

Kat Villanueva: 0:00

Hi, my name is Kat Villanueva.

Ryan Miner: 0:02

And I'm Ryan Miner.

Kat Villanueva: 0:03

We are the hosts of the Coffee & Care Podcast - a podcast that dissects the American healthcare continuum. In each episode, Ryan and I unpack trending healthcare topics, and we unwind a specific area of the vast and complex care continuum. Grab a cup of coffee and ready yourself for an educational journey.

Ryan Miner: 0:23

This is **episode five**, featuring **Marianne Sciucco**, a nurse, dementia daughter, author, and co-founder, and manager of [AlzAuthors](#), the global community of authors writing about Alzheimer's and dementia from personal experience - to help others on that path.

Marianne, Hi! Where are you coming from today? Where are you stationed at?

Marianne Sciucco: 0:41

Hi, I'm from upstate New York.

Ryan Miner: 0:43

So, what's happening? Tell us a little bit about [AlzAuthors](#).

Marianne Sciucco: 0:48

[AlzAuthors](#) is, as you said, it's a global community. We're a 501 c 3 nonprofit. We just celebrated our sixth birthday. We're all volunteers. It started as a group of daughters of dementia who had written books about their experiences. My book is a novel, and the other two authors I began with - Jean Lee and Vicki Tapia - had each written memoirs about the caregiving experiences with both parents at the same time having dementia.

So after we published our book, we were trying to market them, of course. And it was really difficult finding an audience because it's such a little niche of a genre.

They've got the idea that perhaps if I banded together with other authors of books like mine, that we could help to promote each other and help raise awareness of Alzheimer's and dementia.

So the three of us got together, and we did a one-month social media campaign in June 2015, just to try to do that. And we found that we really liked each other, and we enjoyed doing what we were doing. So we decided later on in the year in November, which is National Caregiver Appreciation Month, that we would do it again.

And then the following June rolled around, we got together and said, 'Well, why don't we expand this? Why don't we just do for the month of June one blog post every day, Monday through Friday, from a new author who has written a book about Alzheimer's and dementia from personal experience?

And we'll just present that as part of the Alzheimer's and Brain Awareness Month initiative.'

So, we did that.

And at the end of the month, we just wanted to keep it going.

So since 2016 June, we've been publishing a new author and a new book on our website every week. Now we have almost 300 authors and more than 300 books in our bookstore.

Since then, we've gone on to create a podcast, which we launched in November. And we have traveling libraries, which are collections of our books, you know, physical books, real books.

So some of us have in different cities across the country that we can bring to events; caregivers can see the books and feel them and look at them and rifle through the pages and see if they find something that they might be interested in to help them on the caregiver journey.

Kat Villanueva: 3:01

So, the physical books, are they available in local bookstores or, you know, online?

Marianne Sciucco: 3:07

Yeah, all the books are available through Amazon.

So we're an Amazon Associate: I'll give that disclaimer, which means when if somebody purchases a purchase book through our website or through any of our social media, we may get a few cents as a thank you from Amazon.

Kat Villanueva 3:24

Yeah!

Marianne Sciucco: 3:24

So, it's not a big moneymaker - but you know, it's something.

But anyway, all the books are available through most online booksellers and in bookstores - if people would just have to go in and ask for it; might be able to get it at your library; you can buy them direct from the authors themselves, on their websites.

So every week, we have a new author who writes us an essay about the story behind their story.

Why did they write this book? It gets a little deep and a little insightful. And it's the design is to help people find an author and a book that might resonate with them, where they can see that this person's story is like mine, and maybe I can learn something from this, maybe this will help me; and, at the very least, to know that I am not alone. Somebody else has already done this, and if they can get through it, then I can get through it, too.

So we offer knowledge, comfort, and support; those are our three pillars for providing easy access to books because you can look up Alzheimer's and dementia books anywhere; you can go on Amazon and search = and there are thousands of them.

What we do is we vet the books: We actually read them and look through them and investigate so that when somebody finds a book on our site, they can feel confident that it's got high quality. It's been evaluated by people who are who have already been on that journey.

Kat Villanueva 4:44

That's great! Well, 300 authors in six years, is amazing!

Marianne Sciucco 4:50

Yeah, we're, we're busy. We, in the beginning, when we started, we said 'How are we going to find these people? Why would they want to write anything for us?' It wasn't hard at all. We had an abundance of people, so that that's one of the reasons we kept going. But what's been going on now is we don't even look for people; they come to us.

Kat Villanueva 5:05

Yeah, yeah, that's wonderful!

Marianne Sciucco 5:07

I recently had a woman - I just received her book today as a matter of fact - and she wrote in her application submission form that she'd been following us for years and we inspired her to write her own story.

And one of the reasons she wanted to write it was so she could put it in [AlzAuthors](#), which was unbelievable that somebody would feel that way about us.

Ryan Miner 5:28

So you're a nurse.

Marianne Sciucco 5:29

I am a nurse. I'm a registered nurse.

Ryan Miner 5:31

Are you still practicing?

Marianne Sciucco 5:32

Yes.

Ryan Miner 5:32

And what's your specialty?

Marianne Sciucco 5:33

My specialty these days is college health.

Well, I work at a college; I'm a campus nurse, and I work with students at [unintelligible]. So, our students run the gamut from teens to senior citizens.

We're also responsible for providing services to our faculty and staff, and we do have a daycare on site. So we were also responsible for responding to any kind of situations that might occur or physically, we would encounter anyone along the line. So it's kind of interesting.

So I'm not in Alzheimer's world anymore, as far as my job goes; other than that, I make sure that the Alzheimer's Association comes to campus every semester to put on some kind of educational program.

Ryan Miner 6:19

You're a dementia daughter?

Marianne Sciucco 6:21

Yes!

Ryan Miner 6:21

Which one of your parents has dementia?

Marianne Sciucco 6:24

My stepfather had dementia. He had three different types of dementia, which they call mixed dementia - Alzheimer's, vascular, and frontotemporal lobe. So that happened after I'd written my book and after I'd started [AlzAuthors](#).

Prior to that, most of my experience with dementia was working in dementia - in dementia wards - and with dementia patients and their families in the hospital. I was a case manager, and I had three aunts that had dementia. Although I wasn't responsible for them or a hands-on caregiver, I experienced what it was like to have somebody that you love not know who you were anymore, and also visiting them and facilities and stuff.

So, I was in tune with a lot, and I enjoy working with dementia. These are patients who can love, and I would love to be with them and care for them. It's different than other kinds of nursing. And I started doing that when I was, you know, my early nursing days. When I left, you know, hospital work, and I went to the college now I don't get that anymore.

Kat Villanueva 7:24

I wanted to know from you, what do you think is the most challenging that you've encountered so far in as far as families - caring for children, caring for parents with Alzheimer's?

Marianne Sciucco 7:37

First of all, one of the major obstacles is denial. Neither the child is in denial of the parent's situation or a parent is in denial. So, you need to overcome that hurdle and get everybody on the same page; so that number one, you can get a medical diagnosis.

If there's any suspicion that there's something wrong with your loved one - and it doesn't have to be in an elderly person, it could be somebody in their 30s and 40s who are exhibiting cognitive decline, that needs to be investigated - you need to find out why this is happening. And if there's something that can be done to mitigate that, or to correct it, you would want to do that. But if you find that that's not the case, you need to come up with some kind of long-term plan to provide for the care of that person throughout the rest of their lives.

And so once you get over that denial hurdle, now you can start moving in that direction. And then what you need to do is you need to get educated: you need to learn; you need to find out what is this about; what can I expect; what can be done; what resources are available in my community? Because both communities across the United States have services - and a lot of people are not aware of that, and they don't know to ask, and you can't count on your doctor to give you all this information; they need to go out and do it on your own.

You would contact the Office of Aging in your community or elder services, the Alzheimer's Association. There are a lot of really good places to go to get the answers you need and to find programs that might be helpful. There are daycare programs for people with dementia that help the family but also help the person, help them stay active and connected with their community.

There are other services where you can have home health care and things like that. And then the other obstacle is the financial piece. Unfortunately, care for persons with dementia at home or even in a facility is not covered by Medicare, which a lot of people don't realize.

So, you either need to use your own funds or exhaust your funds and go on public assistance for that.

So there are mechanisms that you can put in place to prepare for that if you need to. You also have to make sure that people can access the benefits that they might have earned through their employment like 403 B's, 401, K's, pensions, things like that; long term health insurance, and other stuff, because that may need to be activated sooner than you anticipated.

The financial piece is huge, and the legal piece, where you would need to make sure you had documentation in place before things get really bad - because once a person is diagnosed with

dementia, they can't sign the papers, they can't sign a power of attorney. Somebody has to be able to manage that person's affairs when they can't.

You need a health care proxy and need a living will; there should be a will. I mean, there's just a lot to do. And a lot of people tend to push that aside and end up in a real problem later on down the road. It just adds more stress to the situation.

Ryan Miner 10:37

Marianne, I'm sure that in your career, you have worked with home care agencies to either help someone supplement care or to have around-the-clock care, versus someone inside of an assisted living community or someone in an assisted living community could benefit from home care.

Tell us a little bit about your approach to that. How can home care better work with memory care communities?

How can we better work in the community to unify around a specific message?

Or maybe it's a PR campaign?

Or maybe it's something else?

What can we do to better support people with our services, and who would you see as our logical partners?

Marianne Sciucco 11:21

One of the negatives that I encountered with home care is the expense. For example, when my mom was ill - she did not have dementia, but she was ill and at home - we were paying up to \$28 an hour for her care, to have somebody come to the house, which was going to wipe out her life savings in a matter of months. So that's a huge consideration and a big factor in why people are resistant to seeking homecare. How can I pay for it? So that's something that I think needs to be considered.

Everybody has expenses; we know that, but um, on the positive side, there was a lot to be gained by having caregivers that you trust. Now we've had, we had caregivers from my mom, and we had different agencies and different people. And there were some people that she just loved and just loved having somebody come; she's a social person.

So she would love it to have somebody come to the house, you know, Monday, Wednesday, Friday afternoon, and that person was there just for her. And that person paid her attention for the entire time. And they laughed and joked, and they watch TV, and they did things. They took her to the bathroom. They made her lunch. And she really enjoyed that. And what was great

about that is then the caregiver who was staying with her - the live-in family member - that freed that person up so that that person could attend to whatever they had to do, whether it was, you know, go grocery shopping, or go to do laundry, or just go out and see a friend. You know, she would want to visit her daughter.

So she knew that when she when the caregiver came from the agency for three, four hours, she was free now. She could go, and you know, take care of her life because often a caregiver has to give up a lot of their own life for that person.

You know, my mom was a person who couldn't be left alone. Period. So somebody always had to be present - you know, whether it was me or one of my brothers or her niece that lived with her, or a hired person. We had people who would stay with... her when my brother - she lived with him when they would go to work, you know; otherwise, they couldn't go to work. And that's not a really realistic situation for most people - to give up their employment. People don't want to give up their employment in their 50s and 60s because they can't get back in. So that's a huge dilemma for this population - because when people are in their 70s, 80s, 90s, then their children are in 50s and 60s; they have to work.

Ryan Miner 13:44

What about federal legislation? Have you been following any of what could become, I think, an alternative, or what could become something very positive?

In fact, this past campaign, where the candidates finally were able to talk seriously about affordable long-term care costs, and now that we have a new administration, there's a possibility that it could be potentially subsidized.

People then may be able to afford these more long-term-care costs, and that's always the concern; we run into it all the time. How are we going to pay for it? And when people get the sticker tag, they get sometimes shocked by the cost; this, unfortunately, is the cost of doing business. Caregivers have to make a living, and we have to make a living.

Do you see the potential in the future for federal legislation to change how people can afford these costs?

Marianne Sciucco 14:36

Well, I certainly hope so.

One of the ways would be for there to be tax write-offs for people who are providing care and can't work, or if there was some kind of tax write off you thought. It was one of the things I always say is 'nobody gives you anything because you're taking care of your mother.' You know you don't get discounts on groceries. or utilities, or taxes, or anything. I mean, people are funding this on their own; you know, is it a problem for the government?

I mean, I don't really know, are there other resources available that maybe could be used toward providing for caregivers? Because if people were at home, that's generally going to be cost savings as opposed to going into a facility.

So my stepfather's facility in 2018 charged \$12,000 a month. He and my mom had saved every penny that they earned when they were working. He was in his 80s, so he hadn't worked in over 20-some years. They still wouldn't have had enough money to pay for that. I mean, who does?

Most people don't have that kind of money. Do they have to charge that much money? And that's another issue. It's like, 'Well, why does it cost so much money?' What is behind that? Is that the profit margin? Should it be a profit margin that that large? I don't know; I don't really anything about the financing that goes beyond the fact that I had to pay.

So, that is something that they could look at. I mean, I know that after COVID, there's going to be a deep examination of what goes on in care facilities because that exposed a lot of problems.

Ryan Miner 15:58

Especially in New York.

Marianne Sciucco 15:59

The finances would be one thing. Especially in New York! Yeah, I have my own theory theories about that.

Kat Villanueva 16:04

Well, was that like, a few years ago, or is that like current rates in New York?

Marianne Sciucco 16:11

That was in Massachusetts, and that was in 2018. That's where they lived.

[AD BREAK] Ryan Miner 16:14

We're going to take a quick break, so stay right here with us.

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Now back to the show.

Marianne Sciucco 17:15

And you know, my mom, I'll tell you, what she said - because I said, we need to apply some paperwork to go for Medicare, er, Medicaid, for him to pay for this place. 'Oh, I don't want to do that.'

She was a proud woman; she would work today, and they both worked all their lives. They never accepted any kind of welfare or public assistance; that was not part of the their life. And I said, 'Okay.'

She was very, very stubborn about that. And I say, 'Okay, all right, we're not going to do that, we don't have to.' I said, 'But you need to know that every month, they're going send you a bill for \$12,000 - and you're gonna have to write a check.' And she just looked at me. She said, 'I can't do that.' And I said, 'I know, so that's why we have to fill out this paperwork.'

So then she said, 'Okay!' So we did.

But what I did was I got an elder care attorney, and it was the best money we ever spent. You know, it was expensive; I'm not going to say that it wasn't when the amount of work that we had done. But they, you know, took care of everything. It was a lot of work on my end because I had to put all the pieces together. Still, they put it all together and got everything signed and stamped, and preserved a large portion of the assets - because if you have two people in a situation, one of them can impoverish the other one and leave that other person with nothing, not even their home.

Nobody wants that for the parent or for their vows; you know, you don't want your husband or wife to be homeless or, or to be struggling financially because you had to pay for all this care.

So that was my goal, to make sure that my mom - her security, was intact - that she would not, she wouldn't notice any difference in her standard of living, which wasn't exorbitant or anything. I just didn't want her to have to even feel like she couldn't go to Bingo or something because they had to pay for the nursing home. So the attorney really helped us put all that in place.

You know, I usually say, 'After the doctor says the "D-word," the next call is to your attorney.

And that's what you do next; you start putting that legal process in place, which is hard to do because people have the other "D-word:" denial.

So, get on it for a while, and then you know, then it becomes even more difficult later on.

Ryan Miner 19:13

In your experience, is that denial because families just don't want to face that reality?

Is that part of it? I know it happened in my family.

My grandmother, she was diagnosed with Alzheimer's ten years ago. She's at end-stage now. At first, we didn't know what to do or how to do it. We did our best. I wish we knew where to find more resources, and the Alzheimer's Association was very helpful.

But still, I don't think I would have known ten years ago to pick up a phone and call an eldercare or rather an elder law attorney. No way - not until I got into this industry.

Marianne Sciucco 19:46

Right, that's true.

So when it comes to denial, the first thing in human nature is to resist pain. And whenever you have a major medical diagnosis hit somebody in your family, it means pain is coming. In this case, it's not going to be a good one. So people don't want to deal with that.

And then the other thing you have to deal with, another "**D-word**," is the dynamic in the family. It all depends. If you have a small family, it might be a little easier because there are less characters in play, but you're going to have everybody's going to come to the table with their own point of view of what's going on and what are we gonna do about it. And it's often hard to get a consensus from everyone. And while people are busy arguing, the clock is ticking, and things are not getting done, and it's a dire situation.

And then there's often usually one person who ends up having it all dumped in their lap, whether they choose that or not. And I've encountered that on many, many times.

In my family, I was to take charge person; I was the oldest and the only daughter. So, I was already overseeing and helping my mom and doing things for her the way a daughter does. And my brothers were involved too. But my mother designated me as her, you know, person, or spokesperson or whatever.

So all of that I willingly took on, but it was a lot of work. Because you know, if you're the power of attorney, for instance, or the lead person, sometimes you other people can't even step in and help you. You might be the only person that can sign the document, even if somebody says you know, well, or talk to someone.

So even if you have other family members, I'll make that call for you. They may not be able to make that call because they're not going to have the authorization to speak on behalf of the parent.

So now you get with all that you depending on the severity of the situation - if they live with you, or if you live with them, you know, you're 24/7 in charge. So that's a big part of the whole thing about denial and family dynamic getting in the way.

Kat Villanueva 21:35

Yeah, I can attest to the family dynamics.

And usually, when there is a new diagnosis for, let's say, a parent who had dementia, let's say, right, it's the start of something that is it's going to be life-changing, not just for the mom, but for every person in the family because it's just going to get keep getting worse, right?

Family dynamics are just so difficult to address because all of a sudden, all the children are have a voice and making decisions.

And that's always tough.

I always like to meet some of our clients or have that are in that situation, and I always like bringing in a third party, like a geriatric care manager. And I think they do a really good job in trying to hash out everything and find common ground - and you know, focus on the care for their parent.

Marianne Sciucco 22:26

Yes, that's very important.

A third party can really try to help smooth things out, whether that's somebody from the home care agency, as a nurse - the nurse in charge - or in hospice (they have social workers, and we utilize them a lot).

And that person often would come in and say, 'This is what's going on. And this is what we're going to do.' And people didn't argue with that; they accepted it coming from this professional person, more so than if they were, you know, well, my sister said, you know, what would she know?

Kat Villanueva 22:56

Right.

Marianne Sciucco 22:57

So definitely take advantage of anything - any service like that, that you can get your hands on. Palliative care is great; people with dementia and end-stage Alzheimer's can get Hospice, which can be done at home, that can be done in the facility. I had that both. I had two different hospice agencies at the same time, at one point. I would meet and care for each one of them. Yeah, that was craziness.

But that's how it had to be done. But it was just wonder how you even got through it. I get through all that. I don't even remember anymore.

Ryan Miner 23:28

Well, we find out that in these really tough moments, we have incredible strength that we didn't realize that we have; and it doesn't seem like it at the moment.

I've been there. I'm sure your family has been there. It's been tough for all of us. And we pull it out, and we managed to get through it.

But it's a learning experience that it's really painful, even when it's happening, and then even years afterward.

And I know we've all experienced loss.

I didn't want this to be gloomy, but it's, unfortunately, a stern reality of life. And these are important conversations to have, and sometimes you need cold water thrown on you.

I'm interested in what books should every caregiver read. What should be the Bible of caregiving with respect to Alzheimer's?

Marianne Sciucco 24:12

Well, the one book everybody swears by is the 36 hour day.

Kat Villanueva 24:16

I know, I just got that!

Marianne Sciucco 24:20

Yeah, that's not in our collection.

But yeah - not because we wouldn't want it, but we need the author chapter right essay. Authors of books that are like blockbusters are not willing to do that.

So if you were to go into our on our website, AlzAuthors.com, and look at our bookstore, we have everything categorized. So depending on your situation, if you're caring for your mom or your dad, or your spouse, or your you know, a parent and you have small, raising kids at the same time, caring for a parent, they cross-section with the type of dementia.

So if it's early-onset Alzheimer's or vascular dementia or Lewy Body disease, you can find books that will whittle down to just that situation, caring for a mother with Lewy Body disease.

For instance, Lewy Body is one of the rare dementias. We have several books about that. And you might be able to find something that really relates to your situation. And some of the books are fiction, like mine, and sometimes fiction or a novel or short story can be helpful because it gives it to you in an easily digestible way.

So you're like reading about some story, and they're going through a situation, but while you're reading the story, or you're following along, and you're learning with the characters, some of the books of memoirs.

People have written books, sometimes decades after they've gone through their experience, and they've had time to digest and think about, and process everything. And they feel compelled to share the story so that they can help other people on that, that are now on the journey. And some of the books that caregiver guides, which some of them have written from a professional perspective as well; that will give people tips and, you know, more about how to way to go about doing things.

I would just recommend that people investigate the collection on their own and find something that speaks to them

Kat Villanueva 26:11

Are most of the author's primary caregivers or family caregivers?

Marianne Sciucco 26:15

Yeah, I would say about 90 or more - more than 90% are people who have what we say walk the walk, whether it was their mom, father, grandparent, vows, partner, friend - even had that.

And then several of our books were written by people who currently have the disease and are living with the disease right now. And they have either written a book on their own - literally sat down and typed the words on the page, which is, if anybody's ever tried to write a book, they know what that's like; very hard.

And others were told their story to somebody who did that part for them, but it's their story. So we call it their book. We just did an event last week. It was our very first spiritual question and answer: Everything you always wanted to know about dementia, but we're afraid to ask.

And we had five authors from [AlzAuthors](#) present, available to answer questions about what it's like to live with dementia, how they cope with it, how they manage. It's on our website, on our YouTube channel.

And if anybody's interested in learning more about dementia, that is a great video to watch. It's about just under one hour, but the five people and they had some amazing things to tell us.

Ryan Miner 27:24

Have you ever heard of Teepa Snow?

Marianne Sciucco 27:26

Oh, yeah.

Ryan Miner 27:28

Have you been to one of her seminars or her lectures?

Marianne Sciucco 27:30

Not in person? I've seen them, you know, on video.

Ryan Miner 27:33

Kat and I both went to one in November 2019, down where we live in Montgomery County, at one of the major assisted living communities in Montgomery County. And she came for a day and did the training, and she is very lively.

Kat Villanueva 27:49

She is!

Marianne Sciucco 27:49

Oh, yeah, she is; she's amazing. She's wonderful.

Yeah, I'm one person. I think that it also does a similar thing is Judy Cornish, who wrote "Dementia with Dignity" and "*The Dementia Handbook*." She was my blog, my podcast guest, a couple of weeks ago.

There's a lot of people making a mistake and thinking that somehow they're gonna make they're gonna be able to bring this person back around to our reality. And it's the opposite. You need to enter their reality.

And when people learn to do that, it will take away so much of the stress and strain on both parts. It'll make the other person happy, and it'll make the caregiver, you know, give them a much better day. Because they're not constantly trying to correct somebody into entering into a reality, they can't come into. That's kind of sad when you think about it, but it gives you a lot of freedom once you accept it.

Ryan Miner 28:44

I saw a movie and had heard a discussion back in September of 2019 by the late Glen Campbell's wife. And there's a movie about his life and about dementia and Alzheimer's. Of course, Glen Campbell was a famous musician, and he sang the song "Rhinestone Cowboy."

And that was a really touching movie. It was well done. I think you can still find it on Hulu. And you might be able to find bits and pieces of it on YouTube. But that movie, it's called, "I'll Be Me," and you can download it from Amazon. And then there are also documentaries that you can read.

Glen Campbell's wife spoke to us, and we met her. And that was truly touching. I don't know if you've seen that or not.

Marianne Sciucco 29:28

I have seen that; that is a beautiful movie. And you know, just the fact that he could continue playing the guitar off flawlessly throughout entering into really even deep dementia and perform and sing. I think in the movie, he got to the point where he couldn't remember the words anymore, but all of that.

And we encountered this, and some of the writers - the authors who have written their books - is that they still have those kinds of motor skills that they used all the time. It's like muscle memory. And it means that he would just pick up his guitar stop playing the same song. They Playing for years. And even though he had dementia, his fingers just knew how to where to put those, where to put them on the fret. And it was amazing.

And the same thing with one of my authors, Wendy Mitchell, who wrote "Somebody I Used to Know." And when she told me in our interview that she - her fingers just fly over the keyboard. And when she takes a break - she'll never take a break again because she took a break from her computer and from blogging for a couple of weeks. And when she got back into it, she looked at it, and she couldn't figure out what she needed to do - she had to kind of retrain herself.

So, she blogs every day. She says her blog is her memory; that's how she remembers what happened last week or yesterday because she doesn't remember anything about that. She'll read her blog, which is called "Which Me Am I Today?" And that's an excellent blog to watch. She's not the only one. A lot of people are doing that.

But it's amazing when you think that Peter Berry, who is another one of my authors that was at the event last week. He is a cyclist and has written bicycles his whole life. He rode one, you know, not too long ago; he took a cross-country trip. They live in England, and he's about to go on another one. But he rides his bicycle. It's called "A Penny Far Thing." I don't know if you've ever heard of it, but it's one of those bicycles with the big giant front wheel and the little tiny rear wheel, and he hasn't had any trouble getting on that thing and going.

And we talked about that in the virtual Q & A when people like, how do you remember how to ride a bike? Like how did you get on it? You know, just get on it? I always did. I guess they say you never forget how to ride a bike.

Kat Villanueva 31:29

Yeah.

Ryan Miner 31:30

Yeah!

Marianne Sciucco 31:31

That's a great thing.

For people who have dementia, they have a medical condition, like many other kinds of medical conditions that people have to live with and manage.

However they do, whether it's with medication or lifestyle adjustments, they're still the same people, and they can still keep living the way they've always lived. But maybe they need a little more support. I mean, they might need a little more assistance or help, you know, getting from one thing to the next.

The authors that we've talked to were pretty amazing. And their independent level of independence. Still, some of them in early, what they call early-onset Alzheimer's for more than ten years.

One of them was diagnosed at 39 years of age.

Ryan Miner 32:07

Oh, man,

Marianne Sciucco 32:08

And he started his symptoms started at 39. He was diagnosed at 49.

Kat Villanueva 32:12

What age is the youngest you have encountered so far?

Marianne Sciucco 32:16

Personally, that would have been him.

I did read an article once about a woman in Australia who was diagnosed when she was pregnant. That's how it was discovered. I suppose her pregnancy started off. And I remember reading about that couple, and they had to divorce because they needed public assistance, and they couldn't get it unless they were divorced. That was awful. Not that they didn't stay together - they did - but they were legally no longer married. That's sad. I've heard that there are children that have been diagnosed with dementia - but it's very rare.

Ryan Miner 32:43

This was a good discussion; we hit some high points, and we were able to talk about some great books and resources - not only for caregivers but people who are generally interested in reading and learning more about dementia, myself included.

It's a disease that affects my family directly. We take care of clients with dementia. And it's very personal.

Kat and I are so honored that you have come on and talked to us.

What do you want to wrap up with? What should we know? What's a parting thought that you want to leave us with?

Marianne Sciucco 33:11

One of our themes in [AlzAuthors](#) - I mentioned a few of them, but as pertaining to caregiving - is that there is life after caregiving, and it can be good.

In many of the authors that have written books in our collection are people who have been on that path, and it came to its natural conclusion.

And a lot of times, when caregivers get to that point, they're just so exhausted and spent and defeated, then they may feel life will never be good again. They've given up so much.

How will they get it back?

Now you suddenly have all these hours in your day that were once filled by your loved one's needs - and now they're all your own.

What will I do?

And sometimes people flounder - but as time goes on and you start spreading your wings again, you will have a new life. It can be good.

Kat Villanueva 33:57

Thank you so much, Marianne. That's beautiful.

Marianne Sciucco 34:00

Thank you so much for inviting me. I'm really happy to help you guys because I know you're kicking off your podcast, right?

Ryan Miner 34:06

This is the fifth episode.

Kat Villanueva 34:08

It is our fifth episode!

Marianne Sciucco 34:09

Yeah!

We're only a little bit ahead of you.

I'm on my I'm doing my 30 s right now. So we have a podcast. That's "**Untangling Alzheimer's and Dementia Podcast.**"

Kat Villanueva 34:18

Untangling Alzheimer's, okay

Ryan Miner 34:20

Well, we'll plug that too in the comments, in the description of this.

So, Marianne Sciucco of AlzAuthors.com.

Thank you so much for coming on the podcast today, and we'll check back in with you sometime soon; I know it!

Marianne Sciucco 34:34

Okay, thank you so much!