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Meaningful Lives As We Age

Living Well with Dementia
Applications from the GSA KAER Toolkit for Brain Health
Momentum Discussions Podcast from the Gerontological Society of America
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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.

Jen Pettis:
Welcome to this GSA Momentum Discussions podcast episode titled, Living Well with Dementia, the third 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 the host for today's Momentum Discussion. Today's conversation focuses on a powerful and hopeful topic: What it truly means to live well with dementia, to find purpose, stay engaged, and build a life that's meaningful and connected after diagnosis. Joining me are three remarkable individuals who do exactly that.

Jay Reinstein, a former assistant city manager, was diagnosed with early-onset Alzheimer's and spends his time as an advocate in doing everything possible to reduce the stigma of the disease.

Krissan Lutz Moss, a former nurse with an amazing career, retired from Genentech at 59 due to Lewy body disease. Krissan enjoys volunteering as a "Lewy Buddy" with the Lewy Body Dementia Association through the National Council of Dementia Mines. Krissan enjoys educating and advocating for awareness and treatment of Lewy Body.

Scott Guernsey retired after 40 years of working in the manufacturing sector, concluding his career by consulting in human resources. Scott was diagnosed with vascular dementia after a stroke in 2011, which impacted his memory. He now advocates for giving dementia the recognition to be more normalized.

Jay, Krissan, and Scott, welcome, and thanks so much for joining me today.

Jay, I'd like to start with you. What does living well with dementia mean to you?

Jay Reinstein:
I think the thing that stands out to me first is staying socially connected with friends, family, and support groups, such as the Brotherhood of Dementia Minds. It's also about purpose. When I worked as an assistant city manager, I loved being a public servant. When I had to retire, I felt a huge void in my life, and I needed to fill the void. That purpose has now been advocating for others living with dementia. I enjoy having lunches with friends, going to the movies, and seeing documentaries with my wife. I've taken a ceramics class, go to sporting events, and help others stay involved. To me, that's living well. I've met many people along this journey, and a lot of them feel isolated. I try to help them out a little and give them hope.

The big one is using strategies to help me with my issues due to short-term memory and retention. Now I have lists, and I use voice emails, calendars, and Post-It notes. That sort of thing, to me, in a nutshell, is living well with Alzheimer's. It's not a death sentence. I can still be productive.

Jen Pettis:
Thank you. Krissan, you're a fellow nurse just like me. With your personal journey and professional experiences, you're likely to have unique perspectives on the importance of routines and habits. What daily routines or habits have helped you to continue to live well with dementia?

Krissan Lutz Moss:
I don't know how I could manage without technology. Individuals with Lewy body dementia have difficulty going out into crowds and bright lights. Jay, I'm envious that you go to sports, movies, and other things. I have to be in the right mindset to accomplish that. Technology is really important to me. I use alarms and reminders to help me remember to get ready for bed, take my medications, exercise, and do everything else I'm supposed to do in life. I find that routines are important, and without something to remind me, I struggle to complete them.

One of the most important things for living well is getting a good night's sleep. That can be very difficult. Lewy body dementia, also known as Lewy body disease, can lead to REM sleep behavior disorder. While everybody else is paralyzed during sleep, I'm punching and kicking and having full conversations. I used to do a lot of teaching and lecturing. I have been told I do quite a bit of that during my sleep. It's a lot of fun. It's hard to get a good sleep. I may spend 10 to 12 hours in bed to get seven and a half hours of sleep. I rely heavily on technology to help me get a good night's sleep and to manage my days effectively.

Jen Pettis:
Scott, how have you had to adapt or change any hobbies or things that you enjoy to continue living well with dementia?

Scott Guernsey:
I've had to adjust many of the exercise activities I've been involved in, as I've been pretty athletic throughout my life. I really enjoy that. I've had to make a lot of adjustments to what I'm doing. I used to ride my bike all the time. I'd spend a lot of time outside riding my bike, but I ended up with some balance issues. My balance issues were taking over, and that was becoming a safety issue because I didn't want to fall over in the middle of the street. I've adapted. I have an exercise bike downstairs that I can ride on a regular basis.

I play a lot of golf. I'm not sure if you'd call golf relaxing, but it's certainly enjoyable. I still play golf; however, I no longer keep score, and I bring a dozen golf balls with me because I'm always hitting them into the lake. But I enjoy it. I laugh a lot. I get a lot out of it. I love being out there in the green grass, putting strokes, and all that stuff. It's an activity I love. The last thing I do is swim a lot. I do lap swimming. I swim for exercise. It's good for your breathing. It's good for balance. It's a full-body exercise that's easy on your joints. I can get a really good workout and work my breath and my heart. I'll mention that I had to make some adjustments to that. I've gone to and talked to the lifeguards and told them that I've got a dementia issue and that they ought to keep an extra eye on me in case I start sinking to the bottom. Although I have to approach this with some care, I enjoy doing it as often as possible.

Jay Reinstein:
If I could say just one thing, I am very envious of you, Scott, because I have had a great deal of trouble since being diagnosed, getting motivated, and staying on track. I live very close to a park in my subdivision here, and we have all the exercise equipment imaginable.

However, I'm not walking or doing lightweights, so I become depressed. I need that extra motivation because everything I read and hear emphasizes the importance of exercise in living with this disease: a healthy mind, a healthy body. I'm not doing it. Thank you for reminding me that it's an important part of your life. It needs to be an important part of my life.

Scott Guernsey:
Hey, Jay, get a buddy.

Jen Pettis:
I think Scott's discussion about getting a buddy is a good segue into our next question, which is for you, Jay: What's the role of peer support of other people living with dementia? What role do they play in helping you live fully and meaningfully?

Jay Reinstein:
What stands out to me is the importance of support groups. I'm in three right now. I'm part of the Dementia Minds brotherhood, and I'm in two with Duke University. Being around people who are going through similar issues makes you feel like you're not alone. We can also have those honest conversations that we might not be able to have in front of others who may not understand what we're going through. Peer support is huge. There are a lot of people out there, and I feel like I'm very fortunate that a lot of people along this journey that I've met are very isolated. They're home. They don't do anything. Giving someone a call and getting them involved in support groups is really huge.

I view the support group as a safe space. I can honestly discuss many things with my wife and daughter, but there are some things that I would rather talk about with the guys, and I'm just more comfortable. I think that's a good thing. It also leads to friendships. I want people to look at me, not as Jay with Alzheimer's. With this diagnosis, while I can't do everything I used to do, I can still do a lot of stuff. These friendships are huge.

Jen Pettis:
Krissan, how about care partners and families? How can they best support someone to live well with dementia?

Krissan Lutz Moss:
Meet where I am. On that day, with the type of fluctuating disease that I have, help me figure it out. And I know that's a big ask for those around me. Follow my lead, if you will. I think that's one of the most important things. I think about my daughter, whom I live with, and how she is. I couldn't ask for a better care partner. She's very patient and kind. She and I can have a conversation about difficult things.

I'll give you an example. She and I chatted, and she said, 'Mom, how can I best approach you?' When do you want me to approach you? I said, 'Well, if I leave the cupboard door open or something like that, let's just let it go, if you don't mind. But if it has anything to do with safety, then I want you to talk to me about it.' I won't cook unless she's home. I was scrambling eggs, and I turned off the burner, did everything right, but I evidently didn't get the gas all the way turned off. She'd come in, and the house was full of gas. I went outside to do something. I came back in, and she said, 'Mom, can I chat with you?' We discussed it, and I said, Oh my gosh, the last thing I want to do is blow the house up. Being able to approach us with kindness and not skirt around those difficult issues is really important.

Jen Pettis:
Scott, let's turn to another topic. I think that leads to some pain in all of our eyes. That's stigma, and how stigma often gets in the way of living well with dementia. What do you think healthcare professionals and the broader public need to understand about what's possible after diagnosis to help break down that stigma?

Scott Guernsey:
Well, Jay and Krissan stole my thunder here. One of the first things I thought about when you talked about this question is that having dementia is not a death sentence. It's that you don't necessarily need to listen to comments like 'you don't look like you have dementia.' Then I ask, what does dementia look like? They don't know what the heck that is.

The one thing that does happen is I process stuff slower. It takes me longer. It takes me longer to go to the store.

I ask people to speak more slowly when they're talking to me, because often, they are just using their normal speech patterns. I hear the first part, and I hear the last part, and I miss all in the middle. I've had to ask people, Hey, could you slow down, please? I'm trying again. I don't want to sound like I'm weird. However, I prefer to know who I'm talking to and what I'm discussing. If I don't hear it, if I can't process it, that puts me at a disadvantage. I have to take that extra time to ensure the communication systems are working and that I'm picking up everything I'm supposed to be doing. However, I still have fun and enjoy being with my kids and myself. You need to know. I need to tell people that dementia's not contagious, so you're not going to get it from me.

Jen Pettis:
Jay, you've remained active in advocacy and in civic life. What advice do you have for primary care teams? Thinking about physicians, nurse practitioners, and physician associates that work with them, what advice do you have for them about encouraging people to stay involved and connected to their communities?

Jay Reinstein:
Yeah. Well, I mean, I think you have to remind people that a meaningful life is still possible with a diagnosis. After an Alzheimer's diagnosis, I'm not able to read books anymore. I don't drive. I have problems with short-term memory, but I try to focus on what I can do well and not focus on those issues that I can't. I remember my doctor telling me, “Don’t focus on these things that are stressful for you. Focus on what you can do.” I've been a strong advocate, and there's nothing that brings me more joy than attending the legislature at the local, state, and federal levels. I mean, I've had the opportunity to work with our state legislature on several legislative matters that have been passed. I've attended Congress for the last four years through the Alzheimer's Association.

I was actually selected as the National Advocate of the Year two years ago. It gave me just this lift and this positivity that what we're doing can make a difference.

Your voice, along with others, and speaking with legislators can really move the needle. I found that my getting out there and doing things has made a difference. I love doing it. I encourage people to get involved and reach out to the Alzheimer's Association, as well as other organizations, to advocate even at the local level. You don't have to go all the way up to the state and federal level, but it can make a difference.

I think it's very therapeutic for me because I can really see that we've achieved some legislative successes on the national level, and it's because of people like me, Scott, and Krissan that make it happen. I would encourage caregivers and caretakers to give people that option, because it can really make a difference.

Jen Pettis:
Congratulations, Jay, on your success with advocacy. It's exciting when it works.

Jay Reinstein:
It's exciting.

Scott Guernsey:
I was going to say that, for me, I need to get the message out to the local groups, the local community, local hospitals, and local doctors. I've spent time trying to, sometimes, in a social setting, people that I know, physicians that I know, caretakers that I know, and I'll talk about it. I try to bring it up to a more conscious level. People can see that I don't have two heads, that I can still talk and have a sense of humor.

Krissan Lutz Moss:
I have to jump in because, when I hear the two of you, I think about how critically important that is for that sense of being us remaining to be us. I knew, as a very young nurse, I think I was 19, that the greatest responsibility I had was to be the voice of the patient when they either didn't have a voice at the time or didn't know what to ask for. That has been my North Star throughout my career, whether it was hands-on nursing or working at one of our sponsors, Genentech, for 20-plus years. That was my mission: to find ways, through organizations such as the National Council of Dementia Minds and the Lewy Body Dementia Association, and others, to continue being me with adaptations.

Through the National Council on Dementia Minds, I was able to sit on a committee with the National Academy of Sciences, and now I'm also serving on another one. But when it comes to stigma, I've found that even our smartest and our greatest are the experts out there who have contributed the most to learning about neurodegeneration. That bias is there, and we all have those silos to break down. I think our presence there helps them to understand that. But one of the things that I point out more than ever is that there is no chronic illness, which is what neurodegeneration is. It is a chronic illness. There is not one disease that doesn't have better outcomes if caught early. Early detection, absolutely. It's critically important.

Jen Pettis:
Krissan, a big part of what I've heard from you and your colleagues here, as well as friends on the line, is the support and connection between each other. How have peer networks and other community organizations contributed to your well-being?

Krissan Lutz Moss:
Well, the peer networks go back to my childhood and my large family, as well as my nursing school friends. We've all grown up together, and they are my greatest safe places. I come from a big family. There are seven children. My mother's passed, my father's still alive at 97. Oh, I can keep going, aunts and cousins, and you know what, they still struggle. Yet they approach me with love and understanding. They're not afraid of me. That's a huge network for me in terms of community.

I still find that my best network is through the different organizations and the people I have met through them. I mean, I have some of the dearest friends I will ever have. I may not see them or talk to them all the time, but the depth of love and understanding is there.

Jen Pettis:
I want to turn to Scott. Kind of along that line of clinicians, when we talked about what clinicians, doctors, nurses can do better, how can they better connect people who have dementia with peer networks and community organizations?

Scott Guernsey:
I think that part of the response to that and the action item that should be involved here is developing a written list of all the national, state, and local organizations that support people dealing with dementia, dementia people, dementia minds, whatever it is that have that particular list available that you can give to physicians and practitioners that identify those organizations, provide contact information, including the name of the thing, their phone number email address, maybe that they can take and use.

Krissan Lutz Moss:
If I could add onto that, Jen. Sure. I think it's almost like we need a protocol, so to speak, of how you meet. I had this, so it's pretty easy for me to bring it out and be seen. It took four academic centers before I felt like I got to the right place. Nothing against the first three that I saw. This disease is complex. Lewy body diseases, too, are diagnosed differently. It's like trying to hit a moving target. So, there's no anger out there. However, at the Mayo Clinic in Rochester, I was immediately given tools, such as pamphlets, that I could use to visit the Lewy Body Dementia Resource Center and the Lewy Body Dementia Association site, which was my first point of reference. From there, I met people who led me to the National Council of Dementia Minds and similar organizations. I believe that upfront education is crucial. One of the examples I give is that I was not having visual hallucinations, which is really very common with Lewy body dementia.

My physician, Dr. Bradley Boeve, described to me what it might look like so that I wouldn't be afraid and what I should do if it were to happen. The first time I had that, I was like, Oh, okay. I wasn't terrified. I'm provided with literature. Every time I go in there are books.

I'm a part of many clinical trials, so I do believe I get a little extra time for education. However, through all that education, I've found those networks. One of the women in my support group at the National Council of Dementia Minds has developed a resource list that she shared. It's inclusive. I was impressed.

Jay Reinstein:
If I could just add one thing too and it's just really to piggyback on what both of you said is just really, if there was some website or one place you could go to get information and sort of that toolkit for Lewy body or for vascular dementia where you don't have to go 50 million places, because you got to keep it simple, especially for people that have cognitive issues. I know for me, I get very frustrated when I don't know where to go. However, if you had a clearing house or a single area where people could go, they could find everything, including phone numbers and references, that would make it a lot simpler. Currently, people are going in a million different directions. As Krissan just said, it can be very frustrating if you have to visit three places before receiving the final diagnosis.

I just think it keeps it simple, and that would add a lot of value, especially after you get a diagnosis with all that stress and anxiety.

Jen Pettis:
Well, Jay Krissan, and Scott, I would like to thank you both for sharing your insights, lived experiences, and guidance, for all of us. You've shown us that living well with dementia is not only possible, but also powerful. To our listeners, thank you for joining us for this episode of the GSA Momentum Discussion podcast. We hope you found this conversation informative and inspiring. Thanks again so much, Jay, Krissan, and Scott.

Announcer:
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