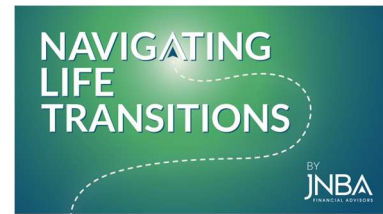


# Podcast Transcript: Navigating a dementia diagnosis and its financial considerations



**Kim Insley:**

I am Kim Insley, and thank you for joining us for Navigating Life Transitions, a podcast where we bring together advisors experienced in financial life planning to talk about ways to navigate life's biggest changes, challenges, opportunities, and decisions. So today, we are talking about considerations that come with a diagnosis of dementia. Now, the U.S. Centers for Disease Control and Prevention estimate 6.9 million Americans age 65 and older are living with dementia. That's one in nine people. And again, we're talking about age 65. So, what do we need to know in the event that we or a loved one is diagnosed with dementia?

Joining me today is Elise Huston, the Director of Advisory Services and a Senior Advisor at JNBA Financial Advisors, and also Jayne Clairmont, who's a nationally recognized consultant and an expert for those living with Alzheimer's and other related dementias. So good to see you both with us.

**Jayne Clairmont:**

Thank you.

**Kim Insley:**

I'm going to start right at the beginning with you, Jayne, and that is how to understand this diagnosis of dementia. So, kind of how do our brains change as we age? What is dementia? I know it's an umbrella term. Can you walk us through that?

**Jayne Clairmont:**

Sure. So, part of the recognition that you said already, at 65 years old, one in nine people is going to get an actual diagnosis. And as you age that person to 75, that number is going to increase to about 25%. What's interesting at 85 years old, we're somewhere in about one in three, one in two are actually going to receive a diagnosis. What's important also is when you talk about the kind of umbrella and when you think about knowing that getting the right diagnosis is important because the neurologist is going to be able to really help distinguish when they look at the brain. And that to me is important because if you know what type of dementia you're dealing with, just like cancer, then you're able to put the right treatment plan in place.

**Kim Insley:**

It's all a little bit different.

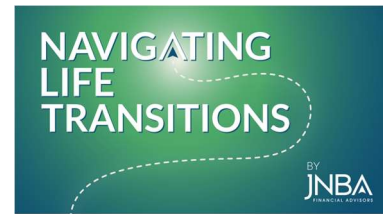
**Jayne Clairmont:**

Very much.

**Kim Insley:**

And I was, so we do a preliminary call to kind of circle up on these thoughts, but when you mention the different stages of dementia or different types, most people think of Alzheimer's, but there's really a wide spectrum.

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## **Jayne Clairmont:**

There is, and when I first started, it was, we used to call it hardening of the arteries, and then later on it became using the umbrella term of dementia. That's the right thing. It's the umbrella, but there's more than 80 types of dementia, more than, but there's five common types. Alzheimer's is the most prevalent, and it's going to affect somewhere about 80% of all the diagnosis will be of the Alzheimer's type.

But we also have other dementias like Lewy body, which Robin Williams ended up with Lewy body. Frontal temporal: Bruce Willis was diagnosed with frontal temporal dementia. We have vascular, which is stroke, and Parkinson's is also a type of dementia. So the recognition back to diagnosis will help really from a clinical standpoint but can help family members. And when you learn more about each type of dementia, you're going to really look at what are the best approaches when you understand.

## **Kim Insley:**

Okay, and I know, Elise, because you work long-term with clients. It could be decades in some cases, so you a lot of times might see something that other people don't, especially if you're seeing someone every few months, you might notice changes that a spouse doesn't necessarily quite see yet because it's a slower progression.

## **Elise Huston:**

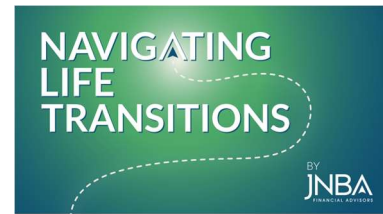
Yeah, completely. We're sitting in a unique seat where we may have known this person through their younger working years, and as they've aged, we've seen some of their health potentially decline. Or to your point, sometimes we don't see people in person maybe. I mean, a lot of us are meeting now phone or Zoom too, and then you meet with someone in person, and you think to yourself either from a physical standpoint or even from that just kind of cognitive ability, quite a decline. And it might change how we ask questions. Just to validate and clarify, again, we all, as you even mentioned, I mean, the fact that more and more of us are diagnosed with some form of dementia as we age, just as you age, the likelihood of seeing cognitive decline increases.

So, it's not always alarming, but it does allow us to just reframe and revalidate that the right estate documents and planning are in place just if that does tend to come to a point in time where other family members want to step in, that sort of thing. But really being in constant contact with your clients, it might raise some alarm bells to say, "Hey, let's get some face time with them. Let's ask some questions." And really say, "How are you feeling? How is your health?" That's often a question we like to ask.

## **Kim Insley:**

And there's a good reason for it. I do want to back up a little bit, Jayne, because you mentioned something really important, to get a qualified diagnosis. So, a lot of people, they see their primary once a year, get their physical, and they figure that's it. If you suspect something or if a family member suspects something, what are the steps to get to that person who's going to be the right person to make the diagnosis?

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## **Jayne Clairmont:**

My hope is the primary recognizes that they are not the expert of the brain, and it's the primary doctor's responsibility to do a handoff for the family to find the right neurologist. Interesting, I was just with the family this morning, and the wife said, "I don't know if we got the right neurologist the first time, but we did the second." And I said, "There is a difference between competency of neurology, so it's getting to the right neurologist." And the other question that this wife asked me today, she said, "Do you think we should do further imaging?" And I said, "If you like to measure, then yes, because we may see some changes from two years ago." So, it's getting to that right team approach of the neurology, their nursing staff, and we'll talk about other resources. So to really be a great guide and set people off on that, I call it the well-being model on the right pathway.

## **Elise Huston:**

Yeah, and I was going to say, I find too, sitting in our unique seat, getting a correct diagnosis also sometimes gives family members permission if they have clarity too on what is the care plan, what is the trajectory of this illness, what timeframes are we talking about? It almost gives them permission to help advocate or take action, not just from a health standpoint, but from their overall well-being, which includes their finances. We will hear from the spouse, partner, or family members around this individual oftentimes, when's the right time to step in, be it, when should I actually start monitoring mom and dad's bank accounts? When should I actually start sitting in on doctor's appointments? Wanting to be respectful of their independence, their desires, their privacy too, but also knowing at some point there's probably that tipping point of when to be a true advocate for them, you need to be more involved.

## **Kim Insley:**

And to get those things in place early so it's not-

## **Elise Huston:**

Yeah, exactly.

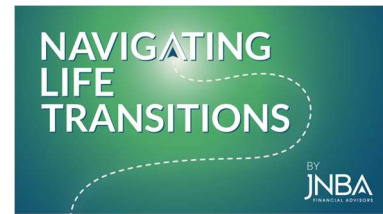
## **Kim Insley:**

Because there is a too late part. And the other thing, I mean, there are all kinds of emotions around this, and for the person who's receiving the diagnosis, Jayne, emotions around that as well. So, if you could speak to that a little bit and then finding that support group that's going to help you through that.

## **Jayne Clairmont:**

I think what's most important, what you just said is recognition of each individual, and we all come to information differently. And when diagnosis is going to happen, you have to sometimes look at the individual, is this going to be a diagnosis that they're going to accept? Is it going to be something that they don't understand now because maybe it's a little bit further down in progression? And that comes back to having trusted people in this circle to determine what does it look like and what would that in terms of telling them. I've seen where people have gone really

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into a significant depression just by the diagnosis. And to be able to couch it maybe differently and to be able to say, "I've got memory issues," meaning we both do, so that we're alike and similar versus you are different because now you have a diagnosis. Then the next step would be in terms of for information is what are we going to look at for great resources that are going to support that person living with, but also family?

## **Kim Insley:**

And then the financial piece of this, because it does bring about some financial concerns, not only treating it, but how to handle the finances of the person, the family, the spouse, the husband, the mom, the dad who are going through this.

## **Elise Huston:**

Yeah, I would say sometimes we'll meet with clients who think, "Oh, we don't need to tell you that. There's nothing you can do with it." But as we've talked about through all these podcasts, everything that you go through in life does end up having some sort of a financial tether or implication. And even if it doesn't directly, we oftentimes know of a lot of other wonderful resources like Jayne and others who can be there for our clients, but specifically from that financial component, looking at what insurance policies do you have in place? If this was an early onset diagnosis of dementia and you were still a working person, what does that maybe mean for a change to your retirement timeline? Maybe you have disability insurance that you've been paying for yourself or through work that now this dementia diagnosis allows you to file a claim. Maybe it is later in life and you want to understand that long-term care insurance policy I've been paying for all these years.

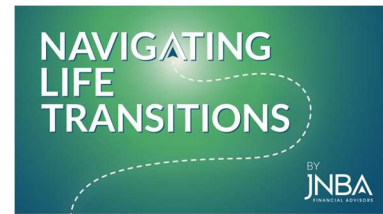
When do I get to start to use that? There's a lot of ways that you can prepare for making sure you have the right financial support for this change, but also talking through how does this change your goals and timeline? I mean, for a lot of couples, and you started to mention it, the person who received the diagnosis has to navigate the emotions of that, but all the people around that person have to navigate the emotions they have with that as well. There's likely a lot of fear, confusion. People are waiting to see, they're wanting to be respectful, not overset, but they're navigating a huge change themselves.

This person that was instrumental in their future, now they could potentially be changing. Maybe their life expectancy has changed. There's a lot that they are navigating. So re-validating what are the priorities. Common question we get from the person with the diagnosis is, "Are my loved ones going to be okay financially after this? I don't want to deplete our resources." So again, meeting with your team, we've covered this in a lot of our other podcasts as well, but just understanding there's a lot of depth to each of those nuanced opportunities financially to make sure that you have prepared for yourself, but also your family and loved ones through this transition.

## **Kim Insley:**

And yeah, there are some really great podcasts on long-term care insurance, understanding Medicare, Medicaid, that whole thing. I mean, it is super complicated.

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**Elise Huston:**

It is, yeah. And then also understanding the role of when do you have that power of attorney or those loved ones start to step in and be more active in your financial matters? All of that. There's a lot of nuances there too, which I know we have some great resources on that you can listen to as well.

**Kim Insley:**

I want to get into the support thing in just a moment, Jayne, but correct me if I'm wrong, I'm recalling that we had a conversation in which you said there are some times where maybe you don't tell the person who has the diagnosis. Why would that be?

**Jayne Clairmont:**

Mental health would be a huge part of this and how that individual had lived with their normal brain versus now it's impaired by having some type of dementia. And in one particular situation I shared, it really wasn't the right decision to give that information to the individual because the loss of self that came from that kind of label of you have Alzheimer's really set that person on a much deeper depression than what they had lived with in life. And so sometimes just couching it differently, Kim, makes all the difference.

And going back to what I said about just validating and saying, "You know what? I've got memory challenges sometimes when I don't sleep well and whatnot," starts to give permission and it's okay. And then it's always trying to move beyond diagnosis to what is life with a well-being life. What does it look like? What can it look like? I was with the family today and this individual is brilliant, but this individual is spending too much time sitting in a chair by themselves, sleeping head down, and an overwhelmed caregiver, a caregiver that has, there is a long-term care policy. And for two years-

**Kim Insley:**

Hadn't activated.

**Jayne Clairmont:**

... has not activated it.

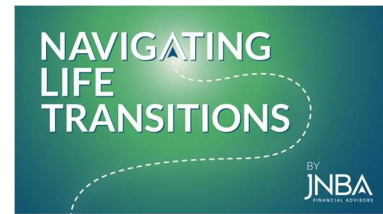
**Kim Insley:**

Oh my goodness.

**Jayne Clairmont:**

And I said, "Let's get it out and let's start working on, because there's probably a 90-day rescission period." And she said, "It is." I said, "Let's get it out." And it's an unlimited policy, which how many have unlimited policies? There's not many. And it was an old policy.

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**Kim Insley:**

Did she feel obligated, I should be doing this for my loved one? Or was it, I don't want to run out of-

**Jayne Clairmont:**

It's a great question. I think it was more of overwhelmed, completely overwhelmed, has started to bring some support mechanisms of people in, but it's not set up and coordinated professionally. Once you start to, I call it synthesize the plan, coordinate it, then all of a sudden you start to get a great rhythm. And that's what the goal is for everyone to live this best life with their best rhythm in life.

**Kim Insley:**

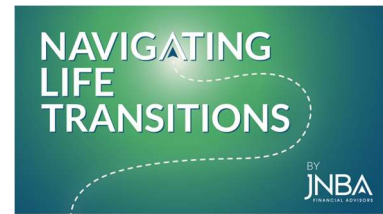
This reminds me so early on in my career and the story that I was working on was it was when assisted suicide was first being legitimized, I guess, in this country. And there was a woman in the market that I was in at the time, and she was one of the first people to utilize this, and she was a younger woman in her fifties who had been diagnosed with Alzheimer's. And so her decision was to get out. She chose that path, and at that time, there was no support system, and she didn't have huge symptoms at the time either. So, I'm wondering if there is a strong support system that can help people understand that there is a life to be led, there is hope there. So, let's talk a little about support, not just from families, caregivers, and also for people who are alone in life. They may not have children; they may not have a spouse.

**Jayne Clairmont:**

Well, I think knowledge is everything in terms of education. So I think having trusted information to draw from for that individual themselves living with, having co-support with other people that have a diagnosis as well. I was sharing with you this rich resource, and it's in Fargo, North Dakota, and it's called The Memory Cafe of the Red River Valley. This is a group of humans living with dementia diagnosis and their loved ones that are on fire. They are being educated, they are having wonderful, purposeful opportunities to do things. I mean really rich opportunities. And so it's being able to reach out into the community and have help maybe with resource gathering to find the right place.

I was sharing with this lovely woman this morning about the North Dakota chapter, and she goes, "Oh, we can go there." And I said, "Well, I don't want you going in January when it's really cold in Fargo." But I said, "Being able to go see a model like that, and then it's being able to kind of put this team together right back here." Mayo Clinic has been a rich resource in the dementia space. I mean, President Reagan was diagnosed there 31 years ago. There's resources through Health Partners, through the Alzheimer's Association. I think that's how I first met you, Kim, was during my time working with the Alzheimer's. We just have to take the time and create, I call it the milieu, the French word for what circles you in your environment to move forward.

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**Kim Insley:**

Right. And then Elise, you're mentioning that there are, you may already have resources that you don't realize you have access to, and you will help clients take a look at that through their insurance policies and whatnot. And getting help for the caregiver I know is hugely important.

**Elise Huston:**

Yeah, certainly. And even just your team of professionals in general, there's a lot of reason why you want to make sure you're working with a team of professionals. We are really big advocates on bringing everybody to the table along the way through life's journey. But this is a moment too where lean into the strengths of that team that you've built. You have these insurance professionals, your financial advisor, your estate attorneys, your tax planning professionals, all of which we can help you to really think through what are those next steps that you should take to make sure that you are well cared for, protected in a position of strength from the financial perspective so that you can really focus on support groups, coming to terms with the diagnosis. Really validating what is most important to not only myself but my family given this change in our family makeup and dynamic now.

I mean, it is a bit of a change, but I do think too, I work with clients who at the beginning, there is some shock at times. There maybe is a little bit of just grief over who they have been and worried about, am I going to lose myself in this? Am I going to lose my spouse in this? And how do we maintain as much of us or as much of me through this process? But there's also a lot of opportunity in there too. I mean, I've worked with a couple of clients who they loved work, they loved working, so they didn't ever officially retire because it brought them so much joy.

Well, with this diagnosis, they decided, okay, I'm going to officially retire just based on re-prioritization of things. And they were able to spend the next handful of years checking every trip off the bucket list, spending all the time they could with kids and grandkids. Really what is most important, it's a great kind of check along the way of saying, am I spending my time the way I really want to? And okay, let's revisit what's important, and maybe we've planned and planned, and let's take advantage of the insurance policies we have in place. Let's make sure that we have all the appropriate estate planning documents at our fingertips and ready to go. And we've worked with our financial advisor to know from a cash flow perspective we can do this, and let's enjoy the time together.

**Kim Insley:**

Yeah, take the burden off of trying to figure out or thinking you can't do it, because sometimes you can do a lot more than you think.

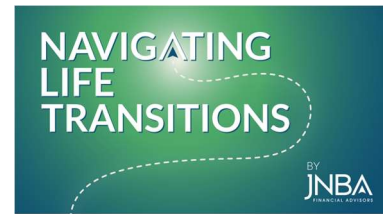
**Elise Huston:**

Right.

**Kim Insley:**

As we wrap up, Jayne, any thoughts you want to leave people with?

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**Jayne Clairmont:**

I think, at least what I was listening to, and it was so special about the family, but there are individuals that don't have family. And today when I was visiting with a couple, we talked about the give back in life sometimes, and maybe now you can go and volunteer and you're able to do some things. And I mentioned, and when I came into JNBA today, there's piles of coats for the coat drive. And I have flyers that I keep in my car because I'm on the board of the Salvation Army. There's so much that still is so rich in life, what do you want to do? So, it's being able to match up maybe some value-added opportunities beyond just maybe travel, beyond just family that gives you that sense of myself, I'm giving back to others. Then you feel so enriched.

**Kim Insley:**

You are valued. Yeah.

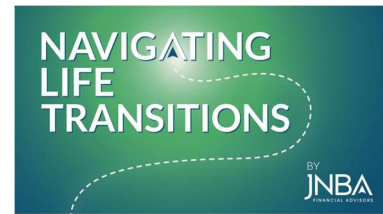
**Jayne Clairmont:**

You are valued.

**Kim Insley:**

Thank you both for being here. I really appreciate it. It's a good conversation, and I want to thank you for listening as well. And we hope that you will listen to all of the other JNBA Navigating Live Transitions podcasts. We've mentioned a few of them, a lot of resources available there. You can see the full list online at [jnba.com](http://jnba.com). There's an insights tab to get to the podcast page. And if you want to learn more about how JNBA can help you with your financial life goals, transitions, etcetera, planning, call them at 952-844-0995, or you can use the contact form on [jnba.com](http://jnba.com) and you can schedule a complimentary, no obligation call with their experienced and multi-generational team. So, thank you again for listening. I'm Kim Insley, and I look forward to navigating more life transitions with you on our next podcast. We'll see you then.

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