

## Ep80: Alzheimer's Disease – America's Healthcare Crisis

September 24, 2021

**PATTI BRENNAN:** Hi, everybody. Welcome to “The Patti Brennan Show.” This show is for those of you who want to protect, grow, and use your assets to live your very best lives.

Today, we're going to be having an important conversation about a disease that affects all of us. It's Alzheimer's. It's the impact of Alzheimer's not just on the individual themselves but the family and society as a whole and what can we do to arrest this awful disease once and for all.

Joining me today is Dr. Jason Karlawish. You guys, I am so excited to have Jason with us. This is just such an honor. I will tell you before we started airing, I said, “Jason, I will tell you I'm really intimidated. You're like a superstar in this field.”

“Really, I bow to you.” Jason has written an amazing book. It's called “The Problem of Alzheimer's – How Science, Culture, and Politics Turned a Rare Disease Into a Crisis and What We Can Do About It.” That's what I loved about this book. I read it over the weekend and last night.

If you're watching this, you're going to see that I have the book here with Post It notes all throughout. There was such good information, dating back, going through the history of the disease, the starts, and the stops, what we've discovered, things that don't work, and maybe a few things that could. Jason, thank you so much for joining us today.

**DR. JASON KARLAWISH:** You're so welcome, Patti. It's a pleasure to be on the show.

**PATTI:** By the way, everybody, you should hear Jason's pedigree. He's the professor of Medicine, Medical Ethics, and Health Policy and Neurology – Jason, I'm not sure how you're doing all this, but it's amazing – at University of Pennsylvania. He's also co-director of the Penn Memory Center. You can't get a better expert on this disease than Dr. Jason Karlawish.

**DR. KARLAWISH:** Thank you.

**PATTI:** With that, let's just start from the beginning. The question I have, that a lot of people



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have, is “What’s the difference between mild memory loss...” I understand that the first symptom of Alzheimer’s is memory loss.

I don’t know about anybody listening to the show, but there are a lot of times when I’m wondering, “Am I beginning to lose it here?” How do we differentiate between mild cognitive impairment, MCI, versus dementia versus Alzheimer’s?

DR. KARLAWISH: Let’s unpack that. Great question. Let’s start with the most basic question that is probably the most common question. What’s the difference between Alzheimer’s disease and dementia?

Simply put, dementia describes someone who has developed disabling cognitive impairments. They have trouble with memory, attention, concentration, multitasking, and those problems with those cognitive abilities are causing them to have disabilities, meaning troubles doing their daily tasks.

Early on, those troubles are things like managing money, deciding what restaurant to go to, traveling to the restaurant, getting the menu, picking what you want to order, and then paying the bill and calculating the tip. All those are cognitively intense tasks, and someone with dementia has trouble doing them. They need someone else to help them. That’s dementia, disabling cognitive impairments.

Alzheimer’s disease is a disease of the brain that causes dementia. It’s not the only disease of the brain that causes dementia. Another common disease of the brain that causes dementia is a disease called Lewy body disease. That’s what Robin Williams, the comic actor, had. He had Lewy body disease.

There’s another disease called frontotemporal lobar degeneration. Very different disease but in the end, the common problem, if you will, is dementia. That’s the difference between Alzheimer’s disease and dementia.

Alzheimer’s, a disease that causes dementia. You threw in mild cognitive impairment. What’s that? In the book, I recount the history of mild cognitive impairment. It’s a relatively recent concept. It’s only about 20 years old when that concept was premiered in the medical literature.

What mild cognitive impairment describes is an individual who has a cognitive impairment that’s causing inefficiencies in daily activities. They take longer to do things that they used to do, if you will, quicker. They may make a mistake, but then they catch it. That’s MCI. Just like dementia, a host of different diseases can cause mild cognitive impairment. One of those diseases is Alzheimer’s disease.

One of the points I make in the book is, once upon a time, you had to have dementia to



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be diagnosed with Alzheimer's. About the turn of the century, the advances in this idea of mild cognitive impairment began to allow someone to be diagnosed with Alzheimer's before they had dementia when they only had mild cognitive impairment.

Again, if you've got a label of mild cognitive impairment, that doesn't mean that you have Alzheimer's disease. The next question is, "What's causing my mild cognitive impairment?" It might be Alzheimer's. It might be another disease. It might frankly be some of the extremes of aging to go with a host of other things that can impair cognition.

MCI needs a workup if you will. That's the kind of thing we do when we see folks at the memory center here at the University of Pennsylvania.

**PATTI:** Do you find that MCI automatically progresses? Does it always get worse, or would it stabilize?

**DR. KARLAWISH:** No, it depends on the cause. In well-done studies of persons with mild cognitive impairment, depending on how they define it, etc., over time, depending on issues of definition and whatnot, about half develop further cognitive problems and develop dementia. That's because they have a disease.

The other half doesn't really change much. Some even revert. Again, it reflects that these are heterogeneous causes causing these problems. If there's one thing I would say to your listeners, if you're told somebody has dementia, it doesn't mean they have Alzheimer's. It means they have a disease.

It might be Alzheimer's. It might be Lewy body disease. It might be a vascular disease. Same thing with MCI. They may have a disease, but also given the subtleties of MCI, they may not have a disease. All the more reason to get those conditions worked up and not just simply go with the label.

**PATTI:** Jason, when you use the words worked up, how exactly is that done? One of the things that I didn't share with you is that, in my former life, I used to be an intensive care nurse. What we learned is that the only time that you really have a definitive diagnosis is on autopsy.

**DR. KARLAWISH:** A definitive diagnosis of Alzheimer's, you're right. Once upon a time and for a long time, that was how you could just tell someone that the cause of their dementia was Alzheimer's, which of course is somewhat ghoulish, because what you're essentially saying to the patient is, "Until you die, I won't be able to tell you definitively whether you have Alzheimer's or not," which means I won't be able to tell you, hence the ghoulish aspect of it.

That's because it's not until you get the brain of the individual and slice it up and look



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under the microscope can you see the characteristic pathologies that are seen with Alzheimer's. The advances though that have occurred – and I talk about this in the book – that is rather spectacular is that we can now visualize those pathologies in a living human being.

We can do brain scans, PET scans in particular, and also analyses of the spinal fluid that can visualize the pathologies that cause someone to develop dementia. That's a set of technologies that are available now but variably available for reasons largely related to the quality or lack of quality of our healthcare system when it comes to the diagnosis and care of older adults with cognitive problems.

PATTI: I would imagine that a lot of people would be reticent to get that diagnosis. I would think that they would be almost afraid, like, "Oh my goodness, I'm going to be labeled as having dementia. People are going to treat me differently."

DR. KARLAWISH: That's exactly right.

PATTI: What are your thoughts on that? Are there advantages, or is this thing just going to progress? It is what it is. You're going to have to figure it out, right?

DR. KARLAWISH: There are two things that we're talking about here, really. One of them is we are talking about stigma, stigma meaning a mark on someone. When other people know that mark, they treat that person differently. They separate from them. They distance from them. They stereotype them. Certainly, if there's any one disease that enjoys, sadly high octane stigma, it's Alzheimer's disease.

The reason why we care about stigma are many. Number one, the well-being of the person who's labeled. But number two, the issue you just raised is when a disease is haunted by stigma, people are reluctant to find out if they have the disease. They avoid the places where the disease is diagnosed. That's understandable. Stigma creates a sense of revulsion, distancing, etc.

Stigma's a very real problem in Alzheimer's because you've got patients, frankly, people out there who have problems but just won't get them worked up and refuse to have it worked up because of stigma. That's one problem right there.

Then the question is, how do we combat stigma? What can we do to do that? One way we do that is we have conversations like this. We raise awareness in the community. Read my book, dare I say. The more something is discussed and talked about, the less stigmatizing it is.

Having said that, though, there are real advantages to getting a diagnosis and to getting a diagnosis early. I think this is why you and I have come together in fact because some



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of the earliest problems with cognitive impairment, they're not troubles with bathing, dressing, grooming, and feeding, late-stage problems.

They're troubles doing very sophisticated cognitive tasks. What's one of those tasks? Managing your money...

PATTI: You bet you.

DR. KARLAWISH: ...paying your bills, all those things that require – what we call in my field – higher cortical function. Early on in this disease, they are impaired. The tragedy of patients who don't get a diagnosis early on, they have these impairments. They start making mistakes. They get defrauded. They lose money. It just becomes this disaster by the time they finally get worked up.

PATTI: Agreed. What I understand with Alzheimer's is, especially in the beginning, you can have good days and not-so-good days. That makes it even worse. It makes it even more difficult. If you're married to somebody, they're just not having a good day. Then you find out three months later that they made an investment in some random offshore thing, and all of your money is gone.

Those are very real stories. People need to understand that, the awareness. Just face these things because there are things that you can do to protect yourselves and help the person.

DR. KARLAWISH: Even if there's not a treatment, and there is a treatment out there now, which we can talk about. I think it's a very debatable and controversial treatment. Even before the FDA approved that drug, which will soon be available perhaps, even before that, there were real concrete things you can do. In the book, I talk about this.

The word I use is planning. They say, "What do you mean, planning? Whether I get on a ventilator or not, get CPR?" No, no. What I'm talking about is planning. I'll speak personally.

If I had cognitive problems, let's say I had MCI, I would want to have a plan in place that someone's watching over how things are going with my money, emphasis on the watching over, not managing it, not joint on all the accounts so they can defraud me but able to watch over and say, "You know what? Actually, you already paid that bill."

Or, "You've bought that thing twice," or, "Wait a minute. What's this purchase, a 20-year maturing security and you're 90 years old? [laughs] You're not going to see that mature in time, probably. So let's have a conversation."

The same thing around driving, you can pick a number of very important activities in daily life that you want a plan in place to monitor. If things are detected, someone can step in



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and help who you trust.

If you wait for a fire, you know you're going to burn some part of the house down. Instead, you can put in alarms and other systems that the place might not catch on fire. If it does, it'll get taken care of very quickly.

That's the model I think that has existed. Unfortunately, though, most family members don't have access to that kind of education, skill-building, because of the limitations of our healthcare system.

PATTI: It is so interesting because, as you were talking, I was thinking, "Boy, I hope my colleagues are listening to this podcast. I hope the financial advisers are out there."

DR. KARLAWISH: They should because they're on the frontline.

PATTI: Exactly, because we know our clients. We know what's normal for them and what's not normal. I will tell you it has come up. Someone will come into me and say, "Patti, I was just speaking with so and so. Something just didn't seem right."

Or, they've been asking for more distributions from their portfolio than ever before, or we'll get a call from the CPA, and the CPA will say, "This person has not filed their taxes. They're not giving me the information. Something's not right." It just raises that red flag to dig a little deeper.

DR. KARLAWISH: Let me speak personally, certainly, in my clinic. I recount them in my book, in my practice, but frankly, I'm going to be candid in my own family. I have witnessed just that the earliest signs and symptoms were things that the tax accountant and the investment manager were picking up.

I'll tell you my own personal story. Frankly, I finally called those folks. They're like, "Yeah, no, I've noticed stuff." I was on top of it early on because it's my gig. It's what I do.

PATTI: It's more than a gig.

DR. KARLAWISH: But I thought to myself, "How many other of your clients are doing this? You're just watching this happen." I thought, "Wow."

PATTI: It's very interesting what we do as a practice. Whenever we take on a client, the first thing that I do is have them sign a form that gives us permission to speak with someone in their family. We don't necessarily give them any personal information, etc., but a trusted person within their family if we notice something isn't quite right.



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DR. KARLAWISH: That is good practice.

PATTI: I want to get it up front while they're healthy, while they understand, and they're in agreement that that's probably the best thing to do. It's really we're just looking out for them.

We're looking out for their family whether it'd be financial damage or otherwise. As you said, some of these people should not be driving a car. That's really important for them to know that we care more about them than their money.

DR. KARLAWISH: The issue here, especially with this disease, is from diagnosis to death, it can last as long as 10 years, very variable. But let's set that aside. If we're talking about a chronic disease, we're talking about a disease which, early on, persons need help. As they get more disabled, they need more help.

In America, that means help that you get because you paid for it. The one thing you don't want to do is go into your retirement with a pile of cash, lose it because of fraud and other bad investments, and then go into developing worsening cognitive problems because then it's either the family or the state that has to step in and pay for the stuff that you could have paid for.

That's why this disease ramifies across families and into society because of the cost of the long-term care paid for mostly now by American families, but I think something that also needs to be addressed on a policy level, of course.

PATTI: It was so interesting that one story that you told in the book about the gentleman whose wife was diagnosed with Alzheimer's. He met with his advisers. His advisers basically gave him three alternatives.

Number one, you could put all of your assets into an irrevocable trust and lose control of that money forever. You're going to have to ask for a dollar to buy a newspaper. You can't do any of that yourself. You're going to have to ask a separate person, an independent person. It's an irrevocable loss of control. That was option number one.

Option number two was, hey, you could get a divorce. Divorce your spouse. That person will receive some of the assets and then eventually go through it, and then they will qualify for Medicaid.

By the way, that first option, which is the irrevocable trust, is a way to try to qualify for Medicaid. For anybody listening to this podcast, please understand the rules of your state and the fact that there is typically a five-year look back if you do attempt to pauperize yourself in this fashion.



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I will tell you, I'm going to come clean with all of you listening, I'm not a big fan of those things at all. Both of these things have a little bit of a moral ramification. It just walks that fine line. It's typically not in your best interest to do either as well. Option one, option two. Option three, of course, is just pay as you go and hope you don't run out of money.

DR. KARLAWISH: Just keep on paying until you hope you don't run out of money. That's what he chose to do, that guy. I remember him well, a husband. They managed to get through it with a lot of assets lost. In fact, she was an early onset case, that is to say, age of onset was before the age of 65, which is uncommon.

That family's faced a lot of strains related to loss of income for retirement as well as for support of adult children beginning careers, education, etc. This is why the disease ramifies into the American family because you've got savings that you need to do things like pay for your well-being in retirement, support the education of other family members, etc.

When that's hoovered up by the cost of long-term care, which can get into triple thousand digits depending on the severity of disability, for the average American family, that's a cost that can be, frankly, bankrupting or at least financially destabilizing.

Again, most Western nations, Germany, etc., have a long-term care social insurance program to minimize that risk upon the well-being of the families. We don't have that in this country. In this country, you just pay until you go, until you qualify for Medicaid, meaning you meet poverty thresholds. Then the state will step in and help out.

I don't think that that's acceptable. That's putting the American family in the front line of a risk that they shouldn't face with their finances and well-being.

PATTI: It's also really short-sighted too.

DR. KARLAWISH: As a society.

PATTI: You think about the cost of this disease and the impact on our economy and the impact on those families. You think, "Geez, if we could just cover it, the impact wouldn't be nearly as great."

DR. KARLAWISH: Exactly. That conversation is lost in policy-making circles. I totally agree. Long-term care social insurance will be expensive. It will require an additional payroll tax. Absolutely. The problem right now is that the American family is paying off the books.

I have family members who will tell you, "I cut back on work. I left the workforce. I didn't advance as far as I could have at work because I had to take care of my mother, my father,



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my husband.” Even folks who are retired will say, “Well, less assets to transfer to the next generation because we’re spending on this.”

It’s a hidden cost in the American economy. The standard complaint, oftentimes from one side of the aisle, is this will require raising taxes and cost billions and billions of dollars. I’m like we’re already spending the billions of dollars it’s costing our economy in terms of efficiency and productivity.

Why don’t we just be honest and face the problem like adults do, and say we’re going to have to ban together, put in a payroll tax, raise the funds, and provide that cushion of long-term care social insurance for the American family who needs it? Germany does it. Japan does it. France does it. For some reason, we just don’t want to do it as a country.

**PATTI:** It’s a very effective solution because it works. When you have social insurance, because private insurance, as you well know, is also out there, it is really, really expensive.

Most people can’t afford it and/or just when they get to the point where they’re ready to make a claim in their 70s or their 80s, the cost of it is skyrocketing, and they can’t afford to make the premium payments, so it lapses. That’s not working.

**DR. KARLAWISH:** Most of those policies only kick in when you’re really disabled. I look at some of the policies people have, and they’re like, “Oh, look at this. I’m covered.”

I’m like, “Well, yeah, but it only really is going to pay for a home health aide to help with bathing, dressing, grooming, and feeding, which is the last few years of the disease. Meanwhile, you’ve got about five or six years of needing supervision, an adult day activity program, etc., and none of those costs are covered by this policy.” A lot of policies are a lot of hats but not much cattle.

**PATTI:** It’s the question of is it hands-on care or standby care.

**DR. KARLAWISH:** It’s the standby care that you really need. For many of my family members, the care that they need until someone really as having trouble with mobility is I need someone around during the day. I can’t be there all the time.

That person’s going to be there to help that person live a day that’s safe, social, and engaged. That’s a very different role than someone who’s going to bathe, dress, groom, feed, and toilet someone.

Families struggle to find that kind of person. Again, I could tell you personally my family’s struggled to find someone. We finally did. The system isn’t in place to access that kind of person. I’m just again fortunate, given my expertise, that I knew what to look for and how to find it. I really pity the average American family who has to struggle with this disease.



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PATTI: I do too. It's really hard to watch. I think about the isolation. That stigma really carries on for the whole family, the spouse, etc. They become that much more isolated. A, they have to be there all the time to take care of that person, and other people aren't coming around as often.

So difficult, so very, very difficult. I really am interested to learn more about the concept of social insurance, and again, these problems – I'm going to be casual here – they drive me nuts because there is a solution. Come on.

We were talking about this again before we came on broadcast, and it's so interesting with COVID 19. You throw enough money at a problem. You can solve it. Look at where we are today.

I know that Alzheimer's is a much more complicated disease. If we come together as a nation and say, "OK, we don't know whether or not we're going to be directly affected by this, but if we are, there's going to be other Americans who are going to help us in the form of this social insurance that will help us provide the care that we need."

DR. KARLAWISH: COVID was a wake-up call that vast problems that ramify across society needs a united social approach. They're not problems that are solved by the grit of the individual. The grit of the individual is needed, but it's only part of the solution. You're right.

What are these problems? The word I use to describe them is they're humanitarian problems. They cut across disciplines, and they ramify outside of just the medical space. You have to approach humanitarian problems united and with a kind of top-down all-hands-on-deck approach. We did it with COVID, more or less. There were moments there where things got a little weird.

DR. KARLAWISH: We can do it with Alzheimer's disease. That is to say dementia. We just have to be united in that. I have hope. America has an Alzheimer's plan. It's not as well known unfortunately as it should be, but it has resulted in some progress, particularly in better understanding the biology of the disease and developing diagnostics and treatments.

Progress has been a little uneven on care, but it's better than what the alternative was, which was zero progress in that space.

PATTI: You've mentioned this Alzheimer's plan a couple of times. What exactly is it? I'm not familiar with it.

DR. KARLAWISH: Most Americans aren't, which is unfortunate because I think it leads to this sense of desperation that we're not doing anything. It's one of the variables that, unfortunately, led to the FDA decision to approve aducanumab, namely this sense of desperation.



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Around about 2011 or so, President Obama signed into law the National Alzheimer's Project Act. In the book, I recount the really brilliant efforts by the Alzheimer's Association to get this to come to law.

One of the strategic things though that was done was to not make it a big public blowout, to not have the president make a public announcement to a bicameral meeting of the Congress that we're going to take on Alzheimer's. A lot of that had to do with it's so hard to unite America and Washington around a problem, especially if they have to spend money, that the better way to do it was to do it quietly.

In summary, when Obama signed that into law to create the National Alzheimer's Project Act, he did it somewhere in Hawaii just about ready to go on his week-long vacation. You can't even find a photograph of him signing that into law.

Anyway, what the Project Act calls for is all federal agencies, departments that in some way involve the lives of persons with dementia need to unite together and put together an Alzheimer's plan. Every year, we revisit that plan as a nation. It's beginning to create some coherence around our approach to the disease.

I'll wrap up with the most impressive thing that's occurred was substantial increases in the NIH funding for Alzheimer's research, such that my colleagues and I now enjoy the ability to get our projects funded and also to train the next generation of researchers and clinicians to take on this problem.

Compared to the way things were five, six years ago, I'm very optimistic. It's all made possible by this National Alzheimer's Project Act, which again as you point out, I'm going to be self-promoting, but until people read my book, most people don't know about it because it just was never promoted.

PATTI:

It is so interesting. I did read about it in the book, and I was thinking, "Wow, where have I been? I never knew that that existed." I feel like it's a shame that it wasn't publicized. Again, it's only through transparency that we take away some of the stigma associated with the disease. It's out there. Let's not pretend that it isn't out there. Let's quantify the cost.

That's also part of this, Jason. We have to make it crystal clear how much money our economy is losing because of this disease. It is billions and billions of dollars. Again, the most recent example is COVID. There isn't one corporation. There isn't even one agency.

The University of Pennsylvania is not going to be able to solve this problem by itself. We need just a massive amount of energy, intellect, and money to attack this head-on.

DR. KARLAWISH: One of the problems about the cost of Alzheimer's disease, which is really better said as



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the cost of dementia to America is that it engages the politics of welfare because the way that you get to the triple-digit billion dollars per year cost of this disease is not the cost to the healthcare system, meaning the cost of drugs, scans, hospital visits, etc.

The way you get to the triple-digit billion dollars annual cost is if you take the work of a caregiver a daughter, a wife, a husband, occasionally a son, and you say, “How many hours a week did you spend giving care to your relative?” They give you that number. Then you say, “If that was a job, how much would you be paid to do it?”

Once you assign a wage to the labor of caregiving and you add up across all the caregivers doing caregiving, that’s the triple-digit billion dollar figure people talk about. The problem, of course, is that that engages the politics of welfare because that’s saying that the work of a caregiver is work that ought to be compensated and counted.

In America, there are some real differences about that. There are some people who think, “That’s just what families should do. That’s a family problem. We’re not going to deal with that problem,” or you have to be poor enough, and then we’ll finally step in and help you out to do that problem.

As long as that’s the conversation that you have, you’re unable to have an honest conversation of American workers are less productive and/or the American family’s savings are being taken up by this disease because you’re caught up in people saying, “That’s welfare issues. Welfare is socialism,” and all of the things.

You find yourself lost in this bizarre political conversation where helping people with Alzheimer’s and their families threatens socialism to America. You’re like, “Wait a minute. How did we arrive at this bizarre conversation that our liberty will be taken away by caring for people with dementia? Our liberty’s being taken away by Alzheimer’s disease, not by trying to help them.”

Yet socialism is this thing that we have to fear. I’m like, “This has nothing to do with socialism.” Yet that’s the conversation that we have. Until we break that rhetorical logjam...It’s almost darkly comic political conversation.

**PATTI:** It’s weird. That’s what it is. I cannot even believe that people could frame it in that way.

**DR. KARLAWISH:** That’s been the rhetoric though. The rhetoric since the ‘80s was...Actually, much of the rhetoric around expanding public welfare was sidetracked into conversations about socialism and the threats of a socialist takeover.

The American Medical Association opposed Medicare. Many politicians backed this because they feared if you have Medicare, that Medicare will lead to a Communist takeover of America. Ronald Reagan, at the time he was an actor in the 1960s, did a PSA record – at



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that time, it was actually a record – in a project that the AMA sponsored called Operation Coffee Cup.

I recount in the book how then actor Reagan was warning the AMA wives if Congress passes what would come to be called Medicare, that's going to lead to socialist takeover of America. You look at this. You have to laugh because it was bizarre.

Yet that was the conversation, and yet that same kind of conversation continues today. The opposition to many of the infrastructure improvements that are proposed in the infrastructure package is this will be socialism. I just shrug my shoulders and say, "But who's going to take care of these problems?" These are big problems. They can't be left to the American family to solve.

**PATTI:** It is so, so interesting. I've got your book in front of me, Jason. I'm reminded of this comparison that you made with solving polio and other comparisons. I'll just read this.

"We could basically do that for the Alzheimer's, colleagues chide me. Build more memory centers, nursing homes, and adult day activity centers. Noodle our way to better team-based care. Set our hospital cell phones to vibrate at night, or they insist, 'We could just cure this damn disease.'"

**DR. KARLAWISH:** They go to polio. They say, "Look at that. With polio, we could have built more iron lungs and everything else. Instead, we discovered the vaccine. Polio became a thing of the past," assuming, of course, someone who has the polio vaccine hidden in a vault doesn't release it and people get vaccinated, witness current problems with COVID.

Anyway, that we're going to drug our way out of this problem, make it like polio, a disease of the past, the problem with that is every bit of the science is showing us that the many diseases that cause dementia are just that. They're many different diseases.

Just like there are many routes to developing cancer depending on the organ, we certainly have made progress in cancer and heart disease with therapies. The notion that we'll never have any heart disease or cancer is just not rational policymaking to say, "That's how we'll solve the problem of cancer and heart disease."

That's the same thing, I think, with this disease. We absolutely should expect progress in developing effective therapeutics such that some people don't experience disabling dementia. Others experience it slower. But sadly, some still don't respond to the therapies. You can't get them, whatever it may be. That's how we have to think about this disease.

The idea of curing Alzheimer's, it's rhetorically powerful. It motivates people. There's no question, but I think we have to have a more rational approach that says, "How can we more effectively treat this disease?" Drugs are part of the solution, but they are not the



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only part of the solution.

**PATTI:** Since you brought up the drugs, I'd love to hear what you think about Biogen's drug and the controversy that is now surrounding it. What do you think?

**DR. KARLAWISH:** I think that the drug should still be available but only after a patient signs an informed consent form to enroll in a research study to finally establish, "Does this drug actually slow the progression of Alzheimer's disease?"

Unfortunately, FDA didn't see it that way and decided that, based on the data Biogen presented them, data that has yet to be published, that the FDA would grant Biogen the ability to sell the drug, although still requiring "a confirmatory study" to establish whether the drug in fact benefits patients.

They did this because they wanted the drug available because patients are desperate. Nothing else is available. I get the argument, but I think most in the field were a little aghast when they saw the FDA's decision because we were really making progress with this drug and other drugs to establish whether drugs like aducanumab change the natural history of the disease.

FDA went ahead and jumped the line and said, "Let's make it available but continue doing studies of it." Try and do a study of a drug like that when it's available commercially is a little difficult to do, plus it sets now an evidence bar that is lower for other drugs out there.

Many of us in the field were very frustrated. We really were making progress with drug discovery. Aducanumab actually may be effective, but the data that were out there don't really show that to the level that I think were necessary to prescribe it.

The FDA didn't see it that way, and now we have this mess. A drug is available with questionable data. At the same time, we still need to do studies to establish whether that drug is effective as well as other drugs that are like it. I think the field finds this an extremely frustrating situation.

**PATTI:** If I hear you right, what I'm hearing is that, because it is available to do a study, one group having the placebo and another group getting the drug, or however you're running these studies, you can't do it as effectively. Is that what you're saying?

**DR. KARLAWISH:** The patients with Alzheimer's shouldn't have to bear this cross, which is, "If you qualify for the drug based on severity, do you want to get the drug clinically, or would you want to enroll in a clinical trial that will help other people, and you may or may not get it?" I think making people make that choice is bizarre.



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PATTI: I see.

DR. KARLAWISH: The other problem, though, is you're putting out a drug that the FDA admits the evidence is, at best, provocative that it may actually alter disease course. FDA's argument was, "We can lower the standard of evidence because there's a regulatory mechanism in place for serious and life-threatening diseases, Alzheimer's is one of them, that allows a drug to be put into practice on the basis of a weaker standard of evidence."

I think many in the field felt the evidence here didn't even rise to that. More research was needed. I know you say, "Well, of course, a physician at the University of Pennsylvania would say more research is needed. That's what you guys and gals do."

My push back is no, no, no, I know what this disease is like. I have this disease going on right now in my family. Yet, for a big, vast, large as this, as complicated as it is, it was premature to put this drug out into the marketplace. It needed more study.

It's going to be difficult to do that study, and the FDA's new evidentiary standard threatens that drugs will be put into practice on the basis of evidence that can't let me confidently say to a patient, "This drug is worth its risks and its worth its costs." For many in the field, it's an extremely frustrating situation that we find ourselves in.

PATTI: Is it something that can be undone?

DR. KARLAWISH: Future drugs, we'll see. There's a drug, for example, that Eli Lilly has called Donanemab. Donanemab is a promising drug. We were all very excited about the data that were published in the "New England Journal of Medicine" in May of 2021.

Now, FDA's lowered the evidentiary standard. We're like, "Wait a minute. Does this mean you're not going to do the confirmatory trial we all really want to see, or are you going to let the trial happen, please?" That's where, I think, the field's a little worried right now.

Aducanumab, Donanemab, and Lecanemab, all these drugs that are showing promising signals are getting out there too damn quickly. That's a real problem to be able to study them and tell patients they're effective and to tell society they're worth the cost. These drugs are expensive, and a lot of people could take them.

PATTI: As I recall, I could be wrong on this Jason, but isn't it true that when Biogen first went to the FDA, when they did it at lower doses, and the FDA did not approve it. Then, later on, they bumped up the doses. They were trying to fool around with that, and that's when the FDA finally said, "OK, you can start."

DR. KARLAWISH: The relationship between FDA and Biogen around this drug is to be better understood. In fact, Janet Woodcock, the acting commissioner of the FDA has called for an Office of the



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Inspector General investigation to look at, more closely, the relationship between FDA employees and Biogen. We'll wait to see what that investigation shows.

The fact that she had to call for that raises real concerns about the nature of the relationship that FDA officials had with the company. They were close, but maybe too close is the concern.

Bottom line, the studies that Biogen did that led up to the data that are available had a lot of decisions made that were more driven by business than science – move things along quickly, get things done without spending a lot of money. I get the perspective of a company. I can't fault a company for doing what companies do.

On the other hand, it didn't serve the science as well as it could have. You're right, one of the issues was they leaped into phase III without really good data around dosing. They had to amend the protocol to change dosing regimens in the middle of the phase III studies, introducing variance and noise in the data.

The other thing they did was they threw a futility analysis into the study. You say, "Well, what the heck is that?" Basically, a futility analysis lets you decide whether there's no chance this study will work.

If that's the case, you just stop it and say, "I'm not going to keep this study going. It costs me money. Why should I spend money on something that has no chance of working within certain levels of probability based on how the analyses are conducted?"

Biogen did that. In fact, they did the futility analyses. The futility analyses said, "It's not going to work, likely," so they shut the study down. More data rolls in. They analyze that data. Guess what? It works in one study but not the other. What you're left with is like a forehead slap of, "This didn't have to happen. These were business decisions."

I'm pro drug. I'm alive because of drugs. Early in my life, I had a very bad illness, and I was saved. I have family members who are alive because of drugs, who are living well because of them. It's not about being pro or anti pharma. It's about being smart about how we use our pharma technology and businesses to develop drugs.

I think there's a lot of concern with the aducanumab decision that something's going awry at the FDA, and they're making decisions that no longer serve public health.

**PATTI:** In addition, or aside from the issue of drug treatments, what else can be done to improve the lives of people who have been diagnosed with dementia and/or Alzheimer's?

**DR. KARLAWISH:** First, let's get them diagnosed. First, we need to create a national network of centers for adult cognitive disorders where folks can go, get evaluated, and get an answer, which may



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be a diagnosis, may not be a diagnosis.

COVID has taught us that we can use telemedicine approaches for some of this, so we don't have to have a center in every urban area, but maybe there are ways to interconnect them. We need centers that can get people a diagnosis.

Then we need to begin to deliver the standard of care. No one should be diagnosed with dementia caused by Alzheimer's, Lewy body disease, whatever the disease may be, and not get education and training for how to identify the common problems, make a plan, and access the services and supports they need. We should do that.

Then back to your industry, we need to get your industry talking with my industry because you gals and guys are on the front line, oftentimes, of detecting things. How could we begin to learn from each other about what's going on with a client so that, rather than just waiting for the disaster, some effort can be made to intervene and talk? That's another area of progress.

More generally, technology holds a lot of possibilities for us to live better with this disease. One of the reasons why, in my family, I'm able to make sure things are OK with a family member is I have online view-only access to a variety of accounts. I can tell when there are problems going on or not. That's because of technology.

So too with the car, monitoring the location of the car. There's a host of ways that technology can allow us to maintain our independence in the community. These are all things we can do now. Everything I've described, we just have to muster the will to do it.

PATTI: I have a dear friend who is at MIT. They have the MIT Age Lab, and I'm on the board there. It's fascinating to me some of the things that MIT is coming up with to help people in these later stages of life, whether they have Alzheimer's or dementia or not – carpeting that can sense when someone has fallen. I think the whole area is so interesting.

To your point, we may not get a “cure” in our lifetime, but we sure can band together and find a better way of approaching this awful disease.

DR. KARLAWISH: Exactly.

PATTI: It's just got to be the American will, banding together and working together to figure out a solution and help to improve the lives of the patients and the families that are dealing with this.

DR. KARLAWISH: A big, vast, national problem requires us to reach back to some of our core values. United we stand, divided we fall. I know that sounds rhetorically cute, but we've lived through a period of time in recent history, recent time – it's not yet history because history has to be



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30 years old to be history...

PATTI: I didn't know that. That's interesting.

DR. KARLAWISH: Technically, what makes something history, it happened 30 years ago or more. Whatever, that's a convention in the field. We've lived through times where we seem to think that the way to advance is to divide. I think that this is the kind of disease where that's not a useful approach. It requires leadership.

PATTI: I agree with you. It's fine to debate. Sometimes, having opposing opinions, together you come up with, ultimately, a better solution. As long as we are focused on the solution, working together to come up with ideas and alternatives, that's the key.

DR. KARLAWISH: For example, a couple more solutions here while we're coming to the end here. We have to rethink the way we run residential long term care. No one wants to "live in a nursing home," but the fact of this disease is for many patients, there does come a point where home no longer works, the space that they called home for a variety of reasons.

I think it's just simply folly to think that all long-term care should be and can only be delivered in the home. Certainly, it should be and should be available. We also need to recognize there's a role for people to move to a residence, a place that they can now call home that's different than the home they were in.

The problem is it's a stereotype is the nursing home. Yeah, many of them are awful, but they're not awful by the nature of being residential long-term care. They're awful because we've never invested in the resources needed, and the regulations needed, and the ownership structures needed to create long term care facilities that actually deliver long-term care services and supports.

Again, that's another thing that can be solved right now. We just have to muster the will to do it. Many of the owners of nursing homes own them because they're great investments of property. They don't really care what the hell goes on inside of it.

Can you imagine if hospitals were run that way? I own this hospital because it's a great real estate investment. I'm trying to do everything I can to cut costs to continue to profit from that. That's the reality with nursing homes in America today. That's bizarre.

PATTI: It's really interesting. Wouldn't it be interesting if we approached this the same way we approach, as you say, hospitals or even schools? There are some pretty nice schools out there. Kids are learning.

It's a really interesting alternative approach. There was a part in your book where you discussed the concept of home. You said that home is where the heart is. I loved that



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comment. I loved that quote because it is so true. People with Alzheimer's and dementia, they don't really know where home is.

DR. KARLAWISH: They can begin to lose that. That's right.

PATTI: I will end with the one story that you told about Justice Sandra Day O'Connor. In fact, you can tell it if you'd like.

DR. KARLAWISH: Justice Sandra Day O'Connor's husband had Alzheimer's disease. He had dementia caused by Alzheimer's disease. The justice herself now recently announced, about a year or two ago, that she herself has Alzheimer's. She retired from the Supreme Court in order to care for her husband.

PATTI: There you go.

DR. KARLAWISH: Good example of the impact of Alzheimer's on the American family and our productivity. A Supreme Court justice stepped down in order to care for her husband.

There came a time in the course of his disease, not uncommon, sadly where he reached a stage of disability where home was no longer working. The home they were in, he was too disabled. He required too much intensive supervision and care that it just wasn't working anymore for Justice O'Connor and the family to do that at home.

They moved him to a new home, to what we would call a nursing home, a long-term care facility, an institutional setting. In that setting, he met another person, another patient, another resident. They developed a relationship. As that relationship developed, he became actually calmer and better accustomed to the environment.

Frankly, it was a private matter that became public because O'Connor is obviously a public figure. The family was willing to confirm that that indeed had happened and that they were letting it happen, that they were understanding that their father had found a relationship that was working for him in his new home that was going to let him live comfortably.

They did what I think is the right thing to do within the boundaries of coercion and other things. They let it happen as opposed to breaking them up and separating them and whatnot.

I tell that story not because I think it's a happy story or a sad story, but it's a story about life. Life is a mix of the happy and the sad. The sooner we see that that's what this disease presents, I think the sooner we're going to be able to live with it.

All disease is bad, by definition. If it wasn't bad, it wouldn't be a disease. This disease is



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uniquely bad. I think we have to be honest in the ways that we think we are best to live with it and not pretend that we can drug it away or ignore it or all the other approaches that are just not very productive approaches.

**PATTI:** Jason Karlawish, I don't know what to say. You have so exceeded my hopes and expectations for this podcast. I have learned so much today. I'm so grateful for your expertise and how you laid things out. I've learned so much. It gets my juices fired up to see what I can do personally to move these things forward. It's just one person and then another person and yet another.

**DR. KARLAWISH:** Thank you, Patti. It really means a lot to hear that from you.

**PATTI:** Grateful to you. We're both in Pennsylvania. I hope that we can keep in touch. I mean it when I tell you I'm happy to step in and help any way that I can.

**DR. KARLAWISH:** Thank you very much. That means a lot to me. I really appreciate that. Greetings to all your listeners. If people want to learn more about the book and my writing and the other work I do, they can visit my website, which is [jasonkarlawish.com](http://jasonkarlawish.com).

**PATTI:** I will tell you I'm holding up the book as we speak on this video. It is literally amazing, just chock full of information. It's also inspiring because there are solutions. There's no one better to lead that charge than Dr. Jason Karlawish.

**DR. KARLAWISH:** Thank you.

**PATTI:** Thank you so much for spending this time with me today and with all of our listeners. Thanks to you for tuning in. I hope this was helpful. If you have any questions, please go to our website at [keyfinancialinc.com](http://keyfinancialinc.com).

In the meantime, stay safe, stay healthy, and know there are people out there who are willing to help. Thanks so much for tuning in. Take care.



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