

Daughterhood the Podcast Episode 20: Dr. Jason Karlawish & The Problem of Alzheimer's

SUMMARY KEYWORDS

alzheimer, disease, dementia, people, caregiver, drug, book, recount, person, caregiving, individuals, support, hilda, studies, memory, care, stigma, called, progress, recognize

RESOURCES MENTIONED

AARP Global counsel on brain health - <https://www.aarp.org/health/brain-health/global-council-on-brain-health/>

Victor Frankl's Man's Search For Meaning

CMMS Centers for Medicare and Medicaid services - <https://www.cms.gov/>

Affordable Care Act - <https://www.healthcare.gov/>

Hilda Pridgeon - <https://thewomensalzheimersmovement.org/the-problem-of-alzheimers-book-excerpt-jason-karlawish/>

Bobbi Glaze - https://www.aberdeennews.com/watertown-couple-instrumental-in-starting-national-alzheimer-s-association/article_7fb10510-e241-5ce6-a945-f89c49373037.html?utm_medium=social&utm_source=facebook_Aberdeen_American_News&fbclid=IWAR2fG5KIFXZxjngroFgDwCP9mmEELyXomt9_laPWm6zs-q8vc3rVGpiF6Tk

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SPEAKERS

Rosanne, Dr Jason Karlawish

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Rosanne 00:44

Hello, and welcome to Daughterhood The Podcast I am your host Rosanne Corcoran Daughterhood circle leader and primary caregiver. Daughterhood is the creation of Anne Tumlinson who has worked on the frontlines in the healthcare field for many years and has seen the multitude of challenges caregivers face our mission is to support and build confidence in women who are managing their parents care. Daughter hood is what happens when we put our lives on hold to take care of our parents. We recognize this care is too much for one person to handle alone, we want to help you see your efforts are not only good enough, they are actually heroic. Our podcast goal is to bring you some insight into navigating the healthcare system, provide resources for you as a caregiver as well as for you as a person and help you know that you don't have to endure this on your own. Join me in Daughterhood. Jason Karlawish is a geriatrician, a writer, a professor of medicine, medical ethics and health policy and neurology at the University of Pennsylvania, and is co director of the Penn Memory Center where he cares for patients. I couldn't wait to speak to Dr. Karlawish about his compelling and eye opening new book, The Problem of Alzheimer's How Science, Culture and Politics Turned a Rare Disease Into a Crisis and What We Can Do About It. It answered so many of my questions regarding research, policy and how we got here. I hope you enjoy our conversation. In reading this book, the path that Alzheimer's takes and you start to see how it evolves. There were so many things that got in the way. And then when you look at the policy that's been against it, and how they viewed it as almost socialism, because you can't have the government helping you. And now here we are, all these years later, we're still struggling with that. Do you do you think that will ever change?

Dr Jason Karlawish 02:26

Yeah. So I think, you know, the, I hear what you're saying Roseanne, which is, you know, have we arrived at a turning point, to use a more political revolution that might have people recognize that, you know, we have a failure in this country to provide an essential piece of infrastructure to provide care. And it's possible, I think because it's not just an alignment of politics. It's also an alignment of culture, and science and practice. And I think science and practice is sort of there. Okay, I think we get what long term care services and supports are, you know, I think culture is I think there, and I think one of the big events that has pushed culture over, perhaps is COVID, because I think the events the last 12 months have woken us all up that how we're all at risk, where either risks to need care, or give care and COVID, then was this awful experiment of what if there's no system to help you provide care? Right, as I wrote, actually, in recent essay, in stat news, you know, COVID, has been this awful sort of awakening of what persons living with dementia their families have experienced for some 40 years. The third of access there, though, is political as politics is an alignment in the national political conversation that sees a way forward on this. And there I think things are much more dicey because essentially, you have a partisan divide that sees no middle ground and or common ground might be the better word here and one party that essentially frames any expansion of the role of government infrastructure as either a no go because it will require increasing revenues through taxation and or just a political non starter because it's deemed socialism and therefore has connotations of loss of liberty and takings and other kinds of things that are attached somewhat inappropriate is often I think, to turn Yes, of socialism. So maybe, but I don't know. Yeah.

Rosanne 04:26

Well, and, and I, I was struck by that 2009 meeting in the senate special committee with Sandra O'Connor. I was struck by that because everybody in the room was for it. Everybody. Everybody agreed that it was awful. We have to do something about this. We have to go forward. And by 2020, they wanted to have a cure. And here we are in 2021. And we're just not we're just not there. I was reading that was like a smack in the face.

Dr Jason Karlawish 04:56

Yeah, the events of the early 20th century. are interesting because by that point, you have bipartisan recognition that Alzheimer's is a problem. Slash dementia is a problem, because in part, many of the Congress, people are experiencing it personally. Susan Collins called call it a family disease. And she's essentially saying, you know, this runs in my family, you know, and the openness with which Congress people were willing to talk about Alzheimer's was very different, which is why, for example, I talked about how in 1990, Senator Hatch did not hatch hatch. Oregon, you know, brings the hearing room to a hush silence talking about his father's dementia. Anyway, everyone recognizes that it's a problem by partisan, there's general agreement, research really be a good thing. But then I think behind closed doors, everything falls apart in terms of what to do about it. And again, it gets wrapped up in the politics of welfare, no politics regarding taxation. And so yeah, it's no surprise that weren't just one, but multiple Alzheimer's breakthrough acts that just failed, because you just didn't have the political will to follow through on the sentiment, the progress and Alzheimer's has always been a story of uneven progress. So you know, let's take stock of some substantial progress that did occur in the 21st century, namely the passage of the national Alzheimer's project act. So now, AIDS cancer and Alzheimer's now are the three diseases that enjoy what are called bypass budgets. So unlike all the other appropriations to NIH appropriations to NIH, for cancer aid, and now Alzheimers since about 2011, are at the request of the NIH for the amount of funds that we need for these specific diseases. And you know, that started in cancer in 1972. Three, don't quote me, but the National Cancer act and AIDS, early 90s. So Alzheimer's is late to the game in that and I will say I, you know, I'm in the field as much as I'm outside the field looking in and in the field. Now, you do feel the wind in the sails now that there's that the funding. And so I'm cautiously optimistic that the research funding now, if it can stay a pace is is a pace, I think the challenge for the scientific community is building the infrastructure of investigators and related individuals to do the research. And that's a challenge. The second thing, though, that that I think remains is the political will to address the restructuring of the healthcare system. Yes. And there, I think the progress that's occurred has largely occurred because it's been under the political radar, namely Center for Medicare and Medicaid Services, CMS has initiated several innovative programs such as conference to primary care, the Affordable Care Act essentially hides within it, a lot of things also, namely cmms that have advanced it. But so progress there is slower, it's less, it's less obvious. But then that gets back to the troubled national conversation over this topic. It is interesting that the COVID relief package as best as one can tell, enjoys general support amongst the American public, regardless of their politics. So it does suggest that when America feels a need, it's willing to take it, it's just we have to find the or the ability of Washington to come together to meet that need.

Rosanne 08:11

And I think that also, you know, goes back to the culture of COVID, affecting the older people, so we don't have to worry about because

Dr Jason Karlawish 08:18

Right or in with Alzheimer's, it was it only fixed effects the old people are, of course, but even more importantly, and they'll always be a wife or mother in law to take care of everyone.

Rosanne 08:28

Right. Absolutely.

Dr Jason Karlawish 08:29

And so the story of Alzheimer's, as I point out in the book, particularly in the whole section, part two, birth of Alzheimer's is really a story of the American women and the and the struggle of America's women to assert and claim their self determination commensurate to what their male colleagues were. And you know, the idea of the of the role of a caregiver is incredibly contemporary, and caregiving has been around since the Bible when you know, Ruth cared for Naomi, you know, her mother in law. But Ruth wasn't called Naomi's mother in law, she just called her beautiful daughter in law. And the idea of being a caregiver only really appeared in the 1980s. And it's a way to sort of say that taking on this role isn't just simply a further extension of the role of mother, or wife. It's a distinct additional role that deserves recognition. And it got it has gotten wide recognition in the social science economics world and to a certain degree, the policymaking world. But that chapter has yet to be finished, in terms of providing long term care, social services and supports like most of her countries do

Rosanne 09:33

Well and you're absolutely right. It's the thought of well, it's your mother, of course, you're going to take care of her or it's your husband, or it's whoever it of

Dr Jason Karlawish 09:40

Of course it is, and that's right. And especially for a disease like this, you can understand why a family member is in the best position to provide carries. Well, what do you mean by that? Well, in a disease like this, the disabilities aren't simply, you know, I can't use my hands so I need someone else to carry things. I'll tell Don't want to carry where to carry it and how to carry it what color to say, Well, whatever someone will do that for you, a robot could do it in this disease, it's not just that my hands don't work, it's that I can't decide what my hands should carry. And because I'm having trouble self determining, and that's where you can understand why a family member is in a really good, morally appropriate position to provide the care because they understand the person and can read them. I'm not saying that a professional can't do that. But a family member certainly can. But that doesn't mean that the fair member has to bear the economic burden of doing that. And that's, I think that the the distinction that's been lost in much the conversation.

Rosanne 10:44

And because they think it's just family, it's just an extension of your caring, which it's so much more and as you say, we are they're an extension of their, their minds.

Dr Jason Karlawish 10:54

Yeah, that's exactly right. Yeah. So two points there. One is, we certainly expect parents to do a lot of things. But we also while we're at it, give them public schools to send their children to as opposed to

saying, you know, go find a good laptop and the zoom thing and find some people to teach your kids I'm joking, right? Yep, we have public schools, we have school buses to pick them up and take them to school, as opposed to you need to drive them to school. So therefore, you're gonna be late to work, you know, and I can run down the list, you know, we have coaches to run the teams rather than you. So you know, I'm not saying older adults with cognitive impairment are children. But for people in whom there are vulnerabilities, particularly cognitive vulnerabilities, society has seen a role of setting up a system to support them. Okay. What's the nature of the cognitive disabilities in persons living with dementia, as you point out, it is that they are disabled. And in some sense, the caregiver is like a cognitive wheelchair. In other words, it provides them that additional kind of extension of their mind, if you will, so that they can fully self determine, which again, highlights the moral importance of caregiving, and also, therefore the need to support caregivers, because it's a morally intense role. It's not just doing it's not just custodial work, you know, it's not just a building.

Rosanne 12:07

No, no, it's not. And it's interesting, because you mentioned, Hilda Pridgeon back in the 80s,

Dr Jason Karlawish 12:14

Hilda Pridgeon

Rosanne 12:15

Trying to get Medicare to cover Adult Day service for her husband and the Medicare man. And he said, What did he say? It's entertainment for him, and it's a vacation for you. And it's so startling to see it in that way, because that's how it's viewed, right? Trying to recalibrate that vision. And that perspective on what caregiving is, is part of the the challenge, I think,

12:40

yeah, well, that's a chapter a crisis in the family. That was a last casualties of the Cold War. Yeah, getting to know Hilda Pridgeon was one of the one of the more satisfying parts of writing this book, both researching her not a lot there, but you could find primary source stuff, or have the access to the archives of the Alzheimer's Association. And then I was able to find her son, her youngest son, Ryan, who was living with her, hers, the older siblings were out of the house by that when she was caring for their father, owl. And, and also, they had founded the organization that was sort of a model for the ultimate Association. Hilda Pridgeon was is a very, she's a hero, and she, I think, is an unrecognized hero. And if there's one mission in the book, it's essentially to bring out her story as an unrecognized hero. Namely, for her just determination, despite all the forces that said no, to change your system, namely, that you know, okay, I have to go to work because I need to bring in income because owl, my husband can't work. So I've got to do that. But on the other hand, Allen needs to be taken care of, so who's going to help me take care of them. And I think her play to the quote, man from Medicare in Minneapolis stands still stands today, which is I know, an adult day activity program is not a pill, but it's the best pill I've got right now for him. So why won't you pay for it? And you know, the response then was a little more blunt than it would be delivered now. But in some sense, it's still the same response that many are giving me now, which is, well, that's just entertainment for him and a vacation for you. So why are we going to pay for it? You know, unless you're poor enough, you know, you can't pay out of pocket in which case Medicaid would step in, but Medicaid is a vastly under resourced system, where

people wait in line to get the services and supports because it's still not provided as an entitlement. Long term care services and supports are not an entitlement Medicaid. So there's still vast structural inequities that exist that existed when Hilda Pridgeon pled to Congress, you know, people are afraid I'm afraid even more afraid than getting the disease we're afraid of having to take care of someone with the disease was what her plea was, and that was 1990.

Rosanne 14:47

Those women came out of that of there has to be something more for me and made the Alzheimer's Association

Dr Jason Karlawish 14:53

The Alzheimer's Association was essentially funded by women. Yes, Jerry Stone bankrolled it and he definitely was led but but for those women there would not be an Alzheimer's Association now. And they their organization, the Minnesota based organization, that was the model for the Alzheimer's Association. And again, I think Hilda Pridgeon and Bobby Glaze are unsung heroes and need to be recognized.

Rosanne 15:14

Absolutely agree. It's, it's shown that adult day services really do prevent placement because of that break for both the caregiver and and the person living with dementia.

Dr Jason Karlawish 15:25

Yeah, no, I was talking with a caregiver of one of my patients. Richard Bartholomew, I can't say his name publicly, because you know, he's, he's been interviewed on a podcast about the experience of caring for his wife, Julia Converse. And Mr. Bartholomew recounts how he looked back after his wife died just this past year, and said, you know, for much of her disease, I realized I never read a book. And the reason why he never read a book was he could never have the time alone, to read, because she was always sort of around, you know, he said, I'd go upstairs, get a pencil, and she'd follow me upstairs. That kind of preoccupation of time and task, and therefore attention is is all too common in the caregiving experience. And so it isn't just about a break. It's about literally, like, unnecessary support that someone needs.

Rosanne 16:15

No, and an absolutely isn't you Oh, you mentioned that the disease is a disease of autonomy, and for both for both the caregiver and the person living with dementia, because we become that extension, because we have to,

Dr Jason Karlawish 16:27

Yeah, that was a key breakthrough. I remember, as I was working on the book, and sort of thinking through the topics and the themes, I suppose baseplates, back up, maybe seven years ago, I had that revelation, that we have to think of this as a disease of autonomy. And that was really one of those moments where it was like a breakthrough about how to talk about this disease in a way that kind of finally captures what is it that's going on? And why is it a disease? I mean, to be sure it's a disease because people are disabled, you know, particularly later in the disease, physically disabled, you know,

semester dress, bathed, groom feed them, but that's the last third of the disease. Is that what it's what's up are the other two thirds and with the other two thirds, this loss of self determination, and you're right and then the next step is of course to realize is one caregiver told me never account in the book, you know, I have Alzheimer's is what he said. And what he was saying was effectively it because of what I have to do for my my wife, as a caregiver, essentially, I have Alzheimer's, that I'm as much wrapped up in the disease that she's wrapped up in the disease. Yeah.

Rosanne 17:29

Because we experienced the same social isolation. We experienced the same everything, because we're here with them.

Dr Jason Karlawish 17:36

Well, yeah, no, I mean, in that case, the I you know, he was there, the doctor's office, I mean, taking her to the doctor did give history for her visit to the doctor alone, then going back home and taking care of her. And you're right, even experiencing the sort of stigmas of the disease. You know, I've recounted the book help Ambassador Annenberg, former ambassador to the United Kingdom under Ronald Reagan recounts later how he doesn't want to see Ronald Reagan, he prefers to remember him as the vital fellow they used to know which candidate mission that he made to a reporter. And I thought that, you know, I quote that in the book as an example of public stigma. That's, that's a friend of Ronald Reagan, saying to the world, I don't want to see ronald reagan anymore, because I prefer to remember him as quote, a vigorous fellow. Well, what he's doing there is he is distancing himself from Reagan. But he also was effectively distancing self, I would assume, from Nancy Reagan, because of course, you know, she was with Ronald Reagan. And so what he's essentially saying is, I'm gonna see Ronald not only see Nancy, and many family members will tell you just that our friends sort of disappear.

Rosanne 18:39

Because it's hard. It's, it's hard, and nobody wants to really look at that, because it makes them feel bad, which I get. But it's still that person, you're still there, you were their friend at one point. And to think that that is lost, and it is, and I, you know, I've seen it, I've experienced it, it's sad.

Dr Jason Karlawish 18:58

Of course it's sad, all disease is bad. If it wasn't bad, it shouldn't be a disease. I agree. This is uniquely bad. But I think it's part of the sort of larger conversation of how as a society, we're going to talk about and think about what it's like to slowly lose your ability to self determine your life. And if you've got a culture that has metaphors and tropes of you know, death before death, and zombie and all these, well, you know, it, you're right, it becomes all the more horrible and horrifying. And you can see why people quote, one of the stay away, that's not to try and make it into unicorns and rainbows. But there it is to say, there might be a different way to have a conversation about this disease. And I, you know, basically the whole fourth part of the book, seeing as a humanitarian problem is kind of dedicated to just that task, which is how can we restructure, you know, medicine is going to do a lot for has done and will do a lot for us with this disease, medicine, diagnostics and therapeutics, but but there's a lot in society that needs to be done so that we can live well with this disease, whether it's this patient or as a caregiver,

Rosanne 20:01

absolutely. And I mean, sad from both from from a caregiver perspective to, to look and think nobody's coming. Nobody calls to even see how, for my mother, nobody even calls to see how she is. That's sad to me. For for to lose that type of relationship. And I think with with the stigma, I don't know if it would change the vernacular of everything. If we went from it's a memory Oh, I forgot, oh, I must have Alzheimer's, but it's not the whole thing. It's the complete and total annihilation of your self. And I don't know if that would help in trying to rein in the stigma or, or how to reorganize that. So that people really understand.

Dr Jason Karlawish 20:44

I would, I would frame it as it's really what this disease does is it recasts the self doesn't obliterated, recasts, you know, one of the points I try to bring out on the book is, in the chapter on the worlds we create it, which is one of the last penultimate chapters of the book, is that we need to start to see how persons living with dementia are capable of creativity. Yes, of course, we have to help them do that. But you know, I devote a fair amount of time to talking about efforts to try and organize and create spaces that allow persons living with dementia to flourish. And I'm critical about it, because I think we have to face some difficult issues about, you know, how do we decorate those spaces, you know, and I talk about the trends to decorate the spaces using the static designs that hearkened back to, you know, the way things looked in the 1940s or 50s, or whatever, I have problems with that, I think there's some grand act of deception going on there, in some sense, you know, like, setting up a library to be like, 1950, you know, in others, the other person, you know, the staff are sort of like, you know, we've created the sort of bizarre other worlds almost, but the point is, is that these are at least sincere efforts to create a space that allows people to flourish, I'm more supportive of efforts of and I recount the work of Van Bastille and what what's what's called creative care to sort of recognize the creative capacities of persons with dementia and recount in great detail the work that she and her colleagues have done to bring out the creativity of persons living with dementia, despite the obviously the fact that, you know, they lack cognitive abilities that they used to have, they're still capable of creative acts.

Rosanne 22:20

Right. You have to join them, you have to meet them where they are, and bring that out.

Dr Jason Karlawish 22:24

Yeah. And I think you know, I'd recount how I you know, the the classic one is the classic dilemma faced by many caregivers, caring for someone with advanced stage dementia is when they ask about a deceased relative, yes. Where's mom, one's mom coming home, like when mom is dead, for God knows how long 50 what do I want to do here? And, you know, the standard way that's framed, and personally, my own practice was, you know, whether to lie or not, you know, whether you say, oh, she'll be home about an hour, you know, and move on to something else, or confront them with the truth and say, you know, mother's been dead for 35 years, you know, and I think it ought to be a moral dilemma, that that decision, but when and does present as a third way, which is to say, Well, you know, if mom were here, what would we be doing with her right now? And to kind of work with it a yes. And question as opposed to a pirate, I'm going to say the truth, or I'm going to say a lie, but rather to say, you know, again, if mom were here, what we do, or wouldn't do so a person turns to their spouse and says, gee, we ought to get married, if we're going to be together so often like this. I mean, I've had that patients,

family members recount that as well, when we are married, well, where would we have the wedding? And what would we do? You know, it doesn't make it any, it doesn't make it better. But I think it gives an opportunity for at least some bi directional, let's work from what you've just said, rather than either endorse it and feel horrible, like, yeah, let's get married, or buy a lie or, you know, oftentimes confront some of the truth, which can be very disturbing. Having said that, you know, I think the truth is good to start with, and I and, you know, but again, for many families that said, it just causes repetitions, problems and distress and despair, like,

Rosanne 24:02

I was just gonna say, which is, which is great the first three times, and then at the point of the 15th, time, after three hours, you're you're just fried, you just, you're

Dr Jason Karlawish 24:14

And they're angry. Why didn't you tell me mother? You know, and yeah,

Rosanne 24:18

There's so many layers to this. And I think that's part of what the challenge is. It's not simply a broken leg, you know, you fix it, you go on your way. There's so many different parts that make this up, and you speak of keeping everyone safe, social and engaged ness. How do you do that?

Dr Jason Karlawish 24:35

Well, first of all, to recognize just that because if you think about it, say social and engage somewhat right about in the book, because some of the third part of the book called living well in the house of Alzheimer's, which is sort of an account of what we can do right now and might not have effective therapeutics, but there are things we can do right now. They're being done just not being done consistently and well enough throughout America. And you know, one of them is in the memory center, we really focus on how to put together helping patients persons living with dementia and their family members put together a day that safe social and engaged. I like that idea of safe social and engage. Because much like the sort of French Revolution idea of liberty, equality and fraternity, you can't have all three, you can't be a society that is fully exercises everyone's liberty, because you're going to have some compromise on equality and purity. And each one if you fully emphasize equality, you will cause some sacrifices to liberty. So, you know, if we think about it, we all strive to have a day that's safe, socially engaged, recognizing we can't be fully safe, because we'll never kind of take a risk we wouldn't get in a car because God no, no, gee, I really want to go outside, go go biking, you know, well, that's could be unsafe, you know, fully engaged. Well, you know, COVID taught us the risks there. I'm joking, you know, through about that, but but my point is, is that we put together a day that balances those considerations, and we do it just implicitly, almost in our daily lives. But in someone living with dementia, it becomes a very explicit act on the part of the caregiver to think about what will be a date of safe, social engaged. And again, the memory center, we spent a lot of time you know, both helping people think about that conceptually. And then applying it now to your particular daily life in terms of where do you live? What's this home? Like? What are the deficits and disabilities, what kind of assistance is needed, what sort of resources are available, and out of that you sort of create this day that safe social engaged,

Rosanne 26:22

And I love that, and when you talk about it in the book, The the memory center, can you tell me about that,

Dr Jason Karlawish 26:28

You know, it's you, we could debate the specifics of the way we structure a visit. And I've talked with colleagues and there's variation and how they organize things. But any decent well run memory center recognizes you need to have some ability to get history information from someone else other than the patient. And here's where some colleagues differ, some get it together with the patient, they have them in the same room, at least they have enough chairs for the many find that it's useful to give people separate space privacy, I tend towards the we tend towards the latter favoring the separate space privacy, both for the person as well as for the family member of it's not just about the family member, but it's also about the person and the course that that adds to time that makes the visit longer. Sure. It also requires frankly, more chairs and a little more space, I'm not joking. And in some busy practices, there's just not enough room, you know, in the in the book, The the chapter a correction and discernment. You know, the efforts of Peggy Knoll, a physician in in Asheville, North Carolina, struggling to set up just that kind of space, you know, and they just wouldn't pay for it, she finally turned it into a not for profit and said I'm gonna do it on my own. And then the key is also then the bringing together at the end of the visits to sort of have a mutual understanding about what we've witnessed, and what we've learned. And I find that a very revelatory moment in my practice, on the regulatory moment, meaning, you know, I've gotten each person's perspective on what's up, and I sort of engaged in kind of a saying back, if you will, of what's been discovered, and I find it regulatory for both people. Because oftentimes, for example, I devote a lot of effort to solicit eliciting from the person with the cognitive problems, their awareness of their cognitive problems. And I think, especially for individuals who come to a memory center, you tend to find that they're very aware of their problems. And I think for the family members, my showing that my displaying now I'll say, I know that you were telling me Ms Corcoran that, you know, you're you've got a memory problem, and it bothers you, but what, but not that much, but what really bothers you is how you think it's upsetting your son so much, right? And the son will be like, wow, I never knew that. She thought that, you know, and it's this moment of sort of revelation, or also sometimes it's like, you know, I noticed Ms Corcoran, and you don't really feel you remember, I mean, you're only here because your son made you come here. Right. And and, you know, but but basically, you're doing fine. It's a sort of like, yeah, you know, that's what we've noticed, you know, so so it's a very useful exercise. It's talk intensive, I will say.

Rosanne 28:53

It sounds it you talk about having a business model, Alzheimers needs a business model. And if

Dr Jason Karlawish 28:58

It does not have a business model

Rosanne 29:00

And when you said that, I was like, yes, because there's not a here, we're going to give you this drug, and this drug is going to work. And we're going to make whatever off of this. So it's hard to get a doctor to say, yeah, this is what this is. And then you have to go to the neurologist, which is months and

months and months that you're waiting. And you've referenced a couple times in the book that it takes eight months to get into see you.

Dr Jason Karlawish 29:21

Yeah, and he also so you know, the line in the book that I think is many people picked up on it certainly provocative is you know, if disease doesn't fully exist in America until it has a business model. Correct. And I think some people will find that a cynical statement. I think it's a very real statement which is, you know, I think we saw it played out in COVID. So during the COVID pandemic, the hospitals were full of the gills, and yet they were losing money hand over foot, you think well no, wait a minute, wait a minute, Whoa, what's going on here? The hospitals are full and yet they're losing money. That's true. For a while the OR's were shut down although the OR's got back in gear. Well, what it showed though, was just that how dependent and the American healthcare system is on certain kinds of procedures, certain kinds of activity. In the cross observations that occur to support that. And so in a system, which is very reliant on a procedure based world, a disease like dementia, which is very talk intensive, and time intensive, is just not going to make money. So it doesn't have a business model. So you're not going to see memory centers all throughout healthcare systems, you're not going to see Adult Day activity programs, part of healthcare systems. So I'll develop that in a minute. But still, without a business model disease doesn't fully flourish in America. And so physicians don't go into it to pursue it, because you know, where's the money? It's not the doctors go into medicine to make money. But I mean, no, they are economic actors. And so you have this memory centers like ours exists, because we are very research intensive, and we cross subsidize as well with philanthropy. You know, all of our caregiving services and supports are made possible by a generous gift from Eli Kaplan. Without his deaf, we couldn't do that, wow. Because if White on billing to recover it, we just we'd have to close down in a month. And so that's why the typical patient comes to our memory Center has a month, if not year long story of going from doctor to doctor trying to get a clear answer about what's going on and never getting a clear answer. And, and I understand why. Because, you know, they're just not equipped. And even if they're equipped to do it, you know, oftentimes zone of the time to do it. And so it's just, it's just kind of a it's it is a tragedy, because it didn't have to be this way.

Rosanne 31:25

No, but how can that? How can we fix aside from getting doctors to go into geriatrics instead of critical care? I mean, how do we fix that?

Dr Jason Karlawish 31:34

Well, you know, I think I don't want to sound too much like an American who always turns to technology to provide the fix. But I do think the events of the last four months have taught us that there are some very quick easy fixes. So you could think about a network of dementia centers where the hub and spoke type tech method allows for greater access to diagnostic services and supports and the events of the last year have shown us that we can do telemedicine, you know, we do need better access to broadband, in all the more shows the best part of our essential infrastructure and not some luxury. But you know, when our memory center pivoted to telemedicine, we certainly gave up a certain amount of data gathering, particularly cognitive testing, but it did a lot, we were still able to gather and conduct our visits. And you could imagine a hub and spoke system, which makes that possible. Now, there's still some structural things that have to be addressed there. For example, we're not allowed to do new

patient visits for persons who are from out of state, because there's all the state licensure laws for metaphor, if you're, you know, go back to 19th century guilds, like behave. But But you know, but for COVID, I mean, I wouldn't even be having this conversation now about the possibilities to telemedicine accepted a very kind of, well, yes, maybe someday, but someday has now arrived. Absolutely. And what a gift that would be, you know, trying to get out of the house sometimes is a bit of a challenge. So, there's a question for my follow up patients to telemedicine visits, particularly the folks who are pretty disabled have been a boon, you know, that? There's no question and frankly, I hope to continue for people who have more advanced stage disease, sure. Periodic in person visits, sure. But the need to sort of come all the way to the memory center for every single visit, I think is just unnecessary at this point.

Rosanne 33:09

Agreed. Now, with that same timeframe of trying to get into see a doctor and trying to get an MRI and trying to get the results with the drugs that we hear. And even the drugs that are in the pipeline, their focus is on early detection, if you know that you have some sort of mild cognitive impairment early, these drugs may help you Well, it's kind of running uphill, because you're trying to get in to get a diagnosis and you can't get in to get a diagnosis. By the time you get the diagnosis. You can't use the drugs but the drugs don't work any like it's

Dr Jason Karlawish 33:38

There's irony in that your right the current, many of the therapies that are being studied Now, none of which are yet available. The one might be approved by FDA soon a drug manufactured by a company called Biogen and the drug is called aducanumab but they study a narrow window of individuals given the severity of their illness. And, and so it does create sort of a, you know, a Goldilocks moment of you know, you're just right for this drug. I think if those drugs begin to be approved, and used, there'll be a rapid sort of additional studies to assess their benefits beyond their narrow window of study. But it'll be a rough couple of years to figure that out. I do have Yeah, a whole, the whole actually first part of the book, Alzheimers unbound is just about is about just this, namely the biomarker redefinition of the disease in an effort to label people as early as possible, even before disabling cognitive impairments. And I do think that in principle that makes a lot of sense. I mean, why wait till you have metastatic cancer to diagnose cancer? Why wait to have a crushing retrosternal chest pain and a transmural EMI before you diagnose heart disease. On the other hand, we just have to accept though that when you start pushing diagnoses very early in the disease course, you have to make decisions about you know, how much and how often for how many people otherwise you subject you know, millions to unnecessary tests and treatments for for long periods of time. So, you know, in principle, it makes sense to diagnose early and treat early, but that will present its own set of challenges. And that's existed across a host of diseases or at breast cancer. For men, when they get a lot gruffy prostate cancer and cardiovascular disease when and how and when to treat it and pressure, elevated pressure, high lipids, I think what's unique about this disease is the stigmas that surround dementia, you know, with disabling kind of impairments spill over to the Alzheimer's label, even if you're not demented. And I point that out in the book of someone who had only mild cognitive impairment, because they will Alzheimers, how much she was crushed by the stigmas of Alzheimer's as well as her daughter.

Rosanne 35:42

Right. And it's, it's hard because in that whole transition, do you want to know, do you not want to know? Should you try? I don't know, it's, it's that constant. If there was a test, and you know, you're doing PET scans for amyloid plaque. And if there was a test, do you want to know that? And you also talk about that you screen people on how they take bad news? Because, I mean, I see it every day, in the different groups online, of if I ever get this, I'm just going to drive off a bridge. And it's, it's like, what do you do? How do you go forward? It's

Dr Jason Karlawish 36:18

Yeah, I think this is part of the cultural conversation that, you know, runs through the book, which is the ways we think about and talk about or don't talk about Alzheimer's disease and dementia influence the way people feel about it. You know, you're right, in the early days, and we're still in the early days of biomarker tests for amyloid plaque and tau tangle, particularly for individuals who are barely impaired or not impaired at all, I think one has to be very careful about why is it you want to learn this test result? And what will you do with it? Most of it's done in the context of research. But you know, once it started, those tests start to enter clinical practice, you know, I think we'll start to be forced to do a national conversation about what it's like to live with a label, when anyone that would meet students think I don't think there's anything wrong with this person, because in fact, there isn't anything wrong with them, except they have a pathophysiology. And he has a very important point. I mean, you know, and I think we should look to some other diseases for sort of both hope and also caution, so and hope you, you can look to cancer, I mean, once upon a time saying I had cancer was to also embrace prickly, stigmatizing label. And of course, that's changed. Now. I think people are very open about talking about that. And in part, I think that's because of treatments that, you know, at least gave the appearance that we can do something, if not, in the last several decades, actual progress and doing something right. Um, but on the other hand, you know, we've made progress in treating depression. And and you could argue we've made progress in treating schizophrenia, and yet those conditions still have a stigma surrounding them as well. And so I think we'll be in for a tough conversation of are we ready? And how can we become more ready to talk about having the risk of developing disabling cognitive impairments in a way that doesn't lead people to be stigmatized and ostracized, that's going to be a challenge for us in our society,

Rosanne 38:01

Especially in a society that doesn't like to age or talk about aging. And then add this on top of you may or may not get it.

Dr Jason Karlawish 38:09

Yeah, that's what I'm going to say, you know, I don't care what one's politics are right now. But I was very bothered that I'm one of the campaign themes used by the opponents of President have now President than candidate Biden was should explicitly try to link him with dementia, Joe Biden, the the dementia and Democrat, you know, and other very explicit just, I thought plainly offensive ads and slogans and messages that explicitly tempted to say, if you said, you know, Joseph Biden is demented, or the White House, you know, what did was one I saw, President Trump retweeted it and where there was a joke that Biden will turn the White House into an assisted living facilities. I mean, I just like I don't care what you think of Biden, and how much you are Trump, that is just unacceptable. political rhetoric.

I hear what side you're on. I am would be I'd be saying the same thing. If the Biden camp had turned around and done the same thing with Trump,

Rosanne 39:09

Right. Agreed, because it only adds to that ongoing stigma.

Dr Jason Karlawish 39:13

Yeah, absolutely.

Rosanne 39:14

Now, I've heard of the Lily's got what is it donanemab

Dr Jason Karlawish 39:18

Yup Lily has drug called donanemab.

Rosanne 39:21

Yes.

Dr Jason Karlawish 39:21

It's an anti amyloid drug Yeah.

Rosanne 39:24

And do you see a progress in that or do you what do you see going forward?

Dr Jason Karlawish 39:29

Well, I think we should expect going forward overall, is that we will begin to have drugs that make a dent in the trajectory of cognitive decline. So right now, someone diagnosed with dementia caused by Alzheimer's lives, the natural history of decline of the disease and by natural history, I mean, essentially the disease uninterrupted by a pharmacologic, therapeutic, okay. And I think that we should anticipate in the coming several years that will be therapies that a physician can prescribe that change that natural history, they don't revert it, they don't halt it, I think there'll be a lot of variability. Some people may have very notable responses, others may not have responses at all, or be able to tolerate the therapies because of side effects, because the drugs do have side effects. So I think the message that I think most reasonable colleagues agree on is we're not going to drug our way into this complicated problem. But we will have drugs that make a dent in the Natural History of the disease. And the drug you mentioned, produced by Lilly still has to go through a very large next phase of study. But to date, the data, they presented our data that say just what I said, No dent in the natural history, I think what's interesting about the approach that Luke that Lily took with their drug was they didn't simply require the subjects to have evidence of elevated amyloid based on PET scans, but they also require them to have evidence of a key, just enough accumulation of tau one of the other pathologic hallmarks of neurodegenerative disease to be eligible to get the drug. So what they were really further, what they were doing was further redefining the disease, based on this drug biomarker interaction, if you have the certain combination of biomarker result, you get this drug, and there starts to be a looping effect there between the drugs benefit, therefore, these tests are needed to be done so that you can get the drug.

And so I think what we're going to start to see is how drug therapies will start to redefine the disease, redefine sort of who has the druggable form of the disease, if you will, none of this is meant as a criticism. It's just simply an observation of what a future would be like when the diseases at least partially druggable for some individuals,

Rosanne 41:34

right. And you mentioned, it's like the different types of cancer, the different there's just different treatment for different cancers. It's the same idea. Yeah. Go ahead.

Dr Jason Karlawish 41:43

I think that the word of choice in the Alzheimer's field now is heterogeneity. You know, the more we study all summertime disease, the more some will say, well, it's really Alzheimer's diseases in the plural, namely, a variety of different pathologies have been at work that contributed more or less to the death of neurons, and the pace of the death of neurons. So again, there may be some individuals who, for some therapies, it's like, some cancers, like it truly became a thing of the past and or a chronic disease, and but there will be something to do with them. There's just no therapy, they respond to or despite therapy still get worse. I think that's a reasonable way to think about a future at least for the next several decades, I would think, yeah.

Rosanne 42:26

Do you think they can speed up the pipeline from start to finish instead of 12-15 years? It's a little

Dr Jason Karlawish 42:32

Um, in fact one of the problems with some of the drugs is that the pipeline has sped up too fast. I think, one of the controversies that surrounds the drug aducanumab, which is before the FDA as we speak, is they skipped phase two testing. So they skip the phase of testing that would have given them more dose information. And so they put together two phase three studies that had two different doses versus placebo. And, and then also, I did an interim futility analysis to also speed up and looking at the data, frankly, so that they didn't make to continue to trial when it wasn't working meetings, meaning spending money, anyway, all these decisions, to get things done quickly. And or cut losses quickly led to a data set now, which is extraordinarily controversial. And it's a really big, big problem.

Rosanne 43:20

Now, what would you advise for prevention? I mean, for those of us that are caring, and we look at this, and we're like, we don't sleep

Dr Jason Karlawish 43:26

For all of us,

Rosanne 43:27

Yes for all of us.

Dr Jason Karlawish 43:28

You know I open up the last part of the book, I came in the part for a humanitarian problem with with actually a chapter called somethings must be working. Because the point I make there is at some of the dark moments in the contemporary history of the disease, when at international meeting, you'll all be hearing yet more than negative drugs, study results, etc. We still are getting back a consistent set of findings from a large well done decades long studies, which were showing in populations in the United States and in other countries that since about the 1970s, onward, the risk of developing dementia has been declining. He said, Well, wait a minute, I thought there were a whole lot of people, there are a whole lot of people because there are a lot of older adults. So therefore, given the age is a chief risk factor. If you've got a lot of older adults, you're gonna have a lot of individuals with dementia, we just don't have as many as we thought we did. So what you're left with is a very interesting thing, which is right here in 2021. We have data from well done studies, multiple well done studies from multiple countries that show reduced risk of developing dementia. Okay, but we don't have any effective treatments for the common causes of dementia and no effective treatment for Alzheimer's disease or Lewy Body disease or Parkinson's disease. Phil will know what's going on here. And the answer is a host of things that we've done that look like they preserve brain health, that they make the brain healthier against the onslaught of pathologies, a lot of it has to do with I think two things, access and opportunity. So early on in life, what we've done Certainly shown us that individuals who have at least 12 years of formal education, basically get out of high school seem to have greater resistance to less likelihood of developing dementia than individuals who don't, there's still plenty of PhDs who get dementia. It's just it's there's a protective aspect to that. And that's been known for a while. I mean, early studies in China, when people who are essentially functionally illiterate showed a strong relationship between illiteracy and developing dementia amongst studies done in China back in the 70s, in the 80s, but after that, it becomes an interesting story across the lifespan of access and opportunity, namely, individuals who had consistent access to health care, particularly cardiovascular health care, had a reduced risk of developing dementia in America up until the Affordable Care Act that meant, you know, having a job and because health insurance was tied to employment and certain kinds of employment at that. And so what you see is this consistent story of cardiovascular health, the lifestyles that surround a healthy cardiovascular lifestyle, education, all have worked to reduce the risk of developing dementia across a variety of developed nations. So those are things that we can do right now. And just to wrap up, I mean, the AARP global Council on brain health, which I'm a member of has done a spectacular job, I think, putting together a variety of materials that summarize the kind of lifestyles that have been associated with brain health, as well as the lifestyles that have been overhyped, that's associated with brain health. So it's the global Council on brain health put out by the American Association of retired persons, I highly recommend it.

Rosanne 46:29

I will look that up. And what do you how do you, you know, caregiver, I watch Wheel of Fortune every night, how do you feel about Prevagen and Focus Factor and all of those types of

Dr Jason Karlawish 46:40

Take the money in you go buy 10 copies of my book, expensive and you can buy about 10 copies of my book, okay. I'm good. Go read that book, because it'll give those copies because people will be grateful. And you'll have engaged social relations, then you have a book club. we've all read my book, and and you've got a social event. So you've done cognitively and socially engaging activity. Yeah, now

it's the FDA is rules around non drug base, but nutraceutical based compounds only require lack of evidence of harm. And the claims of benefit cannot mention a disease. And so you're pretty much less than you can market something for memory. As long as you don't say a disease, you can get away with it. And so we implicate, you know, and many of those companies have skirted the bounds of appropriateness and had one company got big fine for selling their, their brain games with a bit too much emphasis on diseases. It's unfortunate, and I tell people, especially the various pills, save your money and have a good time. You know,

Rosanne 47:45

You got into this because of your grandfather's experience. Yes. And the lady in the tower, and I already feel that you're going at this from personal experience, now that you're caring for your uncle, do you see the difference? Or do you take what you've seen from your patients and bring into your caregiving for him? Or has that brought new things to you?

Dr Jason Karlawish 48:08

Absolutely. I really appreciate how caregiving is about both is a merging of cells, but also a very orchestrated, conducted presentation of the truth in the timing of it. And yeah, no, I it's it's it's not just, you know, task. It's a it's a it's a very, it's a very morally elaborate orchestra.

Rosanne 48:33

It's a dance with a little improv thrown in.

Dr Jason Karlawish 48:36

Yeah, I would resist the dance metaphor is dance is ultimately is certainly highly cognitive. I mean, the arranging the motions of the body crossing midline, things like that are incredible, both aspects of cognition and balance. But this is more like, I guess it might be more like poetry because I think poetry is a little more cognitive than dance, no offense to dance men, but it's more like poetry or, or, or music, I guess, might be the other one where you're really trying to orchestrate as opposed to just dictate.

Rosanne 49:07

You know, it's so - things get so combined. As a caregiver, I'm upside down. You know, my mom's up all night sleeps all day, when you look at this, and I think, oh, my goodness, I'm not sleeping, and that's going to, that's going to affect my health. It's almost like we're caring. And we're hoping that we can make it through the caregiving and not damage ourselves.

Dr Jason Karlawish 49:27

Yeah.

Rosanne 49:27

Does that make sense?

Dr Jason Karlawish 49:29

Well, yeah, no, I mean, I in the book, I recount in the last section, Part Four humanitarian problem, how caregivers are leading living an existential dilemma. And this was taught to me by a caregiver, which is

they're trying to both do everything they possibly can for the relative and at the same time, lead their life and you can't do both, and you just have to see it as a dilemma. And once you see something as a dilemma, you stop trying to get rid of it, because you can't, you can't do both. You have to make compromises. You have to make decisions, it's interesting a lot of caregivers will independently have arrived. They finally found solace and made sense of it all by reading Victor Frankel's Man's Search for Meaning. Yeah. And, you know, Frankel's book was based on his experience living in a concentration camp during the Second World War, and witnessing people's struggle to stay alive under circumstances that were, they had no control. And it's very interesting. Many of them say, Oh, yeah, I read that book to you, right?

Rosanne 50:32

Well, because and that's the thing that happened during COVID people got a little taste of I can't go out. And we live that can't go out have to try to figure out how we're getting out.

Dr Jason Karlawish 50:42

Yes Covid was a total wake up call to America, you want to know what dementia is? Like? Look back at the last year.

Rosanne 50:47

Yes. Are you hopeful looking forward?

Dr Jason Karlawish 50:50

Yes, I am. I'm hopeful that we've had tremendous progress in understanding the biology of the disease. And I recount that in the book, you know, chapters like the Olympics of pharmacokinetics, and whatnot, or Olympics of pharmacodynamics, I should say, tremendous progress in understanding the pathology in the last 20 years, beginnings of progress in therapeutics that I think are encouraging. And I do think the events the last year have really woken us up to the need for care and caregiving. And you know, to go the political climate that seems open to recognizing that, that, as Ronald Reagan joked, you know, the nine most scariest words in the English language are I'm from the government, I'm here to help. I think many of us recognize that. That probably gay isn't funny and B is not true that actually I'm here from the government. I'm here to help. Certainly has a resonance of truth to it. And maybe going forward, we can listen to that.

Rosanne 51:39

A big thank you to Dr. Karlawish for being my guest today. If you would like more information about him, check out his website at JasonKarlawish.com. I hope you enjoyed our podcast today, head over to Daughterhood.org and click on the podcast section for show notes, including the full transcript and links to any resources and information from today's episode. You can also find us on the Whole Care Network, as well as anywhere you listen to your podcasts. We are also on Facebook, Twitter, and Instagram at Daughterhood The Podcast. Feel free to leave me a message and let me know what issues you may be facing and would like to hear more about or even if you just want to say hi, I'd love to hear from you. Also a very special thank you to Susan Rowe for our theme music, the instrumental version of her beautiful song Mama's Eyes, from her album Lessons In Love that you can find on the

iTunes Store. I hope you found what you were looking for today, information, inspiration, or even just a little company. This is Rosanne Corcoran. I hope you join me next time in Daughterhood.