

**Alzheimer's Talks Transcript
The Theft of Memory
with Jonathan Kozol**

July 30, 2015

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

George Vradenburg: Welcome to [Alzheimer's Talks](#), a monthly teleconference series presented by [USAgainstAlzheimer's](#) where we connect you with the leaders in research and policy and, today, caregivers who are working to stop Alzheimer's.

My name is [George Vradenburg](#) and I'm Chairman and Co-Founder of [USAgainstAlzheimer's](#), which is a bold and passionate organization, committed to stopping this disease.

Thank you for joining us today to talk with award-winning author Jonathan Kozol about his latest book, [The Theft of Memory: Losing My Father, One Day at a Time](#), which I highly recommend, having read it in the last couple of weeks.

Just a couple of notes on current events in the Alzheimer's world, a couple of very, very interesting developments.

Last week, the Patient-Centered Outcomes Research Institute, which is a branch of the U.S. government, funded as a result of the Affordable Care Act, [approved USAgainstAlzheimer's proposal for a Patient/Caregiver Driven Research Network](#). Now this will be the first patient and caregiver denominated network that's involving itself in the identification of the research, the citizen participation and research in Alzheimer's. So it's quite an exciting development for us and, we hope, for all persons and families who are affected by this disease.

On Monday, I attended the [National Alzheimer's Project Act Advisory Council](#) meeting, where I have served as a founding member for four years. Interestingly, and excitingly, as a result of commands in the current budget act, the NIH was required to exercise and express its professional judgment on how much would be needed in the Fiscal '17 budget, to stay on track to prevent and treat Alzheimer's by 2025.

[NIH has recommended that in Fiscal 2017 there be an additional \\$323 million above 2016 levels that are invested in Alzheimer's research at NIH](#). As you may or may not know, two key committees, one in the House and one in the Senate, have recommended \$300 to \$350

million in additional research investments in Fiscal '16, so together, if those are acted upon successfully by Congress—and we'll ask everyone on this phone to join USAgainstAlzheimer's and help us to do that—plus the Fiscal '17 recommendations of NIH, annual investment would rise in Fiscal '17 to \$1.3 billion, about double what it is today. That's not as much as scientists say we need to stop this cancer-sized disease, and is far short of the \$6 billion that we annually invest in cancer, but certainly those major steps forward do represent a positive step towards that \$2 billion a year goal that Alzheimer's researchers are calling for.

To get the latest updates on anything in the Alzheimer's field, please go to www.USAgainstAlzheimers.org and sign up, if you have not done that already. We will provide you updates, such as these, and ways that you can engage with us to urge Congress, and other key stakeholders in the efforts to stop this disease, move more quickly.

I hope that you will join us because we need everyone involved. We know that we can stop this disease, but we can't get there without your help. That's the reason we named our organization USAgainstAlzheimer's.

We have over 250 registrants today from forty-one states and the District of Columbia and a couple of countries outside the United States including Canada and Kuwait. Additionally, over 500 people said they couldn't make the live conversation today, but they have asked us for a recap. Our recaps include highlights from the call and a link to the transcript and recording. So we'll send that recap to anyone who is on the call today and it's also available on the USAgainstAlzheimer's website.

Remember, if you have a question during the call, please press *3 on your phone. By pressing *3 you will be placed into the question queue. Please have your question ready to share briefly with a member of our staff, and then we will try to get you on the air live with Jonathan as soon as possible when we open it up for questions. If you are listening to us online you can type your question in the box, and we will get to as many questions as possible after the opening presentation.

With me today is [Meryl Comer](#), a board member of USAgainstAlzheimer's, a co-founder of [WomenAgainstAlzheimer's](#) and herself a twenty-year caregiver for her physician-husband with early onset and her mother with age-related dementia. She herself is an award-winning and bestselling author of a book called [Slow Dancing with a Stranger: Lost and Found in the Age of Alzheimer's](#). One hundred percent of the proceeds from that New York Times bestseller are contributed to Alzheimer's disease research and we thank Meryl for her generosity in doing that. Meryl will be leading the discussion today with Jonathan.

Meryl Comer: Thank you, George. Today, we are excited to welcome [Jonathan Kozol](#) to this special edition of Alzheimer's Talks. He is the award-winning author of [Savage Inequalities](#), [Death at an Early Age](#), and many other books from his fifty years of working with the underserved children and families in our country.

His newest book, [The Theft of Memory: Losing My Father, One Day at a Time](#), chronicles his experience with his father's Alzheimer's disease.

Jonathan, welcome, we're delighted to have you.

Jonathan Kozol: Thanks, it's good to be with you.

Meryl Comer: Many listening in have their own Alzheimer's stories bottled up inside. As an acclaimed author, what was the internal conversation you had with yourself about the pros and cons of writing such an intimate story?

Jonathan Kozol: Well, I really didn't have to make up my mind to write it, it wrote itself. At the time my father was dying—he lived until just seven years ago—at the time he was dying, I just found myself writing about those last years of his life without even thinking about it, almost like keeping a journal. Then after his death, I just kept right on for about a year. At that point, I set it aside, because I wanted some perspective, and I didn't come back to it until two years ago. My father was a doctor, a neurologist—and by that time, I'd had a chance to read files and files that he'd left, on his own career, in which he had been a specialist in brain degeneration, affiliated with Harvard Medical School, so at that point I felt it was okay to finish the book.

Meryl Comer: You write that your father hid the diagnosis from you, the doctors, and even your mother Ruth for more than a year and a half. Contrast awareness of Alzheimer's disease today with the stigma and denial of more than twenty years ago when your father was diagnosed.

Jonathan Kozol: Well, I don't think things were too different in this respect from today. One evening in 1992, my father—he was 86 then—sat me down in his apartment in Boston and described to me attacks that he'd been having. He called them amnesic spells and he also spoke of periods of interrupted consciousness. And drawing on his own sixty years of experience as a neurologist, he diagnosed in himself the early indications of Alzheimer's. Two years later, the diagnosis was confirmed by one of his former students, who has since become one of the leading neurologists in Boston, and two years after that I had to put him in a nursing home.

Meryl Comer: Jonathan, denial by both patients and families is so prevalent. You write that your father's fascination with his own predicament, his sort of inner life, was how you connected with him through the disease progression. How much of your efforts to connect were trial and error and what did you do to try to stimulate that engagement?

Jonathan Kozol: Well, that's a good question. First of all, I might say even after he was in the nursing home and well into the early stages of dementia, he continued to describe his illness as if he were a doctor observing himself, almost as if he were simultaneously the doctor and the patient. It was fascinating the way he did that. But the key thing, from my point of view, in talking with him was first of all, continuity. I had to make certain I could

follow up one conversation with the next one, the next day, next night, or within a short period of time, so that we could build from one conversation to the next.

Second thing is, I'd known him for so long, that even when he said something that didn't seem to make sense at first, I could pick up one word or one phrase that I knew had some significance in his life, and if I repeated that or asked him a pointed question, it would suddenly elicit a whole broader expanse of memory on that subject.

But I think the most important thing, was that I always had what I called real conversations with him, that is to say, and this was true also of the helpers I hired to be his companions when I wasn't there, it was important to me to say real things to him. He'd always had a charming gift of repartee, and that didn't abandon him completely for a long time, so if he said something rather strong with which I disagreed, I would say "I don't agree with you on that" and tell him why. In other words, all my conversations with him carefully avoided that kind of sing-song nursery tone that people too frequently adopt when they talk to people in a nursing home or talk to people who are in early dementia, or late dementia for that matter.

Meryl Comer: You bring up your annoyance with how elderly people are treated, as if they're not physically present or they're unconscious, and if you don't mind, I'll quote from your book. In your book, you're writing about someone who is visiting and they said:

"You're lucky to have had your dad with you for so long. It's going to be hard for you to lose him. After the funeral . . ." I cringed to hear her say this. She was sitting only a few feet from my father. Up until that moment, he'd been looking at his lap and did not appear to be attentive to the conversation. But, at those words, he suddenly looked up and said, not to the woman who had said this, but to the room in general, "Is someone speaking of a funeral?"

And you also spoke about other times when people spoke as if he wasn't there. In your experience, is that endemic to the treatment of Alzheimer's patients?

Jonathan Kozol: I don't know for sure, but I have the impression that it's quite common. Either talking across the patient, as if he weren't there, I'll say 'he' because it was my father, either talking across him as if he's not there, or else saying things that would be terribly upsetting to the patient, as if he can't hear. And in this case, this was a woman who I didn't know, that had come to a birthday party we were having for my father in the nursing home, his 95th birthday. She apparently had known him long ago and this was like a dutiful visit on her part. But, boy, I wish she hadn't come, because she was sitting right near him, and she talked right across the room to me and said "After the funeral, Jonathan . . ." and my father immediately said, "Is someone speaking of a funeral?" I got up right away and went over to my father, I put my hand on his shoulder, and I said "Daddy, people say a lot of stupid things."

In contrast, the helpers that I hired, the companions I found for him, who helped me, these were terrific people who never spoke to him in that artificial way, they talked to him

directly and amusingly. When, sometimes he'd say something funny, maybe not intending to, they'd come right back to him with something funny. They kept that smile in his eyes, they kept him alert, and I think that's crucial to do.

One of the people who particularly was fond of my father was with him at a time when I brought my dog to visit him—I had a golden retriever—and she loved the dog and she's petting the dog and she looks up my father and says, "This one is an angel," meaning the dog, this one is an angel. My father didn't miss a beat. He immediately said, "I'm not sure I'd go that far," and she looked at him and said, "What is she, doctor, if she's not an angel?" and my father said, "Practicing to be an angel."

So I think it's terribly important to keep the wires humming.

Meryl Comer: Your mother was two years older than your father, in relatively good health. Can you explain the dynamic and the challenges when your father, because of a fall, had to be institutionalized, and what it did to your mother?

Jonathan Kozol: Good question. My mother had grown a little scared of my father, before he went into the nursing home, because he was growing terribly restless and gesturing in ways that scared her a bit, as if he might become violent. But after he'd been in the nursing home six years, he kept asking me, "Is it time yet to go home? Are we going to go home now?" He'd do that repeatedly and people in the nursing home said to me, "Well, he's in dementia, you can ignore that, he doesn't know what he's saying," but I thought, "I'm going to take him at his word, I think he does know what he wants." So, I brought him home to the apartment, with my mother living there.

Before I brought him home, I asked my mother if she could handle it, and, he wasn't so restless now, he was more tranquil, and she looked at me right away and she said, "I want him to come home, I want him to live out his life here." And I brought him home; it was quite extraordinary. They had lunch together, even when he needed help eating, they still had lunch together. He would sit at a desk in his living room, which had been his office desk for sixty years, and he had a real look of pride and dignity sitting there. It was quite a moving experience to me, and my mother was happy he was home. She couldn't get the conversation from him that she enjoyed but after Daddy went to be bed her helpers would talk to her at length. She was a little older than my father; she died before he did, a couple of years before him, in 2006, at the age of 102. And my father died also at the age of 102, and I was glad he lived that long. I hear a lot of this end of life discussion and it bothers me somewhat, to be honest.

Meryl Comer: Your father's medical notes and his notebooks on some of his very famous, patients were like a treasure trove for you to piece together his personal history that had been off limits to you. You also recount that your mother even at age 100, was telling stories about her childhood, her travels to Europe, your father's affairs, her own affairs. Have you come to the conclusion that most of our memories are revisionist histories, somewhat?

Jonathan Kozol: It wasn't so much my conclusion as the conclusion of scholars here at the Psych Department at Harvard, and some neuroscientists share this belief, that our memories are not stored away somewhere as if they were in a safe deposit box and when we remember something we simply make a withdrawal. Most of the cutting edge scholars on this subject feel today that there is no storage box; each time we remember something, we're recreating it out of bits and images and tiny pieces of memory, somewhere in our minds, but essentially it's an active reconstruction. That worried me a bit. I got scared when I read that, I thought, "Uh oh, here's a book based on my father's memories, his career, and then, of my memories of his memories," I got worried. Have I got it wrong?

But fortunately he had left behind so many records, so much correspondence with other people, that I was able to check it all out, and it was almost all correct. He had fascinating medical cases for many years. He treated our nation's greatest playwright, Nobel laureate Eugene O'Neill. Later he became an expert court witness in the trial of Patricia Hearst, and still later he helped to discover the man who was the Boston Strangler, found in a clinic, and he interviewed him at long length and I have the tapes and the transcripts of all those interviews. He'd had a fascinating career, and I was glad at the end he was sitting there at his old office desk still making memos to himself, even when they made no sense at all.

Meryl Comer: Jonathan, for those of us who have seen this disease up close and lived with it intimately, we all feel somewhat changed forever. Are you worried about your own mind?

Jonathan Kozol: Yes, of course, but since there's no certainty about the degree, the likelihood of inheriting, or whether you inherit some of the genes or not, there's no knowledge, no certainty about whether someone in that position will actually get Alzheimer's, and because my mother was so clear-headed right to the end, I don't dwell on that. I don't dwell on that. I live in the present day. I'm planning three new books right now.

But I did want to say, one thing that troubled me was I had a very hard time getting my father the medical attention he needed. His doctor, the doctor to whom I was advised to bring him, was almost never available, she very seldom answered phone calls; the companions who stayed with my father would call her when they were worried about something and they said she almost never called them back, they'd get a call back from someone else, an assistant, or an assistant to an assistant, and they never knew whether their question had actually gotten to the doctor or not. It was a terribly frustrating situation, and I think, in part, it's because there are so few people in the field of geriatrics, so few geriatricians being turned out by medical schools that the case loads are tremendous. I don't know if other people have experienced that. It certainly, it was very painful for me. And in a sense the companions I hired became his real doctors.

Meryl Comer: Unfortunately I think that is the shared experience by most of us who've had to fight for doctors' attention, care, or a diagnosis. I was very touched by the homage that you pay to your father's caregivers. You talk about Sylvia as a ferocious champion and defender of your father's life and wrote, "As long as any of the satisfactions she detected in him remained, so it was small sparks of humor, spirited resistance to demands she made,

or simply a smile, which was all she asked for in exchange.” This is not custodial care; it’s special care. Can you describe the type of care that they gave your father?

Jonathan Kozol: First of all, it was very affectionate. It wasn’t that plastic kind of friendliness that people must learn about in training, “This is the way to talk to an Alzheimer’s patient, smile and say ‘How are we feeling today?’” No, it was none of that, it was real conversation, and they loved battling with him over things he said, and amazingly, they brought visitors there to spark his response. Once, Sylvia brought her husband up to visit, and this was when my father had had Alzheimer’s by now for almost ten years, and her husband sat down next to Dad, and my father looked at him right away and said “Sir, I think you are a gentleman.” And I don’t know what happened next, Sylvia told me this; I think my father put his arm around Sylvia’s waist, because he really liked her, he was affectionate, and he was hugging her slightly, and her husband joked and said, “Hey, watch out, that’s my wife.” My father answered, “I guess he’s not a gentleman, after all.” That was Sylvia’s genius, to bring life into that, into his life.

Meryl Comer: There are very small victories and they have to be honored and celebrated. I’ve always been distressed that Alzheimer’s leaves such a gaping hole in the intergenerational narrative, that the stories and family lore don’t get passed down and the connection lost between grandparent and grandchild. Can you speak about that lost connection because you were able to find a way in, to create the connective tissue.

Jonathan Kozol: That’s the thing, of course; by writing this book I hope to perpetuate a great deal of my father’s legacy to the next generations and the young physicians who are reading it now. I’m getting a lot of emails from doctors, some of them knew him in his prime when they were medical students.

But the main thing that I kept seeing, we were able to communicate somehow for a long, long time after he was diagnosed. It went on right to the time he was in the nursing home, right up to the time when he asked me for the final time, “Are we going home? Are we going home now?” and I remember I said “Yes, Daddy, this time we really are.” I brought him home and I remember . . . How can I put it? There are a lot of people, I see this in the newspapers sometimes; a journalist in Boston said this recently, they say essentially that once a person has Alzheimer’s, they become, quote, a stranger; the other, and lose all the elements of their personality that we knew and loved before, and as the journalist here in Boston wrote, pray for them to die as soon as possible. I never prayed for my father to die. I saw the resilience of his personality and his sweetness and his humor, and I’m glad he lived a good old life, and he had a great appetite right up to the end.

Meryl Comer: I’m glad you shared that perspective. The purposefulness of giving dignity to a patient’s life sustains those very compassionate caregivers, and it’s really somewhat descriptive of how you were able to connect with your father.

Knowing what you know through your work with under-served children and families, I was eager to hear your reaction to [statistics that in New York State alone, twenty-three percent of caregivers are under the age of eighteen](#). So we have children in the position of

being caregivers, delinquent in school, and suffering the stigma of the disease in their family. Can you put that in perspective since you've spent your life in education?

Jonathan Kozol: Well, first of all, although I know some remarkable eighteen-year-olds, who could possibly fill that role, overall, I have a strong belief that you need mature and wise people who have lived through difficult challenges themselves in life so they are at least middle aged people in order to have any comprehension of what the patient is going through.

But I would say, there's one connection I would make between my father's situation and the fifty years that I've spent working with very low-income black and Hispanic children in New York and in Boston, and it's this: When advocates for children like myself, when we go up to Congress and we say, "You know, you could prevent a lot of problems later on if you would give three full years of wonderful pre-school to all the poorest children in America," and members of Congress or the Senate will typically say to me, "That sounds very nice, but how much money will that actually save us later on?" They want to know if there's a cost/benefit to doing this, and I always hate that question. I've said to them sometimes, "Forget about the economics, why not give these children a chance to be happy before they die."

And the same economic factor is in play with the elderly, no matter what the integrity and decency of a doctor dealing with Alzheimer's patients. When they started talking to me about end of life possibilities, and how maybe he shouldn't live any longer, I always had this terrible feeling that they were trying to reconcile their sense of ethics with economic necessity. And that troubled me profoundly, as if—they weren't saying this—but as if our society was saying, a 100-year-old neurologist isn't contributing to the national wealth, he's just using up our taxes, so why let him live. That's the feeling that I got.

Meryl Comer: We want to open the lines to questions and George is going to join. Perhaps about the father-son relationship, George?

George Vradenburg: Well, what's so striking to me is how exceptional your father was, and how exceptional you are, in your ability to continue that dialog and that relationship for, I guess, twenty years from the time that he self-identified as having Alzheimer's.

Jonathan Kozol: Let's see, from 1992 to 2008.

George Vradenburg: Didn't you say that he had identified even earlier?

Jonathan Kozol: That's right, something like eighteen years, that's right.

George Vradenburg: It's quite extraordinary. We have a question here online from Jan who asks, what was the most surprising thing you learned in writing the book?

Jonathan Kozol: I think probably the most surprising thing I learned was when I looked back at notes that he'd been sending me while he was in the nursing home, which I'd filed

away and didn't discover until recently. I realized suddenly that at least through his tenth or twelfth year of Alzheimer's, he kept on writing notes to me, and some of them were partly incomprehensible but some had real, surprising, amazing cogency, and clarity to them. For example, he wrote one note to me that said, "Dear Jonathan, my son, someone we know has been extremely ill." (Ha! He's still speaking as if he were the doctor watching himself.) "Someone we know has recently been ill. Fate matters. Remember age and circumstance. Your one father, Daddy." Those things kept coming up. I think that's what surprised me most.

George Vradenburg: We have a question online from Ana Robles Rhoads who says I am on chapter nine in your book, LOVE IT!!!, in capital letters with exclamation points. What advice would you give caregivers in terms of dealing with their doctors?

Jonathan Kozol: Good question. I'd give them the same advice that I was given when I had that long frustrating period going on for years with his physician. People who are close to me . . . I grew up in Boston and because of my father, I'd always been part of the medical world in Boston so I had a lot of acquaintances in fairly high positions in this medical community. One of them said to me, "Jonathan, be respectful, because people who go into geriatrics, at least in the beginning, tend to do it out of a sense of ethics, a sense of morality, but when you get to the point where they can't give you any kind of continuous decent medical care, you've got to be as tough with them as possible. He said, you have no alternative. Keep advocating for your father and don't let the doctor intimidate you by silence. So I kept on doing that.

In the end however, at the very end, I wasn't successful. At the very end, one of his helpers, one day—now this is when he was at home—noticed that he had a recurrence of a urinary infection, which is common among elderly people. She called the doctor's office, and the doctor finally called back but she said she saw no reason to examine him, just go to the drug store and pick up a prescription she'd called in. So they went across the street to the drug store, picked up the prescription, gave it to him, and suddenly they looked at the label and they realized it was a medicine to which he was allergic, and to which the doctor had told them he would have a bad reaction, several years before. So the doctor inadvertently prescribed, I guess, she just didn't check her records. And he immediately vomited copiously and went into cardiac arrest, and died. So that's how he died, partly, I would say almost directly, because of medical negligence.

George Vradenburg: You spoke so lovingly of Sylvia in the book, and on this phone call. Is this loving, affectionate, playful, intellectual relationship that she and your father developed, can you teach that? Can you educate people to be able to do that? Or is that something just in Sylvia's nature and how in the hell did you find her?

Jonathan Kozol: I found her, actually, through an agency, a small unusual agency that somehow had a gift for locating unusually personable, likable, interesting people. One of the other helpers they found for my father was an artist who wore a jaunty blue beret and had a wild sense of humor which my father loved. Another was a doctor, a Cuban doctor, who hadn't yet gotten certified in the United States, and he would spend hours with my

father. When my father was flipping through neurology magazines, which kept coming in, my father would pick on a word and he would talk with my father about it because he knew medical vocabulary.

I'm not sure you can teach that. I just don't think anyone should be allowed to fill that role, unless it's a really likable person, unless it's somebody that you or I would like to sit with on an cross-country flight, instead of the person we would avoid. I say the same thing with young children. Yes, we need teachers to be trained in education colleges, but still, I wouldn't allow anybody to go into the first grade unless that person is really likable and going to make the children smile.

George Vradenburg: Now Peggy Brick asks a question here, online, that relates to this. She says a continuing care retirement community can prepare all residents to relate to those with dementia. Have you seen any advantage in living in such a supportive community?

Jonathan Kozol: I haven't personally, but I hear repeatedly from others that it's a very good experience, especially if the retirement community is somehow attached to a nursing home, so that if one of the residents later needs to be hospitalized, it won't be an abrupt transition. But in my experience, I didn't see that. My folks, my mother and father, had thought about moving to that kind of setting, but in the end, I'm not quite sure why, but both of them liked the idea of staying in their own home, my mother particularly. They lived in a high-rise building in Boston, with windows that looked across . . . anyone who knows Boston will know that there's a famous river here that separates Boston from the universities in Cambridge. Dad, sitting at that desk in the end, could look across the river and see the university where he was educated. I'm glad they made the choice they did.

Meryl Comer: Jonathan - There's a movement in Europe coming our way, actually it was just announced at the White House Conference on Aging, about initiatives in six states to become dementia friendly. What in your view would it take for communities to become dementia friendly? What might it look like?

Jonathan Kozol: Well, at least in the early stages of dementia, when a person is still out in the world, just beginning to have difficulties, I think it's just a matter of educating the public in respectfulness, in respecting the dignity of every human being no matter how they falter, no matter how they might go into a bookstore and ask for a book and seem confused and pick the wrong title, that kind of thing. I think the best thing those states can do to be dementia friendly is to work with the medical schools, work with the major medical schools to entice more and more people to come into the field. Young physicians—I'm told this by doctors—young physicians don't want to go into geriatrics because the pay scale is so low. They can make far more money in almost every other specialty. In the long run, I'm afraid, money talks. Maybe those states can work with the medical schools, maybe the states can provide some incentives, cash incentives like loan forgiveness, to those medical students who do go into this field.

George Vradenburg: That's an excellent suggestion. We've got a caller, Sharman Walker. Miss Walker, would you like to ask your question?

Caller: Yes, my mother was diagnosed one year ago, in April, and she, over the last couple of months, has gotten progressively worse every day. Is there anything that you can take to slow down the progression of memory loss?

Jonathan Kozol: I was assured by a specialist in Boston that at that time, that was ten years or fifteen years ago, there was no medication or treatment that could slow down the loss of memory, except, I was told, and I kind of believe, that the only way you can slow down the loss of memory sometimes is by keeping the patient's mind as active as possible. But in your case it sounds as though you're at a point where that's really difficult. Do I understand correctly?

Caller: That is correct.

Jonathan Kozol: I think it's possible, Meryl will have a better answer to that than I do, but I do know, now, cutting edge doctors are talking about possible ways to slow down or postpone, to delay, the onset of complete dementia, or maybe even to delay the onset of any dementia, but I'm not certain of that, and I think that's all in the experimental stage unless Meryl knows more than I on that subject.

Meryl Comer: Let me deal with the immediacy of your challenge. Unfortunately there is no disease-modifying therapy, only drugs that may treat the symptoms. From my own experience, go with them; don't try to hold on to what was or where they were, and try to live with them in the moment and in their reality. It will be very challenging; it's a very confounding time in the disease, but for your own health and state of mind, go with them.

Jonathan Kozol: I like that advice.

George Vradenburg: It sounded liked you stayed with your father every moment, and it's quite extraordinary.

Jonathan Kozol: Well, I couldn't do it constantly. As you'll see in the book, there were moments; I'm in the public light somewhat because my books on children have been in schools; *Amazing Grace* and *Savage Inequalities* have been national bestsellers. So sometimes I had to go away to California to lecture or to New York to a conference, but once he got Alzheimer's, I tried to set aside entire periods of months where I wouldn't interrupt, so I could see him with great continuity. I found that was terribly important.

George Vradenburg: But what I guess I was going to emphasize was how much you stayed with him at every stage. You dealt with him as he could be, as his mind went, you went with it and you picked up on words or phrases that triggered things with him, and it's just a remarkable expression of love, his for you and you for him.

Jonathan Kozol: Thank you.

George Vradenburg: Jonathan, wow, thank you for being with us.

Meryl Comer: Thank you, Jonathan.

George Vradenburg: Thank you for being with us. We'd encourage everyone on the phone to read his book, [The Theft of Memory: Losing My Father, One Day at a Time](#). There are still other questions and comments that we got here from other people, on the phone and online, and we apologize, we couldn't get to all of you today, but thank you all, to everyone on the phone or online for participating today.

In about a week, we'll have a copy of this recording and a transcript on our website so you can share the transcript and Jonathan's really special story with your friends and with your family members.

Just a little programming note: Our next call will be August 19, at 3 p.m. Eastern, with [Dr. Scott Mackin](#). He is Associate Professor in the Department of Psychiatry at UCSF (University of California San Francisco) School of Medicine and one of the Lead Scientific Investigators of the [Brain Health Registry](#). Dr. Mackin is also the Principal Investigator for the [Alzheimer's Disease Neuroimaging Initiative Depression Project \(ADNI-D\)](#), which seeks to develop a greater understanding of mental illness and late-life depression and how that relates to cognitive decline. He will speak about the trial, that he's currently working on, to enroll participants, as well as the scientific research behind the study.

[If you would like to register for the call on August 19 at 3 p.m. Eastern, please click here.](#)

As always, please stay on the line if you would like to leave us a message with a question or comment. We are particularly interested in what you would like to discuss on future calls.

Thank you all for joining us today. Have a great afternoon and thank you so very much, Jonathan Kozol.