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Meaningful Lives As We Age

Dementia Diagnosis to One Year Out: Perspectives of People Living with Dementia
Applications from the GSA KAER Toolkit for Brain Health
Momentum Discussions Podcast from the Gerontological Society of America
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Guests:
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Miriam Owens
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Announcer:
Welcome to the Gerontological Society of America's Momentum Discussion, where we explore groundbreaking topics in the field of aging.

Jennifer Pettis:
Welcome to this GSA Momentum discussion podcast episode titled Dementia Diagnosis to One Year Out: Perspectives of People Living with Dementia. The second 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 in this three-part podcast series. My name is Jen Pettis, and I'm the Director of Strategic Alliances at the Gerontological Society of America. I'm pleased to serve as a host for today's Momentum Discussion. Today, we're diving into a critical, but often overlooked part of the dementia journey: the first year after diagnosis. That time can be filled with confusion, grief, questions, and decisions, but also growth, clarity, and community.

I am joined by three individuals who know this first-hand. Seth Stern, an OB-GYN physician who concluded his practice after 37 years of dedicated service to his patients who was diagnosed with frontotemporal degeneration in 2022. We're also joined by Miriam Owens, who was diagnosed with dementia with Lewy bodies in December of 2022 and has since become an advocate for improving the experience for others in the early stages of dementia. Finally, we're joined by Phyllis Cole, who was diagnosed with early vascular dementia about a year ago and is extremely optimistic about new findings around causative factors for dementia and new approaches to treatment. Seth, Miriam, and Phyllis, welcome and thank you for joining me today.

Seth, let's start with you. Can you take us back to that moment that you received your diagnosis, sharing a bit about how that was delivered and what you were told or not told?

Seth Stern:
Essentially, reaching my diagnosis took about five years, during which I underwent significant testing over the years, and I couldn't really get a diagnosis. In 2021, they performed a PET MRI, which revealed significant changes. I saw some specialists, and it was confirmed that I had FTD. Regarding being told that I have FTD, again, I had seen the PET MRI report before I was told, but the physician who ordered the test told me, "You have FTD, frontotemporal degeneration, you need to be seen by a specialist and try to enjoy the rest of your life." I was told over the phone, not in person.

Jennifer Pettis:
It sounds like you were seeing that specialist, but then no additional follow-up with the person who delivered the diagnosis.

Seth Stern:
Right. I didn't have an additional follow-up with the primary. I saw two nationally known FTD specialists at NYU and Columbia in New York City. I underwent repeat neuroimaging with an advanced PET MRI machine with someone who specializes and has received multiple awards in the diagnosis of FTD.

Jennifer Pettis:
Miriam, I'll turn to you now. When you left your doctor's office after getting your diagnosis, what did the following days and weeks feel like, and what guidance were you given to help navigate those next few days and next few steps?

Miriam Owens: I was accurately diagnosed at my very first visit with my neurologist. Unfortunately, I received no guidance whatsoever. To be honest, the way that the diagnosis was delivered to me was pretty nonchalant. At that time, I had very limited knowledge of dementia. I guess I assumed it wasn't a big deal. The doctor did not seem unnerved or upset. He didn't give me any guidance. I left the office thinking, Okay, there's a name for this, and I'll be fine. I'll adapt, or maybe it'll even go away. I don't know. I did my own research in the weeks that followed and came to realize that this indeed was life changing and that I would have to pivot and adapt to the new diagnosis, and for years going forward.

Jennifer Pettis:
Phyllis, how about you? Can you tell me a little bit about how the doctors shared your dementia diagnosis and how they prepared you for that first year following?

Phyllis Cole:
Like several people I know, there was more than one diagnosis. My very first one was when I was told I had MCI seven years ago. Really, nothing followed that. To me, it wasn't a big deal. It was normal for people to experience that. My second one was the one I'm counting, which was about a year ago. I went to my primary, and he said my MCI is a lot worse. He said, unfortunately, that there are no good neurologists that he would recommend, but there is a good neuropsychiatrist. I went to see her, and she did a lot of the testing with the brain scan and all kinds of things. While we were waiting for all of that, she treated me for anxiety.

I'd come to an appointment, and the nurse would say, "What are you even here for?" Everything's a no. That was kind of a bust. I did talk her into something. I underwent biofeedback for about three or four months, which was interesting. Very interesting. I learned that I'm operating on delta waves all the time, and I have a really low blood flow situation, but it didn't seem to help. After about three or four months, I quit and began conducting my own research, which has led me to where I am today. That's just that first year. I will say that when she actually read the scans to me and told me I have early dementia, probably vascular in nature, she said, but you know, there's nothing that can be done. It's probably time for you to find an elderly lawyer and get your affairs in order. That's what I was told.

Jennifer Pettis:
Unfortunately, we hear that all too often: the same sentiment. Seth, what, if any, resources were presented to you at the time of your diagnosis?

Seth Stern:
One of the centers in New York had asked me to participate in one of their research studies. But otherwise no real direction or anything. Supposedly, social work is supposed to reach out, and that didn't occur. Basically, I just did research on the internet on dementia. I fell into an excellent group, the National Council of Dementia Minds. They're very supportive and instructive. After receiving the diagnosis, I looked up FTD and came across the Association for FTD, which has been very supportive and educational. Being able to speak to and see people who have your condition is reassuring. But otherwise, nobody hand fed me or told me where to go, what to do, what to think.

Jennifer Pettis:
I see both Miriam and Phyllis kind of in agreement on nodding their heads a bit, Seth, as you're talking. Miriam, as you listened to Seth's reflections, what information do you wish you had had? What information or guidance do you feel was missing for you during that year? What would you have liked to have received for help?

Miriam Owens:
First and foremost, like Seth, I didn't receive any guidance or direction. What would've been helpful at that point was information about diagnosis websites, written material resources, such as support groups, and, ideally, a care manager from the outset. I think the assumption is that folks in the early stages of dementia or with younger onset dementia don't need that level of support early on because, well, stereotypically, a person with dementia is in a corner and not aware of what's going on. I think people make the mistake of thinking that from the outset, there is little that we need and little that we can offer. It would've been nice to have those resources. Also, just some semblance of community and acceptance as a space in the community that said, "Hey, we see you and we know you're still capable of so much. Here's where you fit in." I have three big Cs, and capable is first on my list. Dementia does take away a lot, but there's still so much that we can do, so much that we feel, so much that we need; we're still people, the same people. It would have been helpful to have that from the outset.

Jennifer Pettis:
If I could ask you a follow-up to that, when you talk about a care navigator or care manager, what would be the one or two things that that person could do right off the bat that would help that person who receives that new diagnosis?

Miriam Owens:
Someone's doctor suggested getting an elder care attorney. But not just the legal support, but also emotional and spiritual support, if that's what's needed and desired. I need someone to coordinate care for me as a whole person.

Jennifer Pettis:
Really helping with connections.

Miriam Owens:
Yes, that would've been very helpful.

Jennifer Pettis:
Phyllis, what types of supports and services did you use during that first year, and how well did they meet your needs? What would've made them meet your needs better?

Phyllis Cole:
Just like Miriam and Seth, I had to find my own resources, and the one that has made the biggest difference is Dr. Dale Bredesen's book, "The End of Alzheimer's Program." I dug into everything. I read that book cover to cover by audiobook; I don't read anything in hard copy anymore. It just clicked with me. He has a comprehensive protocol with seven key pillars. The first one was diet and exercise. I jumped on those and followed the diet plan and exercise ideas he suggested. While I was doing that, I was also looking for a provider because I needed a functional medicine type doctor to follow his protocol, as that is the approach he advocates.

Because the idea that he talks about is that it's not just one thing. It's hundreds of things that need to be addressed. He calls them different insults. To determine which insults were being directed at me, we conducted extensive testing. I needed a doctor to walk me through that. Luckily, I found one that is certified by Dr. Bredesen directly. He's the president of the board at his clinic, and it's only a two-hour drive from me. I've been under treatment with her for about nine months.

I had been working on a weight loss, the diet, food plan, sleep plan, and exercise plan. I lost 110 pounds. That cleared up a whole lot of metabolic issues that are also insults that cause cognitive decline.

However, the testing they conducted narrowed down my main issues to mold toxins, mold and yeast toxins, and vascular issues that were well-known, although many had already been addressed by my cardiologist. I'm also participating in a clinical study that is purely observational. About every four months, I go in and do testing. Every time I turn around, I'm getting better and better and better just from following the Apollo protocol. You can find them at apollohealth.com. The other thing I have to say, because it's also been the biggest thing, is support groups through the National Council of Dementia Minds. Seth mentioned that a great organization can't say enough about it.

Jennifer Pettis:
Great. Thank you, Seth. Go ahead.

Seth Stern:
In addition, I had forgotten that in the early part of my journey. I came across an excellent book. It's called 'What If It's Not Alzheimer's: A Caregiver's Guide to Dementia' edited by Gary Radden and Lisa Radden. It goes over several different types of dementias. You have some information about each category, which provides a little basic information that really helped and reassured me by giving me more insight.

Jennifer Pettis:
Seth, were there any health care or service providers, thinking of providers outside of the health care arena, but maybe community services or other types of services that played a key role in your early journey, and as you continue this journey, what would make a particular service provider helpful?

Seth Stern:
I think that one thing that helped me with my journey was my attitude. I was not only involved with the delivery of several thousand babies, but I also taught for several medical schools. I wanted to continue helping others, even though I wasn't able to see or deal with patients directly. I went out of my way to educate others, provide support, offer advice, and give them direction. Part of that involved a full-length article by the Wall Street Journal. I've been interviewed on TV several times. I was invited to speak at the National Institute of Health, and I was encouraged to improve funding for research on different types of dementia.

I've been invited to speak at several national conferences regarding dementia, as well as FTD. Participating in various types of groups has helped me become a stronger individual. The fact that Bruce Willis came out about his FTD, and I was diagnosed at about the same time. And after I saw that his family came out, I decided to come out. That's when all this is essentially pursued. I think one of the things that really motivated me was this unfortunate occurrence with Bruce Willis, that he has the same condition that I have.

Jennifer Pettis:
We often hear people who say, "The People magazine for dementia," or something similar. When you mention FTD, people often think of Bruce Willis, or they mention a different condition and it is oftentimes these kinds of celebrities that bring a condition to the forefront.

Seth Stern:
And I also just want to suggest that if people are on this journey, whether in the very beginning or more advanced, if they're not exactly sure what's going on, make sure you have someone supportive who goes with you to the doctor's appointments or is aware of what's going on, and try to keep a journal. I kept on being tested over and over again for five years before they came to a diagnosis. Then they said, "Well, how long has this been going on? I said, well, at least several years. They asked if there was any way to prove it. I kept a diary, and they looked at it. The diary went back to 2017, and I kept track of things that were atypical for me. They said, "This has been going on for years."

Even though I scored very high on my cognitive tests, they said, No, this has been going on. On one hand like, I took a five and I repeated a six-hour cognitive test, and they said, The good thing is you scored very high, maybe because you were being involved with taking care of high-risk obstetrics and you were doing advanced robotic surgery, and that's why you were scoring so well. But overall, the findings were consistent with those of FTD. Definitely keeping a diary, having someone to be supportive of you is helpful.

Jennifer Pettis:
Miriam, based on your experience in thinking about your first year after diagnosis, what specific resources and tools do you think should be made available to every person who's newly diagnosed with some type of dementia?

Miriam Owens:
A care manager from the beginning, not mid-stage, not end-stage; someone who you are connected with right from the beginning, because we have the data and the information that shows that dementia is a progressive disease, and so that support will become more and more critical, but it doesn't make it unnecessary from the beginning. That's the one I would probably stress the most. I believe there's a lot of reform that needs to happen surrounding insurance, including what's covered and when, along this journey. There's so much that is not covered from the beginning. As we advocate for those of us with dementia and our care partners and families and folks like you, who do this awesome podcast and work in your fields, we have to draw attention to the fact that people are living longer.

Dementia isn't just a disease for older people, as you know, people once believed. In fact, there are people who are very young. I was diagnosed at 54. With younger-onset dementia comes a huge shift because I had to stop working. I had to close my business. That kind of turns the household finances upside down. It's just a number of things that come into play. A person with dementia who seems not to need the level of support from the very beginning does, in fact, need that support.

Jennifer Pettis:
Great. Go ahead, Seth.

Seth Stern:
Also, consider suggesting that you find out what you have early in your search. If you truly believe you have something, then stick with it. If one physician doesn't necessarily give you the answers that you truly believe are going on, then search out other opinions. In New York, I visited four doctors, all of whom were nationally known specialists. However, early on, I encourage you to take action, even before receiving a diagnosis. I recommend obtaining proper medical insurance, life insurance, and, especially, long-term care insurance.

Once you get a diagnosis, you will not be able to get this type of insurance that's necessary. They're like, well, you have this disease, it's too bad, it's too late. Before you undergo genetic testing, for example, get these different insurances, because, like I said, you need to protect yourself as well as your family.

Phyllis Cole:
I totally agree with what Seth said about being relentless in the pursuit of a diagnosis. However, one caveat I want to mention is that as the medical community learns more about the disease, they become less likely to make a definitive diagnosis, and I suppose they become less comfortable doing so. My current neurologist won't even do that because there are so many causes, and he calls them insults within my system; who knows what is really causing it or what is really the biggest problem that I have? He's comfortable just saying likely to have Alzheimer's.

Miriam Owens:
To add a little to what Phyllis just said, I'm not sure about every type of dementia, but I know that dementia with Lewy bodies cannot be confirmed as a diagnosis while you're alive; the diagnosis comes postmortem. Even though my doctor knew or was pretty sure that that was the diagnosis, he was reluctant as well to say definitively that this was dementia with Lewy bodies. It took a very detailed symptom history, which I kept in the way that Seth did for many months. A DaTscan was slightly abnormal. Then I was given the Syn-One Test skin test. That was the third and final piece for which the test came back positive. It was enough for my doctor to feel comfortable saying definitively that my diagnosis was dementia with Lewy bodies. That test cost me over $2,000 because it was not covered by insurance, but it was the only way that I was going to be approved for Social Security disability. It's horrific what you have to go through sometimes to get a diagnosis and then get the support that you need.

Jennifer Pettis:
Thank you all for sharing your insights and for taking the time to join us for this podcast episode. We appreciate you sharing your insights with our listeners. Thank you also for all your advocacy for others who are on this journey with dementia as part of the National Council of Dementia Minds. We're so lucky to partner with them for this series of podcast episodes. Thanks also to our listeners of this GSA Momentum Discussion podcast. Thank you again, Seth, Miriam, and Phyllis.

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