish, we will certainly pass that along to the family. Greg, you're a hero to all of us, for your honesty

Greg O'Brien: I'm just a stupid Irishman.

Meryl Comer: Well, we need more like you then. We need more like you. I think the spirit in which we all fight, we're families that have lived the disease, are living it, I'm still living it, twenty-one years later, now with my mother, and we have to change it for the next generation and for those of us and we can do it but it really, your writing, Trish's blogging, the spirit in which we attack things, I think we have to believe that it makes the difference, and we're beginning to have it resonate and people coming out of the shadows around this disease is probably a hallmark, a first step, in that direction. So thank you so much for joining us today, thank you to our audience, I'm sure you have another bestseller in your revised edition, Greg, and be well. Stay well and we'll continue the journey with you. All our love. Take good care.

Greg O'Brien: God bless you. Thank you for listening. I hope this was helpful.

Meryl Comer: Thank you to our audience for joining us today. Have a good afternoon.

Greg O'Brien: Thank you.