

BOOKS AND IDEAS PODCAST

With Ginger Campbell, MD

Episode #36

Interview with Daniel George, PhD, Co-Author of *The Myth of Alzheimer's: What You Aren't Being Told About Today's Most Dreaded Diagnosis*

Aired April 28, 2010

[music]

INTRODUCTION

This is Episode 36 of *Books and Ideas*, and I'm your host, Dr. Ginger Campbell. Today's episode is a short interview with Daniel George, co-author with [Dr. Peter Whitehouse](#) of the book, [*The Myth of Alzheimer's: What You Aren't Being Told About Today's Most Dreaded Diagnosis*](#).

This interview is a companion to *Brain Science Podcast* [Episode 68](#), in which I interviewed Dr. Whitehouse. You don't have to have heard Dr. Whitehouse's interview to enjoy this conversation, but I hope you will go back and listen to *Brain Science Podcast* [Episode 68](#) if you haven't heard it yet.

I'm going to get right into the interview, but I do want to mention our sponsor, [Audible.com](#), and the fact that *The Myth of Alzheimer's* is available on Audible; which means that if you aren't currently a member of Audible you can get this book as a free audiobook download by going to [audiblepodcast.com/booksandideas](#).

As always, you can get the show notes and episode transcripts for this episode at booksandideas.com, and you can send me email at docartemis@gmail.com.

I'll be back after the interview with a few brief announcements.

[music]

INTERVIEW

Dr. Campbell: My guest today is [Daniel George](#), the co-author of *The Myth of Alzheimer's*, and this is going to be to supplement the conversation I already had with his co-author, Peter Whitehouse. Thanks for coming on the show today, Danny.

Dr. George: Thanks for having me, Ginger.

Dr. Campbell: I guess first off I want to thank you personally for sending me this book, because I have to admit that just because of the way publishers like to name books, the title to me is the kind of title I would probably have ignored if I was just walking through the bookstore. But once I actually sat down and was reading it I totally resonated with it almost immediately. So, thank you for that contribution.

Dr. George: Well, thank you for giving us a chance—and that old axiom of not judging a book by its cover, I suppose.

Dr. Campbell: I must say, just for the sake of listeners, I do get quite a few books sent to me—there is a mailing address on the website—and I appreciate that, but it is rare for a book to actually make it on to the show.

So, why don't you start out by telling us a little bit about your background—how you came to work with Dr. Whitehouse, maybe, and then get involved in this book.

Dr. George: Sure. I was an English and philosophy major in undergrad, but did a senior independent study on Alzheimer's disease, specifically looking at a narrative therapy technique that was being used in assisted living homes, called [TimeSlips](#), which was developed by a theater professor named [Ann Basting](#), who is at the [University of Wisconsin, Milwaukee](#). I did this senior independent study, and once I graduated from college in 2004 I sort of was having a moment of despair, trying to figure out what I was going to do with my life.

So, I turned to Google, and I Googled 'Cleveland narrative Alzheimer's dementia,' and Peter Whitehouse's name came up. And so, I went to his office with a copy of my independent study. He wasn't there, so I sort of audaciously slipped it under his door and, to my surprise, got a call back a week later asking if I could be a research assistant at the [Memory and Aging Center](#), where he practiced as a geriatric neurologist.

That's the story of how Peter and I met. And I was just thrilled, because he helped develop the first drugs for Alzheimer's disease, and yet he was adapting his practice when I met him to be more narrative-focused, and to be open to more psychosocial interventions for caring and enhancing quality of life for people with neurocognitive disabilities.

Dr. Campbell: And then you went to graduate school?

Dr. George: That's right. After a year of being a research assistant for Peter I was fortunate enough to be accepted to the [medical anthropology program](#) at [Oxford University](#) in England. I never thought I'd get a chance to do something

like that, so I seized the opportunity. I did a one-year Master of Science degree over there.

And when I found out that Peter and I had sold the manuscript for our book—which he kindly enlisted my help on—I decided to do a doctorate in medical anthropology at Oxford. The advance that we got on the book actually allowed me to pay for my living expenses over there. So, I'm very grateful for meeting Peter, and for his bringing me in on this exciting project that we've been developing the last couple of years.

Dr. Campbell: This is a little bit off subject, but what is medical anthropology?

Dr. George: That's a very valid question. [Medical anthropology](#) has emerged sort of organically next to the ascendancy of biomedicine. So, whereas reductionist medicine looks at medicine at the molecular level, medical anthropologists try to look at the social and cultural components of health and disease, looking not only at cultural factors, but also political economy and economic factors that play into health outcomes. We're not in any way an enemy of biomedicine, but we try to have a more expansive holistic outlook on why people are well and ill over time.

Dr. Campbell: It sounds like we could have a whole interview on that sometime, maybe in the future.

Dr. George: Absolutely. I'd love to.

Dr. Campbell: So, getting back to *The Myth of Alzheimer's*, what was your role in doing this book?

Dr. George: Well, Peter is obviously the scientist and expert, but I did my Master's thesis on the history of Alzheimer's disease, and on prevention. So, I brought an anthropological perspective to the book and a historical perspective to

the book, and tried to help communicate some of the complex ideas—because this is a very complex disease and syndrome—in a way that I was able to carry out as an English major who loved to write. It was really a symbiotic writing relationship with Peter, and we did it while I was overseas through Track Changes on Microsoft Word, and it was a fun, creative process.

Dr. Campbell: Did you do a lot of the research into the history of [Dr. Alzheimer](#) and [Kraepelin](#), and then the politics of what happened in the late '70s and early '80s?

Dr. George: Yes, I did a lot of that research. And we had the help of a historian at Penn State named [Jesse Ballenger](#), who is a world expert on the history of Alzheimer's disease. But I really delved into the folios—the first case of Alzheimer's disease that Alzheimer recorded with a woman named [Auguste D](#)—and tried to understand what was going on there, and read Kraepelin's first publication on Alzheimer's disease, which occurred in 1910, and all the subsequent literature that has emerged in the last 100 years on Alzheimer's disease. So, I was lucky to be able to immerse myself in that historical literature.

Dr. Campbell: One reason why I resonated so much with this book is that I guess I was going to medical school right at the cusp of the changing definition or usage of the term 'Alzheimer's,' because I can remember in med school (I graduated in 1984) Alzheimer's disease was premature senility. And also, of course, we were taught that you didn't really diagnose it until postmortem.

And then over the years we've just gotten to where we hear things like if you live to be 85 you have a 50% chance of getting Alzheimer's disease. And it's like all of a sudden dementia equals Alzheimer's disease, unless it's vascular, or Parkinson's, or something with a specific etiology. Can you say something about how that change came about?

Dr. George: Sure. I think that's a really incisive point. I think you're absolutely right that Alzheimer's disease has sort of become a shorthand for any age-related change that we have in our late-life years—or even someone my age, in his twenties, can say I had an Alzheimer's moment. So, it's sort of a shorthand for memory loss.

Let's go back to Dr. Alzheimer. The first few cases he looked at were what he considered presenile dementia. The first woman, Auguste D, who I mentioned, was a 51-year-old housewife who had a precipitous decline and fairly severe symptoms. He also looked at a few other cases of people in their early fifties. And, as you said, the reason why these were significant was because they were very early in the life course. They were suffering from the symptoms you would expect to see from someone in their sixties, seventies, or eighties.

So, the first cases of Alzheimer's disease were what we would now call [autosomal dominant](#) early onset cases, which are a very rare genetic mutation in the population. But we've extended that label 'Alzheimer's disease' now on to the later sporadic forms of dementia that occur in the seventies, eighties, and nineties. So, we've replaced this idea of senility—which is sort of a vague term, kind of encompassing the cognitive and functional changes that occur with age—with a specific disease label, 'Alzheimer's disease.' And that has accelerated in the '70s, '80s, and '90s—so, right in the heart of when you were becoming a doctor.

Dr. Campbell: I couldn't help but thinking (and you did mention this in the book) about the role of the diagnostic coding that also came into usage during that same period, where doctors, when we bill insurance companies, are forced to code diagnosis for everybody. If we don't have a code, we don't get paid. This also pushes people toward labeling their patients with diagnoses, even though we all know in the back of our minds that we can't prove anyone has Alzheimer's while they're alive.

Dr. George: Right. And it was in the [DSM-IV](#), which was published in 1994, that Alzheimer's disease really rose to prominence. But even before that, in the '80s, you saw winds of change. [Alzheimer's Disease International](#) emerged in 1982. [The Alzheimer's Association](#) in America emerged in the '80s. And actually November of 1988 was declared Alzheimer's Disease Month for the United States, because of the successful lobbying of the Alzheimer's Association. And then a few years later you saw the *Diagnostic and Statistical Manual* reflecting that more specific diagnosis in its pages.

Dr. Campbell: Yes. And I will mention, as a practicing physician there's a lot of pressure for diagnoses to be more specific, whether or not it's justified.

Dr. George: Right. Absolutely.

Dr. Campbell: That, and then, of course, with Peter we talked about the motivations for getting research funding by having it be a disease that we could then have a war on, and all that. So, I don't want to rehash that.

Are you still working in this? Are you doing anything with this narrative treatment method now?

Dr. George: Yes, I'm actually having some of the medical students I teach at [Penn State College of Medicine](#) in the Department of Humanities do the narrative therapy technique with elders from a local residential community who are affected by dementia. We're going to start doing that in April. And I'm actually going to try to collect some data to measure whether this narrative therapy has any impact on the attitudes of my medical students towards the elders.

Because what happens so frequently in these sessions is you get a group of people with dementia, and you give them a picture that's sort of surreal—like nuns holding shotguns, or an elephant sitting on a park bench next to a young girl—and you have them tell a story about what's happening in that picture. You

wouldn't believe the imagery, ideas, and statements that come out of these storytelling circles. And everything gets written down in the form of a prose poem. So, at the end of a session 10 people with dementia have kind of co-assembled a brilliant, witty, and satirical short story, or prose poem.

What I'm going to have the medical students do is actually participate in the storytelling circle and facilitate these stories. Now, we know that it benefits elders, because they laugh, they don't feel the pressure to communicate in a coherent and linear way as they so often feel amongst their peers, they develop more rapport with their caregivers and with each other, and it's just an opportunity to have fun.

One of my favorite *Brain Science Podcasts* was [Stuart Brown—Play](#). We can't forget that that's an essential aspect of wellness. So, what I want to measure is whether that has any benefit for our students—for their perspective on aging people.

Dr. Campbell: That sounds like a really good idea. I remember when I was a resident, I was in a family practice residency where we didn't have that much of an inpatient population. The inpatients that we did have, a lot of them were nursing home patients who belonged to various private physicians in the community.

And so, we often would have a whole batch of patients on our service, none of whom could even have a conversation with us. It was very depressing. And I remember that my diet really went downhill during that period, because I kind of thought, if this is what it's going to mean to be old, I'd rather just eat, drink, and be merry, so to speak.

Dr. George: Yes, live it up. Right? No kidding! We're starting to see that there are all different ways to connect with people who may have some severe cognitive

and functional loss. Music is a very powerful way of engaging long-term memories, or even procedural memories. Sometimes if you sit a person with dementia down in front of a piano they can play an old hymn or an old melody. Dancing—again, that body memory, that muscle memory that stays in you, even if you are losing some cognitive functioning. Art therapy, pet therapy, touch therapy: there are all these different ways to engage older folks without relying on a pharmacological solution.

Dr. Campbell: And then the most important aspect that is emphasized in your book is that if we change the story we tell about brain aging from this idea of this hopeless incurable disease that robs us of our personhood to, ‘I have more brain aging, maybe, than the next guy,’ then the person is still a person. That’s really important. I think the reason why most of us, at least of a certain age, think of Alzheimer’s or dementia as the worst possible thing we could get (we would rather get cancer, or just drop dead, than to get that) is because we all fear losing who we are.

Dr. George: Right. It’s understandable that that’s so terrifying. I live in a very high-tech world, and have a lot of my gadgets and passwords stored in my memory. It’s fearful to think of losing that.

However, we are more than memory. And the current disease narrative, as you mentioned, puts the emphasis only on the deficits, the tragedy, the horror, and the fear. Those are clearly part of the story, but the story is also more dynamic than that. There’s quality of life at the end of life; there’s capacity for giving back, and having a sense of purpose, and having relationships. Sometimes relationships can deepen if somebody has dementia.

Peter and I have a friend named Ann Davidson, who was a caregiver for her husband, who was a former Stanford endocrinologist. She wrote a book about her caregiving experience, and fought with the publisher to have it titled,

[*Alzheimer's, A Love Story*](#)¹. They didn't want the word 'love' to be in the title; they wanted it to evoke that fear narrative that we have, or the horror. But Ann said, 'No, this is about a relationship that evolved and adapted, and was something that I really felt affectionate towards in the end.'

Dr. Campbell: As I told Peter at the end of our conversation yesterday, I think that the underlying theme of your book really is one of hope, because if we look at it under the current model it doesn't look that hopeful (unless you are a big believer in the magic pill, which I am not); it looks pretty dire. But instead, you've come up with a way of looking at it that I think is hopeful.

Then we've got a place now (and we didn't have a chance to talk about this yesterday) to use all that brain plasticity that we're learning about. The current model of looking at dementia pretty much ignores the new evidence about plasticity—among other things.

Dr. George: Yes, I think that's absolutely right. Peter and I like to talk about it as lifelong learning. I'm sure he mentioned in his interview the [intergenerational school](#) that he started with his wife in Cleveland—which is actually where I did my doctoral research.

I don't want to say too much about the school, but it is a place where we bring in folks who have dementia, who live in assisted living homes. And not only do we use them as mentors with our students at the school, but we also have the students teach them. For instance, we had the students teach a computer class on how to put a PowerPoint together, or how to plan a trip online, with people who had some degree of memory challenges.

And so, we're trying to break down this caricature of people with Alzheimer's as lost selves—people who are just passively fading away, like the people you were

¹ *Alzheimer's, a Love Story: One Year in My Husband's Journey* by Ann Davidson

talking about in the wards who were just sitting there with vacant expressions. Clearly we can't expect a high degree of functionality, but that doesn't mean that these folks don't have something to give back, or don't have the capacity to learn.

Dr. Campbell: I think there is evidence that if we were to use the fact that we've got some plasticity, early on in the diagnosis, people's prognosis and the amount of time they could be as independent as they would like could probably be increased better than giving them pills that don't really do much of anything.

Dr. George: I think that's right. And I think if I was a doctor I would prescribe the *Brain Science Podcast*—and I mean that in all seriousness. Look at iTunes now. You can get free lectures from Berkeley, Yale, and Oxford, and all these wonderful educational materials completely free of charge.

Peter and I like to call books 'neurocognitive multi-neurotransmitter enhancement devices'—which can be more profound than pills, in some cases, because if you're learning, clearly it's affecting your brain. If you're listening to the *Brain Science Podcast* or another program, clearly that's going to help you. So, I think thinking outside the box—outside of very instrumental reductionist solutions—is progress.

Dr. Campbell: Absolutely. Before we close is there anything else you would like to share with my listeners?

Dr. George: I'd just like to humbly thank you, Ginger. I've been a long-time fan of the show since I discovered it on a road trip to Birmingham, actually, last summer. I really appreciate this community space that you've created online, where we can share ideas, and share our visions of a more hopeful and compassionate world.

Dr. Campbell: Thank you, Danny.

[music]

I want to thank Daniel George for being my guest on this month's *Books and Ideas*, and remind you that you can hear the full conversation with Dr. Whitehouse at brainsciencepodcast.com. It's Episode 68.

With regards to the schedule for *Books and Ideas*, I have a couple more podcasts planned that I will probably post unevenly over the next few months. I don't have an exact schedule for now, so I recommend that you subscribe, so that you'll get the episodes automatically. You can do that in iTunes or at booksandideas.com.

And before I close I will remind you that, besides the website, you can follow me on [Twitter](#). I'm Doc Artemis on Twitter. And on Facebook I have a [Ginger Campbell, M.D. Fan page](#), as well as Fan pages for [Books and Ideas](#) and the [Brain Science Podcast](#). I'd love to hear from you, so please send me email at docartemis@gmail.com.

Thanks again for listening. I look forward to talking with you again very soon.

[music]

This recording is copyright 2010 Virginia Campbell, MD.

[music]

Theme music for *Books and Ideas* is "The Open Door" by Beatnik Turtle. Be sure to visit their website at beatnikturtle.com.

[music]

Transcribed by [Lori Wolfson](#)
All errors or omissions responsibility of the transcriber