

Empowering Sons and Daughters of People with Younger Onset 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 Discussions podcast, where we explore the groundbreaking topics and advancements that are generating significant excitement in the field of aging.

Jen Pettis:

Welcome to this GSA Momentum Discussions podcast episode titled, *Empowering Sons and Daughters of People with Younger Onset Dementia*. Momentum Discussions highlight topics experiencing great momentum in the field of gerontology. We are grateful to Eisai, Genentech, Lilly, and Otsuka for their support of the [GSA KAER Toolkit for Brain Health](#) and today's podcast episode. My name is Jen Pettis, and I'm the Director of [Strategic Alliances](#) at the Gerontological Society of America (GSA). I am recording this podcast episode live in the podcast booth at GSA 2024 in Seattle, Washington. I am delighted to be joined by Patti LaFleur. Patti is the [Youth and Lighthouse](#) Outreach Lead for [Lorenzo's House](#), a nonprofit social impact organization designed to empower youth and families living with younger onset dementia. Welcome Patti. I'm so glad you could be here.

Patti LaFleur:

Thank you, Jen. I'm so excited to be here to help spread the word about younger families living with younger-onset dementia. Thank you for having me.

Jen Pettis:

I'd like to start by just asking you to tell us a little bit about yourself and share some pieces of your care partner journey with your late mom. Specifically, what does it mean to be a daughter of someone with younger onset dementia, and how did you get connected to Lorenzo's House?

Patti LaFleur:

When we break the silence and share our stories, we empower ourselves, we dismantle stigma, and we shine a light on our unseen community: Families affected by younger onset dementia. I am Patti, the daughter of Linda, who so bravely walked with younger onset dementia for over 10 years. Our journey profoundly shaped my life, and I'm humbled today to share pieces of my story, recognizing that my voice represents millions of young people like me, the children of a parent with younger onset dementia. My mom illuminated every room she entered, and still beneath her radiant exterior, brain change appeared when I was in my early twenties. For over 10 years, we witnessed heartache, and we shared countless moments of connection and love. As I walked alongside my mom, I became her advocate and unwavering champion. I discovered the power of empathy, compassion, and community. Today, I carry those lessons I learned and the memories I cherish.

My mom's legacy is undeniably etched upon my heart, and for the rest of my life, I will carry her light. After being a teacher for several years and caring for my mom, I found Lorenzo's House as a daughter myself. I connected with our founder, Diana, on Zoom, and I finally felt seen on this journey and like I found my home. Today, I'm honored to serve as Lorenzo's House Youth Initiatives Lead, where I walk alongside sons and daughters like me. No one understands this journey except us. It's a place of healing for myself and so many others across the globe. We're Alexis Grace, who is in Mississippi and caring for her mom. We're Anderline is in Kenya who had to choose between studying at university or caring for her mom. We're Avi who is nine years old in Philly who wants to ride his bike all day, but he has to come home to brain change with his dad in his home and show up as a son of brain change. Without Lorenzo's House, we wouldn't know where to find the strength, but together, we do. At Lorenzo's House, our youth are our compass, and we're building global leadership by empowering young people across the world for those now and for those who walk behind us.

Jen Pettis:

What is the founding story of Lorenzo's House, what's the mission, and what is this that you all describe as the audacious goal?

Patti LaFleur:

Lorenzo's House was founded in 2021 when Diana, our founder's husband Lorenzo, was diagnosed with younger-onset Alzheimer's. At the time of diagnosis, her boys were nine and 13, and she was looking for a place for herself to find community. She was looking for a place for her boys to find others who understood what it meant to be sons of brain change in their home. With her entrepreneurial background (she built a network of charter schools on the South Side of Chicago), she built Lorenzo's House as a place for families of similar profile: Younger with young kids who have this diagnosis of the family. Today, we've quickly become a trusted organization. We serve over 2,500 people in 47 states and 16 countries.

Patti LaFleur:

Our mission at Lorenzo's House is to empower the sons, daughters, and their families affected by younger onset dementia, those diagnosed before the age of 65, by shifting the narrative, curing isolation, building community, and driving dementia justice. Our goal at Lorenzo's House is to find each other and lean on each other, and we also need to inform experts everywhere. We will be the change makers, the sons and daughters of this condition, enlightening experts across the globe, sitting at every table where decisions are made, educating policymakers, and sharing the invaluable expertise we have acquired firsthand through our intimate understanding of this journey. We carry a unique perspective that must be heard.

Jen Pettis:

I understand that Lorenzo's House has three pillar programs. Tell us about them.

Patti LaFleur:

At Lorenzo's House, we have three pillar programs that are our solution to the global problem. We have a match, clubs, and a summit. Our match is a one-to-one care-to-care match model of a peer of a similar profile. Recently, we've connected two daughters who lived 10 minutes apart from each other, and we connected with them together. They have become good friends, but they didn't know anyone in their own world who was walking this journey. Now, they have someone to lean on, connect with, and truly understand. We also have [clubs](#). We have a Bright Brunch for our female care partners, a Light Lounge for our male care partners, and a Light Club and Shine On for the sons and daughters that have a parent with this condition. Our Light Clubs are for those whose person is still walking with the condition. Our Shine On space is for those who have passed. In our Light Clubs, we bring together youth from across the globe. It's their space to connect with others who truly understand, share common stories, and build a growing youth alliance. We serve children as young as four, so we have a four-to-seven-year-old group that uses picture books to tell their story and think about brain change. We have an eight-to-12-year-old group that incorporates play. We have a 13-to-17-year-old group, which really thinks about what it means to tell your friends about your journey, what it means when you're out at the store, you're at Costco, or you're somewhere in the world, and you experience moments of stigma and how do you navigate what that looks like? Our young adults are building that space. They are the leaders in that space. They co-facilitate the sessions and help build tools and strategies to incorporate mindfulness.

Our third pillar program is our summit. We have a [Virtual Youth Summit](#) that unites young people from across the globe, which takes place in June. It is a virtual conference where we partner with social workers, neurologists, speech-language pathologists, occupational therapists, and art therapists, who are positioned alongside our youth. We have youth leaders who help build, facilitate, and develop these sessions to ensure they are meaningful and make sense for our young people.

At Lorenzo's House, we have learned to lean in and listen to our young people. Something that has emerged from our Youth Summit is this idea of [Dementia Justice](#) and how we advocate for a more inclusive society. We are where we are seen and heard. At our Youth Summit this year, we had our first-ever Youth for Dementia Justice panel.

Jen Pettis:

Interesting. Tell me more about that panel.

Patti LaFleur:

At the panel, we had six young people from around the globe. We had Will from the UK, Ila from El Salvador, and members from Canada and the United States. They were really thinking about what it means to dismantle stigma. When you have experienced these moments, how do you navigate them? Then, they build out their personal definition of what dementia justice means to them. For some of our friends, that means taking their dad to Disneyland and feeling like their dad can be part of the community and not getting weird looks. For others, it means access to resources. It means access to a world where people understand their parent's condition and can lean in, listen, and show up in really powerful ways.

That has also led us to create our Younger-Onset Dementia Global Youth Alliance, our Global Advocacy Initiative, which has been really influenced by the growing community of sons and daughters. The vision of our Global Youth Alliance is to unite like-minded people to raise awareness end stigma, refine policy, and build a more informed and empathetic world.

Jen Pettis:

What do you feel are some of the biggest gaps for supporting caregivers of all persons living with dementia, particularly gaps for caregivers of people with younger-onset Alzheimer's or dementia?

Patti LaFleur:

I think one of the biggest gaps is lack of awareness. Often, when I would share my story with others in the community, whether it was friends or family or out in public, I would share my story of my mom having dementia. I would say that it was before the age of 65. People were really surprised to hear that. As we continue to talk about Lorenzo's House, we talk about these families that we are serving that are in their thirties and forties, and they have small children in the home still. People have no understanding or awareness of this happening. I think that is one big key.

Another gap that I feel is the lack of support, whether it is financially, emotionally, or medically, really the lack of having a quality care team that can really support you with this diagnosis. I still hear often of people getting diagnosed with dementia and then their neurologist just sending them home without a care team or a plan or support.

I think another thing that is a big gap specifically for the younger-onset community is that they're often misdiagnosed or undiagnosed for many years. I know personally that for my mom, it took several years to get an accurate diagnosis. I often hear when I'm meeting with families that they say that they were diagnosed with things like depression, anxiety, and adult-onset attention-deficit/hyperactivity disorder (ADHD). They continue not to feel that they're being listened to by their doctor when they're describing the symptoms that they're experiencing. It's often such a long process actually to get an accurate diagnosis.

Jen Pettis:

You mentioned stigma earlier, Patti, and I think a lot of that goes back to the stigma associated with dementia, in general. In that the picture in so many people's heads is this person with gray hair who's in a wheelchair who's an older adult, who's perhaps in the end stages of their disease and in a nursing home. We know that's not the face of many people with dementia. That certainly, I think, contributes to the stigma.

Patti LaFleur:

We've had families that have shared with us that even their doctor has said they are too young to have dementia. Then, a year or two years later, they find out that's what it is. Imagine if they had been able to start treatments or think about lifestyle factors they could change at that moment, how much better their quality of life would have been.

Jen Pettis:

Absolutely. Finally, Patti, I'd like to learn from you, considering your experiences as a care partner. What's your dream for other sons and daughters walking this younger-onset parent journey, and also your dream for Lorenzo's House?

Patti LaFleur:

My big dream is for other sons and daughters to feel seen on this journey, find each other, find community and care, and feel like people understand their story. It goes back to that stigma. How are we creating a more empathetic and supportive world for young people navigating this journey? Often, the youngest people in our community, the sons and daughters, don't identify as caregivers; they identify as sons and daughters. How are we making them feel supported and that they have the tools in their toolbox to show up for their family and themselves?

Jen Pettis:

Patti, thank you so much for joining me in the podcast booth at GSA 2024 in Seattle. What final thoughts would you like to leave our listeners with?

Patti LaFleur:

I think it's important to say that Lorenzo's House is about two things. These two things are things that we have learned from young people by leaning in and really listening. As young people, as the sons and daughters, we need care, community, and support. We need others who understand our journey so intimately. We need others who will show up for us and help us feel supported, but we also need awareness. We need a world that understands our journey and truly sees what it means to be a son or daughter of this condition.

Jen Pettis:

Again, Patti, thank you for your time and insights today. We also want to thank those who listened to this episode of the [GSA Momentum Discussions podcast](#). We hope you enjoyed it.

Patti LaFleur:

Thank you for having us. We are so honored to be part of this community. Thank you.

Announcer:

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