Speaker 1 [00:00:01] And me and I everybody and welcome back to in social work, the podcast of the University at Buffalo School of Social Work. I'm Peter Sobota. Dementia and Alzheimer's disease. It's enough to promote a fair degree of fear and cognitive distortion in those of us of a certain age. Many of us have heard of the so-called silver tsunami of the 21st century, and that will result in devastating social and economic consequences. Today, our guests are a public health, academic and medical anthropologist and another academic and neurologist who will talk with us about the bio psychosocial issues that both support and in some ways compromise the maintenance of healthy brains. Most of the action, and by that I mean money research, funding and biomedical treatments have been focused on a cure for Alzheimer's disease via pharmaceuticals with an almost zero percent efficacy rate so far. You may have heard about the most recent entry Aduhelm, a medication approved by the FDA in June to great fanfare and controversy. Medicare will be deciding somewhere in the middle of January whether or not they're going to cover treatment without your help. Paradoxically, coupled with the lack of success with hugely funded pharmaceutical cures, has been the declining rates of Alzheimer's disease in the U.S. and Western Europe. All helping professionals and especially social workers will be interested in what our guests have to say about dementia and an eco psychosocial model to treatment and notably prevention. And how old friends like empathy. Fight for equality and racial equity. Increased access to education and public health and medical policy decisions have helped drive down the risk for dementia. Today, we are joined by our guests. Daniel George, Ph.D., M.S., medical anthropologist and Associate Professor at Penn State College of Medicine. Welcome, Danny.

Speaker 2 [00:02:08] Thank you for having us, Peter.

Speaker 1 [00:02:10] And Peter Whitehouse, M.D., Ph.D., professor of neurology at Case Western Reserve

Speaker 3 [00:02:15] University and Professor

Speaker 1 [00:02:17] of Medicine at University of Toronto. Welcome, Peter. Thank you, Peter. As a quick note, before we dive into the podcast, our guests will refer to Aduhelm and Aducanumab. They are the same drug. All right, thanks for joining us. I have to believe that something's up with your choice of the title American dementia for your book. Could you begin by telling us about what you were up to using those words?

Speaker 4 [00:02:45] So our working title was brain health in an unhealthy society.

Speaker 3 [00:02:50] We added

Speaker 4 [00:02:51] American dementia to the beginning

Speaker 3 [00:02:52] of that age to

Speaker 4 [00:02:53] make it easier to say our book American Dementia, but also to

Speaker 3 [00:02:57] signify that we're dealing
Speaker 4 [00:02:59] with this fear and cognitive
distortion. This is a
cultural, cognitive
distortion, Peter, that we are
thinking poorly
about this problem that
we're facing, which is that older people face cognitive challenges.
The problem is we should get lessons
from the past. We don't plan
well for the future, like long
term care or to pay
social workers more, which would be an important part of the future, in my view.
And we are pretty bad
as a species at our activities daily living. We call this a cultural
dementia. We have a chart
in the book where we
say, here's clinical dementia, and here's cultural dementia. So thanks for asking about that.
It is the illustration of
what the main message of the book
is that we need to
think differently about dementia.
Danny, did you want to add on to that?
Yeah, I can add that. You know, another element of dementia is psychosis often.
And part of the
unhealthy society that we describe in the book is
one that has massive
Speaker 2 [00:03:53] inequalities like ours does. That has falling life

Speaker 3 [00:03:55] spans that allows

Speaker 2 [00:03:57] children to have lead poisoning at a

Speaker 3 [00:03:59] scale that's unprecedented in history. And so a

Speaker 2 [00:04:02] lot of our critique is about how we have organized society since the 1970s

Speaker 3 [00:04:06] when we had this sort of birth of

Speaker 2 [00:04:07] neoliberalism, as it's called, or hyper

Speaker 3 [00:04:09] capitalism unleashing

Speaker 2 [00:04:11] the market into all of our lives, stripping away social safety

Speaker 3 [00:04:15] nets, deregulating industries. And, you know, that reflects decisions

Speaker 2 [00:04:19] that we have made, not in the best interests of the collective always. And I would say it is a form of psychosis that we allow that to persist.

Speaker 1 [00:04:27] Well, actually, I think the two of you have gotten ahead of me a little bit, but I know that your book argues for a radical rethinking of health care as usual. Could you give us

Speaker 3 [00:04:37] a summary of what

Speaker 1 [00:04:38] you're advocating for and fighting

Speaker 3 [00:04:41] against, especially

Speaker 1 [00:04:43] when it comes to our approach to Alzheimer's disease and dementia?

Speaker 4 [00:04:47] So let me do the fighting against and then it can have the hopeful message. So I'm a physician, neurologist. I've been involved in the medical model that has led, as you've suggested, Peter to. Lots of money being spent, tens of billions, if

Speaker 3 [00:05:02] not more, trying to develop molecular reductionistic,

Speaker 4 [00:05:06] biomedical answers to

Speaker 3 [00:05:08] dementia and Aduhelm. The drug

Speaker 4 [00:05:12] that you mentioned

Speaker 3 [00:05:12] in your introduction
Speaker 4 [00:05:14] is a very good example of that

Speaker 3 [00:05:16] because it

Speaker 4 [00:05:17] is a drug that was

Speaker 3 [00:05:18] approved.

Speaker 4 [00:05:19] Unfortunately, it was a debacle, really a disaster on the

Speaker 3 [00:05:23] basis of the drug's ability

Speaker 4 [00:05:25] to improve a molecule in the

Speaker 3 [00:05:27] brain amyloid without

Speaker 4 [00:05:29] clinical evidence or adequate clinical

Speaker 3 [00:05:31] evidence. So we are fighting this idea that all the answers

Speaker 4 [00:05:36] to

Speaker 3 [00:05:36] brain aging and medical

Speaker 4 [00:05:38] diseases lie in medicine. Said medical diseases, which is why I
made the plug for social work. This is all about community and all

Speaker 3 [00:05:46] about addressing

Speaker 4 [00:05:47] the problem more broadly with Johnny will talk about a middle. Who
are we fighting while we're fighting the idea that money is the main value in society? That if
somebody gets a Nobel Prize and becomes famous and starts a biotech

Speaker 3 [00:05:59] company and claims that they can address these

Speaker 4 [00:06:01] problems, all of a sudden they're famous.

Speaker 3 [00:06:03] Their wealthy people have gotten wealthy on promises, and that's
destructive.

Speaker 4 [00:06:07] It's destructive in the dementia field. It's destructive in society as a
whole. So we're really

Speaker 3 [00:06:11] challenging at a fundamental

Speaker 4 [00:06:13] level. As I said before, the cultural misunderstandings we have of
dementia, which are also cultural misunderstandings of what it means to be an older
human being in our society.

Speaker 1 [00:06:21] And this is going to be the hopeful part. Sure.

Speaker 2 [00:06:26] Yeah, I'm happy to take that
Speaker 3 [00:06:28] side of it. As Peter

Speaker 2 [00:06:29] saying, the narrative of the last 40 50 years of Alzheimer's disease has been

Speaker 3 [00:06:34] that if we throw enough money

Speaker 2 [00:06:35] into research and markets, science will eventually produce a cure. And that has been the sort of guiding story. But of course, that hasn't come to fruition, as you have alluded to already, both leaders

Speaker 3 [00:06:45] have alluded to. And so

Speaker 2 [00:06:46] when you start looking at what is actually driving down dementia rates, as you alluded to Peter

Speaker 3 [00:06:51] in your introduction, it has to do with

Speaker 2 [00:06:53] collective investments that were made in the 20th

Speaker 3 [00:06:55] century after the

Speaker 2 [00:06:56] World Wars and the Great Depression. It has nothing to do with markets producing innovations at scale with the population. It has everything

Speaker 3 [00:07:03] to do with more inclusive

Speaker 2 [00:07:04] prosperity and collective infrastructure programs and

Speaker 3 [00:07:08] investments, and those

Speaker 2 [00:07:09] have rebounded to better brain health for people who are now in their graying years. And so what are we fighting for? We're fighting for a forward looking

Speaker 3 [00:07:16] vision that reclaims

Speaker 2 [00:07:17] some of those ideals

Speaker 3 [00:07:19] and values and then

Speaker 2 [00:07:20] rescues our way of thinking about Alzheimer's in society in general from this tyranny of markets,

Speaker 3 [00:07:25] this sort of market fundamentalism that has

Speaker 2 [00:07:27] dominated my whole life. Frankly, I'm in my thirties and that's all I've known. And then I'll just add on to that. We're also arguing for better care of the elderly, more humane care of folks who are currently warehoused in homes, very grave label of Alzheimer's disease and dementia, and sort of excised from the relationships we know we're sustaining for them and for their quality of life. And so we're arguing not just
Speaker 3 [00:07:49] for a different way of

Speaker 2 [00:07:50] thinking about Alzheimer's as a

Speaker 3 [00:07:51] disease or syndrome, but also a better way of caring

Speaker 2 [00:07:54] for people who may have cognitive frailty.

Speaker 1 [00:07:57] Yeah, I want to ask you actually about all of that, and I will so we can drill down

Speaker 3 [00:08:01] a little bit. But if I

Speaker 1 [00:08:03] could, before we go there, I'm going to actually weigh in here as probably a person who has maybe slightly better than a way knowledge of the neurology and many of the things that you're

Speaker 3 [00:08:14] talking about. So I'm just going to ask what I

Speaker 1 [00:08:16] would call a regular person's question what's the difference between an aging brain and Alzheimer's disease?

Speaker 4 [00:08:26] That is the question, right? It's a very good question. I mean, when Bob Butler started the national and sort of aging in 1974, he said we need to have a disease. So he carved this idea out. But Alzheimer's disease is a discrete disease different than normal aging. There is no way to tell, other than the matter of degree, the difference between people's brains that are

Speaker 3 [00:08:52] aging without dementia

Speaker 4 [00:08:54] and those

Speaker 3 [00:08:55] that are aging with the

Speaker 4 [00:08:56] cognitive

Speaker 3 [00:08:57] challenges. And there's this gray zone that is

Speaker 4 [00:08:59] involved in the labeling of this drug mild cognitive impairment. So the fact is we are on a continuum. All of us.

Speaker 3 [00:09:06] We have changes

Speaker 4 [00:09:07] in nerve cells. We have changes in amyloid. That protein that I mentioned was used to approve the drug. There are people

Speaker 3 [00:09:13] who do not have

Speaker 4 [00:09:14] cognitive

Speaker 3 [00:09:15] impairment, many of them who have amyloid
Speaker 4 [00:09:17] in their brains. We don't even know whether amyloid is a bad protein or not.

Speaker 3 [00:09:21] So the

Speaker 4 [00:09:22] fact is that if you google the myth

Speaker 3 [00:09:24] of Alzheimer's, you won't get our

Speaker 4 [00:09:25] book title. Our first book,

Speaker 3 [00:09:27] you'll get Alzheimer's

Speaker 4 [00:09:28] disease is not normal aging. Well, it's

Speaker 3 [00:09:31] actually

Speaker 4 [00:09:31] almost normal. If you live long enough to have some significant

Speaker 3 [00:09:35] cognitive impairment that is

Speaker 4 [00:09:37] a distortion. It is a distortion of what this whole field was based that Alzheimer's is somehow different than normal aging. Let me just say that I attended grand rounds at the University of Toronto, and basically the speaker from

Speaker 3 [00:09:49] Israel asked, Will we

Speaker 4 [00:09:50] ever find a cure for Alzheimer's? And at the end of the day, he said, Well, it's essentially like asking, Will we ever find a cure for brain aging?

Speaker 3 [00:09:57] So if

Speaker 4 [00:09:58] you ask that question, you will begin to wonder what is this that we're trying to do with all these molecules, fix brain

Speaker 3 [00:10:05] aging or treat a

Speaker 4 [00:10:06] specific disease? That question, you asked is the

Speaker 3 [00:10:09] fundamental unanswered question

Speaker 4 [00:10:11] by a field that has presumed that this is somehow different, singular and curable?

Speaker 1 [00:10:17] Wow.

Speaker 2 [00:10:18] Danny, yeah, I think Peter's answer nails it

Speaker 3 [00:10:21] and basically constructing

Speaker 2 [00:10:23] Alzheimer's as a disease in the 1970s, as Bob Butler and his colleagues did is more of a political decision, a political shibboleths than a scientific
Speaker 3 [00:10:31] reality. And it

Speaker 2 [00:10:32] basically allowed for the

Speaker 3 [00:10:33] NIA to secure its

Speaker 2 [00:10:35] funding and to compete against other major chronic

Speaker 3 [00:10:37] diseases and the sort of public health gantlet.

Speaker 2 [00:10:40] And so we're left

Speaker 3 [00:10:41] with the sort of fallout of that

Speaker 2 [00:10:42] in many ways where most scientists, if you pin them

Speaker 3 [00:10:45] down, will say,

Speaker 2 [00:10:46] Well, we don't know Alzheimer's to be differentiated from normal brain aging. We know Alzheimer's to be heterogeneous and syndrome all rather than one thing. And as Peters alluded

Speaker 3 [00:10:56] to, the notion that plaques

Speaker 2 [00:10:58] are what's driving the disease process is very controversial,

Speaker 3 [00:11:01] and all of the anti

Speaker 2 [00:11:02] amyloid drugs that we've tried have

Speaker 3 [00:11:04] not worked. So what we're

Speaker 2 [00:11:05] dealing with

Speaker 3 [00:11:06] here is improper

Speaker 2 [00:11:07] construction of a disease that just doesn't match the

Speaker 3 [00:11:09] reality. And you know,

Speaker 2 [00:11:11] somebody like Ivan Illiu,

Speaker 3 [00:11:12] the great medical anthropologist

Speaker 2 [00:11:14] and sociologist, would have a field day with Alzheimer's disease

Speaker 3 [00:11:17] because we've set up a

Speaker 2 [00:11:18] proposition of being able to cure something that is intimately related

Speaker 3 [00:11:22] to aging. And what has that
Speaker 2 [00:11:23] done to their culture? What has that done to the way that we think of ourselves as embodied people who age?

Speaker 3 [00:11:28] And that's sort of

Speaker 2 [00:11:29] just the water that we're swimming in now.

Speaker 1 [00:11:31] Yeah, talk about inheritance, huh? That's a large narrative that just informs how we all think about it. It's also very

Speaker 3 [00:11:40] interesting to me, you know, listening to you talk. I couldn't help

Speaker 1 [00:11:43] but think there seemed to be some parallels

Speaker 3 [00:11:45] between Alzheimer's dementia as a disease and

Speaker 1 [00:11:49] the so-called

Speaker 3 [00:11:50] disease of addiction and alcoholism, where there has been this kind

Speaker 1 [00:11:55] of model that has been held up as the standard. But as time has gone on, there has been lots of chipping

Speaker 3 [00:12:03] away at what

Speaker 1 [00:12:04] this really is.

Speaker 4 [00:12:06] But I think that's an important point. You're right,

Speaker 3 [00:12:08] and we think of

Speaker 4 [00:12:09] dementia and Alzheimer's as a lever to get people to think about the social construction. Let's use that word of disease in

Speaker 3 [00:12:16] general because there is

Speaker 4 [00:12:17] so much fear, so much money associated with Alzheimer's. We hope that people can kind of, if not, switch the switch, at least realize that you

Speaker 3 [00:12:24] could maybe change

Speaker 4 [00:12:25] the illumination or ruminate a

Speaker 3 [00:12:27] little differently. Because when you define

Speaker 4 [00:12:30] something as a disease, you hand it over to doctors, a molecular biologist and pharmaceutical

Speaker 3 [00:12:35] companies. When you say it's a

Speaker 4 [00:12:36] syndrome heterogeneous that affects everybody to one degree
Speaker 3 [00:12:39] or another, it becomes

Speaker 4 [00:12:40] a public health

Speaker 3 [00:12:41] issue. More than that,

Speaker 4 [00:12:42] a societal issue. The trouble is, you can't make as much money out of public health as you can out of trying to sell people pills.

Speaker 1 [00:12:50] Yeah, let's circle back because I think I mentioned and I know you have written that dementia rates in the U.S. and Western Europe have

Speaker 3 [00:12:58] fallen in, I

Speaker 1 [00:12:59] think the past, you know, better than I 10 years. Could you say more about why the two of you believe that's happened?

Speaker 2 [00:13:07] Yeah, absolutely. So as you alluded to in your introduction, Peter, we have this notion, this trope in the way we tell a story of Alzheimer's, that it's a tsunami, the numbers are going to keep going up and it's going to cripple our health care system. But yeah, in the last decade and actually in the last 40 years, we've seen a per decade reduction in risk for both dementia. And specifically, Alzheimer's
disease of about

Speaker 2 [00:13:28] 15 percent in

Speaker 3 [00:13:29] both cases.

Speaker 2 [00:13:30] And so we've seen that not just in the United States, but also in Canada and for other Western European countries that you mentioned and those are all linked to. As Peter has already

Speaker 3 [00:13:39] pointed out, public health and infrastructural

Speaker 2 [00:13:42] and programmatic

Speaker 3 [00:13:43] changes that sort of

Speaker 2 [00:13:44] were operationalized in the mid 20th century as a result of the traumas of the World Wars, the

Speaker 3 [00:13:48] Great Depression. I can just

Speaker 2 [00:13:50] unpack that a little

Speaker 3 [00:13:50] bit, too. We had the GI

Speaker 2 [00:13:52] Bill right for veterans coming back from World War Two. Tens of millions of troops got access to higher education, which we know is a cognitively beneficial
Those resources weren't enjoyed equitably in the culture because we still had segregated universities and colleges at the time,

**Speaker 3** [00:14:07] which is unfortunate and maybe a part of

**Speaker 2** [00:14:09] the reason why African-Americans and people of color are more affected.

**Speaker 3** [00:14:12] But the GI

**Speaker 2** [00:14:13] Bill was

**Speaker 3** [00:14:13] a major part of IT expansion

**Speaker 2** [00:14:15] of state universities during the Cold War and the competition with Russia, again rising access to health,

**Speaker 3** [00:14:20] education or to education writ large and then Pell

**Speaker 2** [00:14:23] Grants and other opportunities for socially marginalized folks to attend college. We know through the theory of cognitive

**Speaker 3** [00:14:29] reserve that higher

**Speaker 2** [00:14:30] education or any formal education or just learning in general, has a buffering effect

**Speaker 3** [00:14:35] on brain aging, which allows

**Speaker 2** [00:14:36] people to resist the neural pathologies that occur with age.

**Speaker 3** [00:14:39] So the GI

**Speaker 2** [00:14:40] Bill is a big part of this story. Also, we know that vascular health is intimately related to brain health. What's good for the heart is good for the

**Speaker 3** [00:14:46] head, as they say, and all

**Speaker 2** [00:14:48] of these countries, including the United States, which put Medicare and Medicaid into place. But the other countries put universal health care systems

**Speaker 3** [00:14:54] in place that are controlling

**Speaker 2** [00:14:55] hypertension, high cholesterol,

**Speaker 3** [00:14:57] diabetes, things that

**Speaker 2** [00:14:58] obviously redound in better brain health. Smoking cessation

**Speaker 3** [00:15:02] campaigns launched in the

**Speaker 2** [00:15:03] 1960s have been remarkably effective in driving down rates of
Speaker 3 [00:15:06] smoking from the 40 percentile range in the US in the late sixties, to now about 14 percent. And then the last thing I'll mention is we were able to get lead out of our gasoline in the 1970s through the Clean Air Act and the EPA's regulatory flexing. We lowered blood lead level rates from about 80 percent from 1970 to the 1990s led, of course, as a major known neurotoxin and a risk factor for heart disease. When you start putting a context around this finding that dementia rates are declining over the last 40 years for people who are growing older, that is the context that we need to interpret the data in. It's these programs, infrastructure and opportunities that were extended again in an egalitarian way across the whole of society. That's where we're seeing the sort of causality here. So in many ways, up front prevention from a wide ecological perspective seems to have a much better track record than the search for the magic pill.

Speaker 2 [00:15:22] Yeah, and you use the word eco psycho, social and social workers will be familiar because it was invented close to you at the University of Rochester bio psychosocial and people say, Well, why did you invent that term? It's exactly to
Speaker 4 [00:16:17] make the point that we've been working so far on This Morning. Doctors get the biology wrong. They think it's all

Speaker 3 [00:16:23] about molecules and drugs

Speaker 4 [00:16:25] and proteins and genes. You need to see health as part of a larger ecosystem and to just continue

Speaker 3 [00:16:32] for one more minute. The lessons

Speaker 4 [00:16:33] from the past about lead, for example, are no

Speaker 3 [00:16:37] brainers.

Speaker 4 [00:16:38] Lead is a

Speaker 3 [00:16:38] toxin.

Speaker 4 [00:16:39] It's damaged kids. It continues to damage kids. So going forward, that is where we should put energy in. And if the Alzheimer's Association ever had the moral courage to say, if we want to prevent late life dementia, we prevent killing nerve cells in kids.

Speaker 3 [00:16:53] They should take that if you want, I will say one other

Speaker 4 [00:16:56] thing, and that's a brainer. I gave you a no brainer. This is a brainer. Why are we concerned about brain health?

Speaker 3 [00:17:01] Why not just

Speaker 4 [00:17:01] health in

Speaker 3 [00:17:01] general? Because, as Danny

Speaker 4 [00:17:03] said, lots of factors like vascular factors that affect the

Speaker 3 [00:17:06] whole body because the brain

Speaker 4 [00:17:07] is the principal organ of learning. It's not the only

Speaker 3 [00:17:10] organ of learning. We have to learn

Speaker 4 [00:17:11] with our entire bodies, but that's where I think we really went wrong,

Speaker 3 [00:17:15] too. And it's another

Speaker 4 [00:17:16] illustration of why dementia

Speaker 3 [00:17:17] can be a lover. We've devalued education of

Speaker 4 [00:17:20] children, we've
Speaker 3 [00:17:21] devalued college.

Speaker 4 [00:17:23] We've got away with programs like the GI Bill.

Speaker 3 [00:17:25] That is the

Speaker 4 [00:17:26] way for

Speaker 3 [00:17:26] us to support brain health,

Speaker 4 [00:17:28] education. And by the way, when we get ourselves educated, we will be healthier about

Speaker 3 [00:17:33] lots of things, including tackling

Speaker 4 [00:17:35] the climate crisis seriously.

Speaker 1 [00:17:37] Yeah. So how much grief do you get from colleagues, from the associations, from foundations? I'd love to think that you don't get any, but I'm not that naive.

Speaker 4 [00:17:52] Well, Peter, I'm going to answer that because I've been in the field longer and worked actively with the organization. I just stuck it to the Alzheimer's Association. You know, a friend of mine who helped invent the Alzheimer's field said they've abandoned their mission. I won't tell you who that is. They've distorted things to the point that we're really headed down the wrong path, in our view. What do they usually do? Well, if somebody's speaking truth to power, you don't want to take them on because the truth may come out so you ignore them. But I will tell you, Peter, that what will

Speaker 3 [00:18:07] happen this week? This is a prediction. It's going to get their attention.

Speaker 4 [00:18:24] There's going to

Speaker 3 [00:18:24] be more failures

Speaker 4 [00:18:26] of the drug with the Europeans nonce they won't publish it of. The new commissioner may get asked about a.m. out tomorrow

Speaker 3 [00:18:34] and there's going to be

Speaker 4 [00:18:35] more calls in the public space and in the expert space for

Speaker 3 [00:18:39] withdrawing the drug.

Speaker 4 [00:18:40] It is possible to withdraw this drug. Lots of people think it

Speaker 3 [00:18:43] was a mistake when we
Speaker 4 [00:18:45] started doing that kind of stuff. My prediction is it's going to be harder to ignore us because it's not just us, it's a bunch of other

Speaker 3 [00:18:51] people who are concerned

Speaker 4 [00:18:53] about the future of health

Speaker 3 [00:18:54] in this country. The distortions

Speaker 4 [00:18:56] that occurred at the FDA process with the accelerated approval which has distorted the approval of

Speaker 3 [00:19:00] other drugs the whole way in

Speaker 4 [00:19:02] which the pharmaceutical industry manipulates our health care system, including preventing Medicare,

Speaker 3 [00:19:07] the biggest payer from negotiating

Speaker 4 [00:19:09] drug prices.

Speaker 3 [00:19:10] So this all

Speaker 4 [00:19:11] connects

Speaker 3 [00:19:11] into a bigger

Speaker 4 [00:19:13] picture which included, as you may be aware, that Medicare announced a $20 a month increase for every Medicare

Speaker 3 [00:19:20] beneficiary, half of which was based

Speaker 4 [00:19:22] on the idea that they might have to pay for this drug. There are models suggest that this drug alone could bankrupt Medicare. What on earth are we doing?

Speaker 3 [00:19:31] This is the time to say to the

Speaker 4 [00:19:33] people that have been ignoring these issues. No, you can't anymore.

Speaker 2 [00:19:37] And if I could jump in here, everything Peter is saying is true. But let me be the moderator here a little bit and say that I want to throw the baby out with the bathwater with the Alzheimer's Association because they have a national organization and they have local chapters and their local chapters

Speaker 3 [00:19:50] do great work in Buffalo

Speaker 2 [00:19:52] and Cleveland, where my family benefited from their services. The local chapters do great work and are often very alienated from the corporate style governance in Chicago of Alzheimer's Association. They're in bed with industry at the national level.
Speaker 3 [00:20:05] They took money from Biogen.

Speaker 2 [00:20:07] We know that they were a major part of the push to get that drug approved because they've been promising a drug for so long, for decades as part of this narrative that they've sort of lost their grasp with reality. Unfortunately, so they are implicated in hypercapitalism. They're part of this beast that has been unleashed since the 1970s. And so in so much as we push back against that, as Peter saying, we typically get ignored.

Speaker 3 [00:20:29] But I think things are ramping up. And I know this podcast won't be out this week, but I think when it does come out in the next month or so, things could look a lot differently on that front. With aducanumab?

Speaker 1 [00:20:39] Yeah. In preparing and talking with you, I read, I think, the latest issue of STAT and they were mentioning how this is not going to go well. So, you know, just by the way, we're families and patients strong and vocal advocates for the decision in June by the FDA. Weren't they mobilized to?

Speaker 1 [00:20:49] Get in front of the FDA themselves.

Speaker 4 [00:21:03] Yeah. In preparing and talking with you, I read, I think, the latest issue of STAT and they were mentioning how this is not going to go well at the cost and the lack of efficacy.

Speaker 1 [00:20:49] So we're families and patients strong and vocal advocates for the decision in June by the FDA. Weren't they mobilized to?

Speaker 4 [00:21:03] Get in front of the FDA themselves.

Speaker 4 [00:21:05] So this is an interesting issue

Speaker 3 [00:21:07] because I was on the FDA committee a number of years ago when we approved the

Speaker 3 [00:21:12] first drugs and whether
Speaker 4 [00:21:13] It's Alzheimer's or ALS. You always get people coming to testify.

Speaker 3 [00:21:18] Rightfully, they should saying, we

Speaker 4 [00:21:19] need this drug. We're desperate. And that's what the Alzheimer's Association has been saying. We're desperate. We haven't had a drug in almost 20 years. They actually got called out in the Journal of the American Medical

Speaker 3 [00:21:28] Association by pointing out

Speaker 4 [00:21:30] that desperation is not an argument for proving a drug. And the fact is, they always selectively bring people to the meeting. So the Alzheimer's Association brought all those people, and there are certainly people with dementia who believe that they're willing to, you know, sell their mother to get the latest drug. Maybe that's an unfair example, but you

Speaker 3 [00:21:48] know, they're desperate. But there's

Speaker 4 [00:21:49] also a silent

Speaker 3 [00:21:51] majority, including

Speaker 4 [00:21:52] people with mild cognitive impairment. Remember, that's one of the indications

Speaker 3 [00:21:57] of this drug. And people with

Speaker 4 [00:21:58] mild cognitive impairment have no impairment of activities of daily living, including thinking

Speaker 3 [00:22:02] straight about what they

Speaker 4 [00:22:04] want for themselves and

Speaker 3 [00:22:05] their families.

Speaker 4 [00:22:06] So people with dementia are just as broad as all of us.

Speaker 3 [00:22:10] There are some people that will push

Speaker 4 [00:22:12] for a medicine, and

Speaker 3 [00:22:13] there are some that are more cautious.

Speaker 4 [00:22:14] But who do you hear? You hear the people that the drug companies and the Alzheimer's Association, you know, pay literally to come to these hearings to give testimony

Speaker 3 [00:22:23] that favors them. It's not a balanced approach. We have to

Speaker 4 [00:22:26] hear the voices of people with dementia, but we can't assume that every voice of dementia is the
Speaker 3 [00:22:30] same voice and that the National Alzheimer's Association or anybody else is representing that field adequately.

Speaker 3 [00:22:37] And for either of you, really, what do you think the consequences are most practically?

Speaker 4 [00:22:42] So again, just speaking as a clinician, hope there's a lot of what people want from a doctor. They need hope. But the consequence of what the field has done is create false hope.

Speaker 4 [00:22:54] If you can say that somebody, as the Alzheimer's Association have said, we're going to have a cure if you just write a check by 2025, that's literally what they've said. And if they say, as they did in 2015, if we have this drug will save Medicare hundreds of billions of dollars, they've distorted hope.

Speaker 3 [00:23:07] will save Medicare hundreds of billions of dollars,

Speaker 3 [00:23:11] they've distorted hope.

Speaker 4 [00:23:13] They've said this.

Speaker 3 [00:23:14] We are your hope, give us money,

Speaker 4 [00:23:16] etc., etc. So what's lost? What's the downside to hope? What we really can do as individuals and as communities and as a society to address aging in a different way. Out of that comes more hope for people with dementia. And for all of us, if we stop dehumanizing people with dementia, we can rehumanize ourselves.

Speaker 2 [00:23:38] And if I can add another word to false hope
here, I think a loss of trust
to, you know, we've seen in the last decade, especially just broad lack of trust in American institutions, right? And the FDA has really damaged its credibility with this decision, but also with things like opioids in the 90s. There's a real sense that these regulatory agencies are not working for us. You know, the FDA gets a massive percentage of its operating budget from industry itself through user fees.
So I think when we look at this in the middle of a pandemic, when we've got major vaccine hesitancy at the broad population level, it's comprehensible when you think about the loss of faith and trust in the institutions that we have. This is going back even things like Iraq and bailing out the banks and Enron. And it's been a really bad couple of decades on that front. And I almost don't blame people for not trusting government bodies, regulatory agencies at this time. And I think the Ajit Khanabad story is one that's going to just further diminish people's trust in those institutions, which I find very regrettable because again, remembering the wisdom from the past requires us to look at public health and these institutions as being beneficial to
Speaker 3 [00:24:44] the collective. But they've been captured and co-opted in the past several decades.

Speaker 2 [00:24:46] So you guys are unique in that you don't just identify the problem and do some critical thinking about the status quo. But the two of you have articulated a vision and an approach for the future of health, not just treatment of dementia.

Speaker 3 [00:25:01] Could you describe some of the key features of that perspective as you see it?

Speaker 4 [00:25:07] I've been going first. A lot to get through executing.

Speaker 3 [00:25:14] Yes, sure. No. I was going to give Peter a chance just to show respect for my elders. But I know this is this is a part of this story. I'm happy to talk through. So I mean, if we look forward and you know, Peter is set up this helpful notion of what American dementia is for getting the wisdom of the past and not being able to look forward well. But if we did look forward with the wisdom of the past, you could imagine things like providing health care for everybody with 80 or 80 to 90 million people who are or underinsured in this country. Those are people who aren't getting front line care and specifically for things like the vascular risk factors that we've talked about, which are linked to brain health. We could, as people like Bernie Sanders and others have talked about for the past decade, we could make higher education tuition free. Right. And we could
Speaker 2 [00:25:55] provide free vocational training for people. Those are things that would measurably objectively benefit brain health in addition to having massive benefits across the population.

Speaker 3 [00:26:04] We could address the

Speaker 2 [00:26:05] stress and anxiety and depression that are also a part of this. The risk

Speaker 3 [00:26:09] factor for Alzheimer's syndrome, we could provide a

Speaker 2 [00:26:12] living wage, a job guarantee

Speaker 3 [00:26:14] for people. You've mentioned addiction,

Speaker 2 [00:26:16] Peter, and you know, one of the things I'm studying at Penn State is

Speaker 3 [00:26:18] deaths of despair. These extreme and troubling

Speaker 2 [00:26:21] rise in deaths from alcoholism, suicide and drug

Speaker 3 [00:26:24] overdose, and those have

Speaker 2 [00:26:25] gone up exponentially for the past

Speaker 3 [00:26:27] 20 years. And so the

Speaker 2 [00:26:29] despair and anxiety people are feeling in their lives, it's resulted in a loss of life expectancy in the country. I mean, we really need to address

Speaker 3 [00:26:36] those things and addressing them

Speaker 2 [00:26:37] would benefit

Speaker 3 [00:26:38] brain health. And then, of course, we mentioned and letting

Speaker 2 [00:26:40] gasoline in the

Speaker 3 [00:26:41] 1970s and 80s. But now

Speaker 2 [00:26:43] we have led in our

Speaker 3 [00:26:45] drinking water in Buffalo

Speaker 2 [00:26:47] and Cleveland and Flint

Speaker 3 [00:26:48] everywhere that you measure drinking water. There's lead and

Speaker 2 [00:26:52] infrastructural intervention to address. That would obviously be a major boon to brain health.

Speaker 3 [00:26:57] And then just on the care side in terms of the vision
Speaker 2 [00:26:59] that we have for a healthier society, I'll

Speaker 3 [00:27:01] just say national

Speaker 2 [00:27:02] long term care insurance is something that we could have in this country. You know, we spent eight trillion dollars in Iraq and Afghanistan over the last several decades. Why can't we pay for every citizen in this country to be guaranteed the right to long term care in an institution or in their homes, as they do in places like Japan?

Speaker 3 [00:27:18] And then lastly, the arts

Speaker 2 [00:27:20] in dementia care is something Peter and I have both

Speaker 3 [00:27:23] really observed

Speaker 2 [00:27:24] participated

Speaker 3 [00:27:25] in facilitated.

Speaker 2 [00:27:26] It's the most powerful and effective way of improving quality of life for people living with cognitive frailty and memory

Speaker 3 [00:27:32] loss is bringing

Speaker 2 [00:27:33] music, storytelling,

Speaker 3 [00:27:35] dance, intergenerational activities into these

Speaker 2 [00:27:38] sealed off kind of age, segregated spaces and just sort of revivifying them to improve people's

Speaker 3 [00:27:44] lives. Why aren't we funding those things?

Speaker 2 [00:27:46] Why are we throwing billions of dollars at the latest anti amyloid drug?

Speaker 3 [00:27:49] So that's what a

Speaker 2 [00:27:50] healthier society might look like.

Speaker 1 [00:27:52] You know, you guys aren't in

Speaker 3 [00:27:53] enough trouble already.

Speaker 1 [00:27:56] But but now you're going to talk social democracy.

Speaker 4 [00:28:00] Yes, we're not going to talk about them.

Speaker 1 [00:28:04] Oh, come on. They're the same, huh?

Speaker 3 [00:28:07] No. We're going to talk about the
importance of social work and social

play. We're going to
talk about whatever you
call it, the word social.

Looking back and looking currently at countries that have a focus on social programming, social networking, seeing them doing better. We also, though, look to the world and see, regardless of where you are, even in social democracies, even in communist countries, for God's sakes. Income inequity, capitalism in all of. Different forms, even the

form in China drives
towards more people having more money, and then if they get enough money, all of a sudden they're shooting rocket ships into space to occupy

another planet. Well, you

know, could you take some responsibility for the fact that your capitalist

behaviors led to

this planet being in the bad shape as it is? So it's not just a political system that Danny taught me. This, by the way, I think up got more words than he
does, but neoliberalism

is an important word for people not to avoid and to learn about, because it means that regardless of where

you are in the world, there's an

oligarchy.

There's a group of wealthy people who are essentially

controlling the narrative, and part of the narrative they're controlling

is pills for pain,
pills, for depression, pills, for dementia. And it's not the magic we need. We need the magic of community, not the magic of pills.

Yes, interesting. So I think this is a quote from your materials.

Inequality is a public health disaster.
Speaker 1 [00:29:35] You just spoke to that a little bit. I didn't know if you wanted to say more.

Speaker 2 [00:29:38] Yeah. When you look in the grand scope of human history, I mean, there have been some major disasters that

Speaker 3 [00:29:43] have happened, one being the advent of

Speaker 2 [00:29:44] agriculture around 12000 years

Speaker 3 [00:29:46] ago, which led to

Speaker 2 [00:29:47] sort of the reliance on mono crops and those being susceptible to disease and

Speaker 3 [00:29:52] crop failures, very much

Speaker 2 [00:29:53] limiting the

Speaker 3 [00:29:54] human diet in ways that haven't

Speaker 2 [00:29:55] benefited our species so much. We had

Speaker 3 [00:29:57] falling height.

Speaker 2 [00:29:58] You know, until basically until the social welfare states of the 20th century reversed that

Speaker 3 [00:30:02] and then crowding

Speaker 2 [00:30:03] in urban environments was another second disaster that

Speaker 3 [00:30:06] led to, you know, zoonosis

Speaker 2 [00:30:08] the crossing

Speaker 3 [00:30:09] of disease

Speaker 2 [00:30:10] over species boundaries, infectious diseases, those sorts of things. But then, yes, the last the

Speaker 3 [00:30:15] third major disaster

Speaker 2 [00:30:17] that we've had is inequality. And when you get agricultural

Speaker 3 [00:30:20] civilizations that sort of

Speaker 2 [00:30:22] depart from hunter gatherer civilizations that are more

Speaker 3 [00:30:25] egalitarian, you get disparities

Speaker 2 [00:30:27] in wealth and income, you get disproportionate
resources going upwards and you get a serf class that does the actual labor. And that has sort of, as Marx taught us, that's been the sort of defining mode of production that persists in our current era. And we have a chapter in the book that focuses on the fight for 15 movement. And we look at how inequality in our contemporary world plays itself out in terms of brain health. And if you're poor, you can't eat a Mediterranean and low sodium diet that we know is beneficial for brain health. You can't exercise, which we know increases neurotrophic growth factors and benefits the vascular system, et cetera. You have more exposure to air pollution, the lead to other environmental toxins that again damage the brain, create new inflammation, vascular injury engineers poor brain health in ways that are quite dramatic. There's been great studies that have come out that have actually looked at brain bank data and zip codes of people in those areas, and people who live in areas with a higher social vulnerability index have lower brain volume, lower hippocampal volume, higher abnormal proteins like plaques and tangles, and other features of this syndrome of Alzheimer's disease. So yeah, where we live, the class that we're in are major determinants of health of our brains over the course of our lives, and that is a major problem. You guys are not noted for sugarcoating things, and you have kind of gone as far to say that racism and classism raise the risk of dementia. Well, I think it's pretty
Speaker 3 [00:31:54] clear that if you look

Speaker 4 [00:31:56] across minority

Speaker 3 [00:31:57] populations or disadvantaged

Speaker 4 [00:32:00] populations, I mean, let's not get into an argument about whether it's race or class.

Speaker 3 [00:32:04] The fact is just builds on

Speaker 4 [00:32:05] what we were saying that there are issues that people face having to do with skin color and ethnic background and customs. And yes, that is our concern. The challenge that we

Speaker 3 [00:32:16] have as Danny,

Speaker 4 [00:32:17] sometimes as it hasn't said it yet. So I'll say it. We're not political scientists, we are spirited citizens and I'm going to use that expression because it's the message of our intergenerational school.

Speaker 3 [00:32:28] But yes, problems

Speaker 4 [00:32:29] are connected to everything else. And if I were to say one message of our book, it is exactly that. You cannot find a cure for Alzheimer's over here, a cure for adults

Speaker 3 [00:32:38] over here, an improvement

Speaker 4 [00:32:39] in whatever health parameter you want and not see them as

Speaker 3 [00:32:42] interrelated. And the

Speaker 4 [00:32:43] field of dementia thinks they have an infinite amount of money and they have been very successful

Speaker 3 [00:32:48] at getting money. Well, money doesn't

Speaker 4 [00:32:50] buy you happiness and it doesn't buy you a cure. The idea that

Speaker 3 [00:32:53] somehow we've got to think

Speaker 4 [00:32:55] about this differently and

Speaker 3 [00:32:57] education is key. We started three

Speaker 4 [00:32:59] public schools in Cleveland that are intergenerational public schools, where some of my patients went and work with kids, and Danny did his Ph.D. at Oxford

Speaker 3 [00:33:06] studying them. That's the kind
 Speaker 4 [00:33:08] of purpose and joy and passion that we need. The refined and education at all

 Speaker 3 [00:33:13] levels and the

 Speaker 4 [00:33:14] inclusive include people with cognitive challenges. Some of the greatest storytellers in our school where people with dementia because they can remember the stories from the past and share those with

 Speaker 3 [00:33:23] children whose eyes

 Speaker 4 [00:33:24] light up when they

 Speaker 3 [00:33:25] hear how people

 Speaker 4 [00:33:26] saved their nature centers in the 1960s

 Speaker 3 [00:33:29] and hopefully then

 Speaker 4 [00:33:30] figure out what they need to do to help preserve the health of their

 Speaker 3 [00:33:33] community and the future as well.

 Speaker 1 [00:33:35] Danny, did you want to jump? Been there.

 Speaker 2 [00:33:37] Yeah, sure, and I'll maybe politely disagree with my elder on this one. I do think part of the wisdom in looking back and seeing what happened in the 20th century and how effective it's been. All of the policies that we talked about better health care infrastructure

 Speaker 3 [00:33:50] in place, public health

 Speaker 2 [00:33:51] campaigns to

 Speaker 3 [00:33:52] reduce smoking, the GI Bill,

 Speaker 2 [00:33:54] people getting gasoline. Those things were framed in universalist terms.

 Speaker 3 [00:33:59] They weren't framed in particular as terms.

 Speaker 2 [00:34:01] In other words, you know, for one specific racial group. And I think looking forward, there is wisdom in that we can acknowledge that there is structural

 Speaker 3 [00:34:08] racism that has ram a fight over the many

 Speaker 2 [00:34:11] decades, of

 Speaker 3 [00:34:11] course. But if we want to get

 Speaker 2 [00:34:13] something like universal health care, if
Speaker 3 [00:34:14] we want to have jobs

Speaker 2 [00:34:16] guarantees and a living wage put in place as Martin Luther King talked about in his poor people’s campaign in the 60s, I think it is more beneficial to think in universalist

Speaker 3 [00:34:25] terms and in

Speaker 2 [00:34:26] terms of the working class writ large, because that is a

Speaker 3 [00:34:29] bigger, broader, more solid

Speaker 2 [00:34:31] or restrict political movement. And I'll say something controversial here. I think a lot of the hyper racialization of things

Speaker 3 [00:34:37] right now does serve the

Speaker 2 [00:34:38] purpose of capital because it does divide people along racial lines and prevents that sort of thick, solid touristic unification. It's going to be necessary to push back in any direction

Speaker 3 [00:34:49] on the sort of hegemony of

Speaker 2 [00:34:51] capitalism. And I know I sound like a young radical here, but I just think if we see it with clear eyes and

Speaker 3 [00:34:55] learn from what worked in the past, that's where we need to go

Speaker 4 [00:34:59] and still learning things from NPR.

Speaker 1 [00:35:02] Me too. All right. So we're getting close to the end of our time, but there is one thing that I want to ask you both to comment on, and I want to make sure that we get it in is.

Speaker 3 [00:35:12] So if nothing else, the

Speaker 1 [00:35:14] COVID 19 pandemic has really done a terrific job at

Speaker 3 [00:35:19] revealing all of the gaps

Speaker 1 [00:35:21] and cracks in political, social and economic systems, especially here in the US. And if we think about that as community, what makes for a dementia friendly community?

Speaker 4 [00:35:36] So I'll go back to Danny's universalist message. A dementia friendly community is a community that's friendly for everybody. Kids, older people, it says the AARP calls it a livable community. I don't like developing communities for particular populations of people. We create a community

Speaker 3 [00:35:55] where in that case,

Speaker 4 [00:35:57] people are aware of the
Speaker 3 [00:35:58] diversity of people,

Speaker 4 [00:36:00] the diversity of intellectual abilities. We're aware of that in daily life.

Speaker 3 [00:36:04] So, OK,

Speaker 4 [00:36:04] so there are two people that are in that community who, as they age, have had more cognitive challenges. But, you know, appreciation of diversity, whether it's a diversity of life forms or the diversity of cultural backgrounds or the diversity of intellectual abilities.

Speaker 3 [00:36:19] That's what we need. There will be a

Speaker 4 [00:36:20] friendly community for people with dementia and all of us.

Speaker 2 [00:36:23] I think that's a great message.

Speaker 3 [00:36:24] And if we think about like long term

Speaker 2 [00:36:26] care homes specifically, which were of course, ravaged by

Speaker 3 [00:36:29] COVID, especially

Speaker 2 [00:36:30] non-unionized homes, you know, how can we reform those spaces? And I think Intergenerational City is a really critical part of that to build on the universalist theme. They're intergenerational schools, as Peter talked about. But also there's like the co-location of

Speaker 3 [00:36:44] preschools in nursing homes and it's starting

Speaker 2 [00:36:47] to happen in the United

Speaker 3 [00:36:48] States and elsewhere. We have

Speaker 2 [00:36:50] intergenerational

Speaker 3 [00:36:51] housing approaches where

Speaker 2 [00:36:52] like in Cleveland, we have a institute for music, where

Speaker 3 [00:36:55] the students live

Speaker 2 [00:36:57] in the nursing homes for free in exchange for doing

Speaker 3 [00:36:59] concerts.

Speaker 2 [00:37:00] And I have a similar arrangement. Hopefully, post-COVID, with a nursing home here in my medical

Speaker 3 [00:37:05] students who will do
Speaker 2 [00:37:06] some of the arts based creative work at the long term care home in exchange for free room and board.

Speaker 3 [00:37:11] And so I think

Speaker 2 [00:37:13] dementia friendly community is one that's just sort of dissolves and destroys the boundaries, the arbitrary boundaries that we put between people across an

Speaker 3 [00:37:20] age spectrum and looks for opportunities

Speaker 2 [00:37:23] for rich, thick social relationships to form in place of the age segregation that we currently have. There's a lot of good energy happening there. There is a dementia friendly America movement afoot and an age friendly movement afoot that the UN has sort of

Speaker 3 [00:37:37] spearheaded and people

Speaker 2 [00:37:38] can search for those. And there's like trainings that people can do to be more sensitized to memory loss and be better supporters of people with memory loss.

Speaker 3 [00:37:46] But as Peter saying, what a healthier

Speaker 2 [00:37:47] society is, is one that's beneficial across the age spectrum for all of us.

Speaker 4 [00:37:51] And it's a community that has more social workers until they do such a great job that we don't need them anymore.

Speaker 1 [00:37:58] All right. That seems like a great spot to end. Dr. Peter Whitehouse, Dr. Daniel George. It was an absolute pleasure to speak with you both. I enjoyed it a lot. Thanks again for joining us.

Speaker 2 [00:38:08] Likewise, thanks for having us, Peter.

Speaker 1 [00:38:13] Thanks again to Drs. George and Whitehouse, the in social work podcast community is our charitable reward. Steve Sturman, Cate Bearss say Hi Cate. Hey, listeners. She's our graduate production assistant. Our guest booker. She prepares content and does all things technological. And I'm Peter Sobota. Follow us on Facebook and Twitter, and please check out our website, we worked hard on it, Steve, will be upset. Tell us what you would like us to do, what you would like us to explore or what you'd like to hear more about. We'll see you next time, everybody.