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Meaningful Lives As We Age

Benefits of An Early Diagnosis
Applications from the GSA KAER Toolkit for Brain Health
Momentum Discussions Podcast from the Gerontological Society of America
Recorded August 2025



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Guests:
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Doctors with Dementia Group
National Council of Dementia Minds



Joanna Fix, PhD
Former college professor and psychologist

Announcer:
Welcome to the Gerontological Society of America's Momentum Discussion, where we explore groundbreaking topics in the field of aging.

Jen Pettis:
Welcome to this GSA Momentum Discussions podcast episode titled Benefits of an Early Diagnosis, the first in a series of three podcast episodes developed by the Gerontological Society of America (GSA) in collaboration with the National Council of Dementia Minds, the first national 501(c)(3) organization founded and governed by people living with dementia. We're grateful to Eisai, Genentech, Lilly, and Otsuka for their support of the GSA KAER Toolkit for Brain Health and this three-part podcast series. My name is Jen Pettis, and I'm the Director of Strategic Alliances at GSA, and I'm pleased to serve as a host for today's Momentum Discussion.

Today's episode takes on a vitally important topic: how receiving a timely diagnosis of dementia can empower individuals to take control of their health, plan for the future, and live with purpose and dignity. I'm joined by three remarkable guests who are members of the National Council of Dementia Minds. Steven A. Barbieri is an advocate living with dementia and President of the National Council of Dementia Minds. Steven worked for Wells Fargo Bank for 32 years, serving as the Vice President and district manager and is an accomplished martial artist inducted into the elite Black Belt Hall of Fame.

Dr. Joanna Fix is a former college professor with a PhD in psychology. Joanna is a vocal advocate for changing the narrative around Alzheimer's, sharing her experiences to promote awareness and support for those living with the disease.

Dr. David Compton is a retired family physician, a member of the Doctors with Dementia Group at the National Council of Dementia Minds. David is an outspoken advocate for people living with dementia, emphasizing the need to abolish the stigma surrounding cognitive diseases and treat them with the same urgency as other serious illnesses.

Steven, Joanna, and David, welcome and thank you for joining me today.

Joanna, I'd like to begin with you. You were just 48 years old when you were diagnosed with Alzheimer's disease. At an age when most people wouldn't even consider dementia as a possibility, what led you to seek an evaluation, and how did the diagnosis process unfold?

Dr. Joanna Fix:
That's a great question. What led me to seek an evaluation was that I was having executive functioning issues and extreme fatigue as early as five years before my diagnosis. Actually, even before that. The five or four and a half years before my diagnosis is when I was asked to early retire. I'm putting that nicely. A few years before that, I really was experiencing my first symptoms, which had an impact on my ability to function, activities of daily living, and which were impacting my work. I think the second part of that was, How did the diagnosis process unfold? It was a painstaking, arduous process, as you could imagine in my forties. My parents don't have it. It does run in both sides of my family, but I didn't learn that until after my diagnosis, when everything came out.

We didn't discuss that while growing up with our grandparents, aunts, and uncles, who had experienced those things. I went through a painstaking, arduous process of ruling out everything that it could be at my age. They were pretty sure it was MS, but I didn't have any O bands in my spinal fluid.

It took numerous specialists. I had brain imaging, finally a PET scan with something called FBG in the IV lit up my brain like a Christmas tree. David knows what I'm talking about because this is his bailiwick. They said, "You have dementia, and it's the Alzheimer's type of dementia, and this is how we know." I thought, wow, that would've been helpful years ago when we were ruling out all the other stuff. They had actually suspected that and had written that in my radiology reports, which none of the neurologists ever shared with me because they were worried I would not be able to get insurance or employment. That ship had sailed.

Jen Pettis:
Thanks for sharing so much. My goodness. What a journey. It's really interesting that was in your record, but no one shared that with you. That's incredible.

Dr. Joanna Fix:
Interesting and painful.

Jen Pettis:
Troubling. So much of your story there goes back to one of the things David is so passionate about, and that's the stigma. You said you didn't talk about your grandparents, not having that discussion until after you disclosed your diagnosis.

Dr. Joanna Fix:
They were grumpy. We just assumed this was part of old age. I thought, I'm grumpy too. I was a grumpy teenager.

Jen Pettis:
David, as a family physician, you had the clinical background to recognize something wasn't quite right. What prompted you to take the first steps toward diagnosis, and how did obtaining that diagnosis unfold?

Dr. David Compton:
What is interesting is that you have that clinical background to know it, but when it's happening to you, you can't see it. I was having trouble with executive function as well, slowing down in the ability to see patients. Everything was taking much longer. I wasn't sure why. I was being treated for a rather interesting depression, which seems to be associated with this diagnosis as well. The workups are overly convoluted and marred by the stigma of a narrative in our physicians' workforce, which I've been speaking to for years. I'm trying to elevate this thought process in the differentials of individual physicians. Ultimately, it comes down to having a truly effective therapist. I was working with the depression that I recognized was just more than depression.

My wife could pick it up, and a partner I worked with was starting to say, hey, there's a little bit more here. I was sent to Vanderbilt for a 'fitness to practice' evaluation, which they said I couldn't. They were still confused by that. They mentioned that some aspects of my day-long neural cognitive testing were slightly off, so I may want to consider consulting a neurologist. You go through this really long story, you're seeing the wrong neurologist, and you don't want to see your colleagues, but this was somebody I knew. Eventually, I was able to get in with a neurologist, whom I now see, specializing in this area. I was able to get a diagnosis of mild cognitive impairment after imaging and workups. It is a very painful, confusing course on the front end. For everyone I've talked to, it's way too confusing. I know in the medical community, they're still shrouded in the stigma of a narrative that's not correct.

I'm a big believer that the earlier the diagnosis, the better, with anything, whether it be cancer or anything.

Jen Pettis:
How long did that process take for you, David, to get that diagnosis?

Dr. David Compton:
Not as long as some people. It took about two and a half years.

Jen Pettis:
Still a long time.

Dr. David Compton:
I was fortunate to be in the right place, surrounded by the right people, at the right time. Even then, it's so agonizing to be told that you can't quite finish the career you want to finish. You find a way.

Jen Pettis:
Thank you for sharing that. Steven, I understand that you were diagnosed with chronic traumatic encephalopathy (CTE) in 2011. Can you describe the initial signs or events that made you realize you needed to seek care, and then the journey you went on?

Steven Barbieri:
I'm married. I've been married for about 30 years. At the time, this was about 15 years ago, when I was diagnosed. The hard thing was that I wasn't seeing the signs. My wife and I were getting into a lot of arguments, which all boiled down to her asking me to do something and me not doing it. That just sounds like a typical husband, though. The final straw was that I was leaving for work, and my wife, a schoolteacher at the time, asked, "Are you going to be in town today?" Can you pick up the girls from school? I must have told her yes. She went to work, and I went to work, but then I drove two hours out of town to a meeting.

At three o'clock, when the girls were supposed to get picked up, my wife was the first name on the contact list. They called my wife, saying, "Your girls are here." Is somebody on their way to pick them up? My husband's probably running late. Let me call to find out where he's at. She called me, and I said, "Honey, I'm in Fresno," which is two hours away. She said, "You said you'd pick up the girls today!" I said, "No, I don't think so. I'm pretty sure I probably told you I was leaving for a meeting out of town." That was like the final straw. She said, "I'm having your hearing tested." I had my hearing tested. My hearing was fine. I just had a little problem with my left ear.

When you go to a hearing test, not all the machines are in one room. In one room, I completed a few tests, and then they escorted me to another room down the hall, which had several turns, for further testing. When I was done there, they asked me to just go back to the room. They found me in the hallway because I couldn't remember how to get back to the room, which was my first time there. Then, they also noticed that when they were asking me for the hearing test, I kept having to ask him to repeat things, "I'm sorry, what am I supposed to do? I'm sorry, what were those instructions again?" I kept having to repeat things. From there, they contacted my primary care physician and informed him that my hearing was slightly off, but they didn't think that was the main issue and they recommended some cognitive testing. And that's how it started, with cognitive testing.

Like David and Joanne have also said, it's a grueling process because it's very rare that they hit the nail on the head on the very first try when it comes to what type of dementia.
The difficulty arose because they started when I visited a neurologist, the specialist you ideally want to consult, not your primary care physician. You really want to get a referral to see a neurologist. The neurologist did some primary testing, and they first came up with mild cognitive impairment (MCI). They said it could be a lot of stress from your job, everything. I'm like, okay. Then I asked if there was any additional testing we could do.

I came back a few months later, and she did some additional testing. She says, “You know what? I think you actually might just have pseudodementia." I said, "I'm not familiar with pseudodementia." She says pseudodementia is caused by stress and low levels of certain vitamins, like vitamin D, some magnesium, and other things. They thought that if it were pseudodementia, this could be corrected. We help you escape the stressful situation. I thought it was strange because I work out regularly, take vitamins, and do all these things. I asked, is there some additional testing, like scanning, we can do? Again, you have to be your own best advocate. The next thing they did was some additional testing, which led them to think it was frontal temporal lobe dementia, because they did a PET scan.

In the PET scan, they found damage on both sides of my temporal lobe, which they just assumed was frontal temporal lobe dementia. They started treating me for that. It just didn't sound right. They did some additional testing, and they thought maybe it was Alzheimer's. No. The problem was that they never took the time to ask me about my lifestyle. Steven, what do you do for fun? What have you done in the past? Tell me a little bit about yourself. Finally, they sent me to an eight-hour neuropsychologist. The person says, “Steven, I want to get to know you.” He put his folder down and said, “Tell me about yourself. What do you do for fun? Tell me about your background. What did you do growing up?”

The conversation gradually got to martial arts. I've been practicing martial arts all of my life, since I was 16 years old. I got hit in the head, had lots of fights, and had concussions. “Concussions? What other things?” I got hit by a car, hit my head on a diving board. All these things started making more sense, you know. Within 20 minutes, he determined it was your classic case of CTE dementia. From then on, they took the time to explain what was happening. But if I hadn't done the eight-hour testing, they still wouldn't have figured out what it was. That's what they finally landed on as the CTE dementia.

There's a movie that came out with Will Smith called 'Concussion'. I think it was in 2012 with football players. I thought this was a great movie. I'm not familiar with CTE. I'm taking my wife and three young children, who're in their teens, to this movie. Really, not to blow the story, but all the football players in the movies killed themselves through suicide because one of the major side effects of CTE dementia is suicidal tendency. I have to be very careful about any type of medication I take, related to suicidal tendencies. It was one step, followed by more steps. The biggest thing is you just have to keep pushing the neurologists. When they use the word dementia, you have to ask them what type. It's important to ask those additional questions, be your own best advocate.

Jen Pettis:
Steven, how long did it take you to get that diagnosis?

Steven Barbieri:
I think it was just close to a year. The reason mine seemed a little bit quicker is that I kept pushing and asking those questions. When they used the word dementia, I said, “That's like telling somebody they have cancer. You're telling me I have dementia. What type of dementia do I have?"

That's what prompted them to conduct all these additional tests. Had I not prompted them or asked those questions, I'm not sure if I would've gotten those additional tests at that time.

Jen Pettis:
Thank you all for sharing a bit about your story. Now, let's shift gears and discuss why it's so important that a diagnosis occurs earlier for people. Joanna, let's start with you. How can receiving that earlier diagnosis have a positive impact on relationships with family and friends?

Dr. Joanna Fix:
I can only dream of what it would've been like to not go through four and a half, five years of feeling like I was being perceived as a malingerer. I think that after my diagnosis, I printed off paperwork, I begged for copies of the radiology report and the doctor's notes and sent them to my family because it really did impact my parents and my brothers very negatively. Not having a diagnosis, not knowing why I was having these issues. It was stressful for everybody.

When you understand what you're dealing with, you can then move forward. When you don't know what you're dealing with, you're stuck. It's like being stuck in a red light; it never turns green. You're just sitting there for what feels like eternity. When my neurologist sat down on the day I got the diagnosis, it was unequivocal that this is clinical, here's your proof. You don't need more second opinions. It was my ninth neurologist.

He gave me the answer that me and my family had been seeking. He gave me a definitive diagnosis. He gave me what I needed to move forward. I feel truly blessed to have both a local and a global community to connect with and receive support from. We're all educators here. We continue to advocate.

As Steven said, we have to be our own best advocate. We have to bolster each other. There's nothing quite like meeting other people with dementia. I say all of my friends, all of the people that I love the most, other than my husband, either have dementia or they work in the field, or they care for a family member. It's a real special thing to realize that I went from being isolated, feeling like I was on a completely different planet during those years preceding getting my diagnosis, because you don't have work anymore, you're acting crazy (at least I was) to all of a sudden, I've got more friends than I've ever had in my life. I've got a fantastic support system. I have a really good life. If Alzheimer's was the price I had to pay to have this really good life, I'm not really that upset about it.

Jen Pettis:
David, how about thinking about navigating changes in work life and social activities? What are some ways an early diagnosis can help with that?

Dr. David Compton:
An early and proper diagnosis of any condition is important. I just want to say that first. This is true of conditions like diabetes, heart disease, and cancer. Everything changes. Your work changes, or how you work, or if you can work. Routines need to change. Relationships have to be reevaluated. The financial impacts are there. The long-term health care needs to be examined. You have to change your lifestyle and work with your medications. Anything you have to do to improve cognition, ensure that any underlying conditions, such as sleep apnea or hypertension, are being treated. Ensure the lipids are treated and developed as part of a routine activity. These are the steps that need to be taken to navigate this. It's an interesting course that you have to go through to reach that point.

I was fortunate to have some good support people around me. I was able to join a support group earlier, when we actually set up a support group specifically for people living with it in the greater Knoxville area back in 2018. That continues to meet in two or three areas.
It's critical to find other people with it, talking to them about their life experiences, and how they navigate this illness. Cognitive issues can manifest in various ways. One story won't be the same for someone else, but it's beneficial to communicate with others about this diagnosis.

Jen Pettis:
Steven, having been in the banking industry, I bet you have a unique perspective on the financial and legal benefits of getting that diagnosis sooner rather than later.

Steven Barbieri:
The benefit is that if you're younger, as Joanna mentioned, being diagnosed at an early age is beneficial. She was 48, I believe, and I was 51 and still working. The benefit of still working is being eligible for long-term disability. I was able to put in a claim, and they're paying me my check until I reach 67. They're now paying me my paycheck for 16 years. The benefit of that is I tell people I paid with after-tax dollars, so my check is now tax-free.

I always remind people around November, when open enrollment is available at work, to sign up for long-term disability. It's important to note that this differs from long-term care, as they don't actually send you the check. They send it to the nursing home, the doctor, or the physician. When I receive long-term disability benefits, I get a check, and then I can use the money as I see fit. I'm always on social media, always blasting reminders around November when open enrollment is approaching at the workplace. Make sure you sign up for your work's long-term disability because often there's no medical testing that you have to do, and it covers anything. You could skateboard and fall off the curb. You could be skiing or doing something else that hurts your back. I was very blessed I had that.

The sad thing is, I've talked to other people who had long-term disability at their work, but they did not get their diagnosis. They were going through the process as if they were being let go from work due to their numerous mistakes. Or, in some cases, a couple of my friends were actually fired. Some other people actually quietly retired. When they finally got their diagnosis several years later, then they went, Oh my God, I have that long-term disability, I could go back and put in a claim. I know a sad story of one of my friends who missed his deadline by two weeks to have put in a filing for his long-term disability. He'd already been away from his work. They basically told him to leave because he was making too many mistakes. It's important to get that early diagnosis because if you have long-term disability, short-term disability, or if you're still working, you qualify for permanent disability through your state at the same time. It's important to do that push, but, as I said, for many of us, it takes sometimes years. We always have to push for that. Okay, you've completed this test, but you don't have your answers yet. What's the next test?

Jen Pettis:
Great insights. Thank you. Joanna, do you know of any resources that become more accessible when a person is diagnosed early?

Dr. Joanna Fix:
I have the Home Community-Based Services, Elderly, Blind, and Disabled waiver. That means my spouse gets paid 40 hours a week to be my full-time care partner, which I prefer to use rather than the term caregiver. What precluded that was my getting social security disability.

Now you can imagine that, almost at the five-year mark, you have a certain amount of credit you've paid into the system when you're employed. When you're sitting there waiting for answers or trying to function, trying to manage your life, that time eventually runs out.
I was six months away from running out of being eligible after being turned down, actually three times, for social security disability, not having that diagnosis until the last six months, when it went in front of a judge. You've got to be your own best advocate and move that needle because this is your life. No one's as interested in your life as you are.

There are financial resources available. You don't have to just live in a hole and lose everything you own. That's been wonderful since I was lighting four fires a year while my husband was at work. I've decided I can't do this anymore. I really need some supervision. I need someone here with me to help me function safely in the house.

I think there is no resource like other people living with dementia. We literally are experienced experts.

Jen Pettis:
That's great advice. David, I'll turn to you now with my last question, and then Steven will have the last word. What one thing do you wish every primary care provider would do when it comes to recognizing and responding to early signs of dementia?

Dr. David Compton:
Listen and respond appropriately to the symptoms that patients are giving you. Don't blow it off thinking it's something else. I'll paraphrase Sir William Osler: if you listen to the patient long enough, they will tell you what's wrong with them. That is true. The symptoms are sometimes right in front of you. We need our physician workforce, whether it be a primary care physician, a neurologist, or anyone in the field. I've had a neurologist be a little slow to make this diagnosis; it depends on the neurologist. Pay attention to these symptoms and follow up on them accordingly. If they're mild, try to focus on that and elevate these diagnoses and the differential when someone comes in with this set of symptoms. It's simple: listen.

Jen Pettis:
Steven, my last question is for you. What advice would you give to someone seeking an early diagnosis?

Steven Barbieri:
I think we've heard the phrase many times today, "You have to be your own best advocate." You have to keep pushing. When you go in there, make sure they don't blow things off. The goal is to get past your primary care physician and see a neurologist. That's the person who's really going to do the diagnosis and get the ball rolling. That's the one that can really order the testing done at the same time. It's important too, not to just fall on the diagnosis of dementia. I've heard people who get on group calls with us say, "I was diagnosed with dementia." I pause, waiting for the next thing they'll say, but they stop. I ask, "Did they tell you what type?" "Oh yeah," they said, "I have dementia." I told them that's like somebody saying you have cancer. The next thing that's important to know is the type of cancer you have, whether it's lung cancer, tongue cancer, breast cancer, or colon cancer, because for each diagnosis, there are different protocols in place. The same is true for dementia, so it's very important to get a diagnosis. The nice thing is that we have people join our calls with the National Council of Dementia Minds who haven't received a diagnosis yet. We point them in the right direction. We tell them, "Make sure you get past your primary care physician and go see your neurologist."

The other thing I tell people is, don't go see the doctor first thing in the morning. Why? That's the best time of the day for us. We just woke up after eight hours of sleep.
We might have had our coffee and a little bit of caffeine. We're ready for the day. We're at our best point of the day. You don't want to go when you're at your best point of the day. I remind people to aim for the last appointment of the day in the office. The reason for that is that it's your worst time. You don't want to go see the doctor when you're at your prime peak of the day. You want them to see what a real day looks like. For most of us, as the day goes on, our symptoms become more noticeable.

I always tell people that when you're going in for testing, don't schedule it for the first thing in the morning when you're at your most alert; try to schedule the appointment for later in the day. Their response is, "I'll be tired at that time." Exactly! "But that's when I stutter and have trouble finding my words." Exactly! That's what you want them to see. They need to see what you really look like. The time of day you visit your doctor is important. You want them to see you at your worst.

Jen Pettis:
Great advice. Joanna, I think you have something to add.

Dr. Joanna Fix:
My specialty was cognitive testing. This is what I did as a psychologist. As a college professor, I taught psychological assessment. I worked with law enforcement and behavioral and intelligence testing. When I started on my diagnostic journey, I went through two of those neuropsychologists. She said, "You seem fine," and everything on the test says you're average or above average. I said, "No, I'm not asking you if there's a problem. I'm telling you there's one. This is my wheelhouse. Okay? I'm sharing my baseline with you because we had to undergo extensive testing on each other during graduate school. It started way up here; now it's way down here."

She was just mind-blown because she couldn't figure out what this meant. I said, "I'm not asking if there's a problem. I'm here to tell you that there's a problem. You're being paid to figure out with me, and I want to know what that problem is." If you're not up for the task, I'll move on to the next specialist. But I am not going to sit here and argue with you about whether I'm having a problem. That's not happening. When you're not getting the information or the support you need, never be afraid to stand up, walk out, or seek another opinion. I got nine, and when I reached nine, I got my answers. Even though that's not what anybody wishes, it is what you have to do. You know yourself better than anybody else. Be your best advocate.

Jen Pettis:
All right. That's a great way to wrap it up. You guys have been terrific guests. Thank you so much for taking the time to share your insights. Most of all, thank you for the advocacy that you all do for everyone who's living with dementia. Thanks to those who are listening to this episode of the podcast. Remember, it's the first in a series of three with our friends at the National Council of Dementia Minds. We hope you'll listen to all three.

Thanks again so much for joining me, Joanna, David, and Steven.

Dr. David Compton:
I really appreciate it.

Dr. Joanna Fix:
Thank you.

Steven Barbieri:
Thank you for the opportunity today to share and have a voice.

Announcer:
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