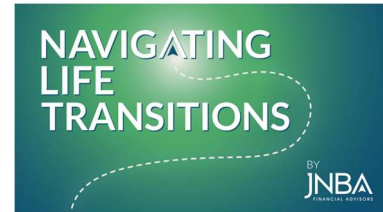


# Podcast Transcript: Navigating Care of Aging Parents



**Kim Insley:**

It's so good to see all of you here and to see some familiar faces, and you made it early on a, what day is this? Thursday morning.

I know. I'm semi-retired, so a lot of times I wake up, "What day is this? Is there anything happening today?"

There's a great thing happening today, and that's you're here. One of the things I really love about JNBA is they really live what they talk about. They really do care about what's going on in your life, and to be able to be in a place to discuss something that all of my friends are discussing and many of us have lived through in a real meaningful way, and to take that home with you today is fantastic. Thank you for being here. Just to let you know, we are recording this on video as well as audio, and this will be available on our Navigating Life Transitions podcast, which I also get to host and really love doing that.

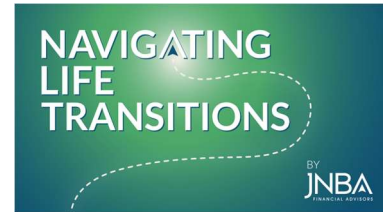
Navigating care for aging parents is tough, right? And for many of us, you don't get trained up for that, you just find yourself in the middle of it. And it could be a loved one, could be an aunt and uncle, a sibling, you just never know when it's going to happen. It's just when it does, you realize you're not as prepared as you think you should be. So, we're all part of this journey, and part of the journey today is to get a little engagement from you all. So, on the table you will see a QR code, and I want you to get your phones out and you're going to scan that QR code. If you need Wi-Fi, it's Westin VIP, but I think the reception in here is pretty good. Scan the code, you'll press on the URL that appears and you should see a Slido thing. Everybody see that? Hands up if you can't see it.

You're going to see a question on there. We're going to ask you to choose up to two words that describe how you feel when supporting your aging loved one. We're going to see a word cloud appear as you start to answer those. Patient. I like patient. Patience is not my strong suit, so. Overwhelmed. For sure. And the bigger the word is, as you all know from your many Zoom meetings, that's what a lot of us are feeling. Scared, love. For me, it was understanding that it was an honor, even as tough as it was, that it felt like I was privileged to be there doing that. Worried, obligation, honored, anxious, grateful, stressed. Yeah. Let's leave that up there as you continue to answer that question. Tired. Yeah. Uncertain. We want to take some of the uncertain. Well, is that promising too much?

A little bit of the uncertainty because you'll get some answers from the people who are to my left here because they've been through it and they have some interesting perspectives, and we had some calls beforehand so that I could get to know them a little bit better. And they're all wonderful, very accomplished people who found themselves in a sea of uncertainty and anxiety and stress and love and feeling honored. And these are all really accomplished people who know this stuff, but when it's you, it's different.

We're going to introduce everybody. Kim Brown, immediately to my left, President of JNBA. Stephanie Rossi, who is a Senior Advisor at JNBA, and her husband Michael Rossi joining us today. He is a nurse who works with hospice clients, so he has a lot of background in that. And Mike Dummer, who is a physician who has also worked in the field of hospice care. Everyone has lived through this aging parent journey, and each of them is going to start by telling a story, a

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little bit about your loved one. Kim, we're going to start with you, and Kim is going to speak about her mother. And I want each of you to tell me first a little bit about your parents and then the journey that you went through, Kim?

## **Kim Brown:**

Okay. Hi, good morning, everyone. Thanks for coming. My mom was a very fiercely independent person. She was widowed, her name is Kathy. She was widowed at 55 when my dad passed away. She never remarried. Her career was a surgical nurse. She worked at Cook County Hospital in Chicago before she moved to North Dakota with my dad. And for most of her life, she was healthy. She was a breast cancer survivor. She did end up having a heart attack and a pacemaker. But the last seven years of her life, I think what was the hardest is she suffered from macular degeneration so she slowly started to lose her eyesight, which that in itself, I will say is a challenge for many facilities. So, if you ever have parents that have that issue, that's something you really need to talk to them about.

But she did well until about the last, she lived independently the entire time. She would rather have been shot than go to assisted living is what she told me, so she did not go to assisted living, which put a lot of pressure on me and my family, mainly me. But I did have good support. I was away from work more often than I wanted to be some days, but the team was very supportive, and I had a very supportive assistant that helped. And in the last year of her life, she struggled, and then we made the choice for hospice, which was also a really big learning for me that I'm happy to share anytime Michael and I talked about that process, and I'm just going to say ask a lot of questions because all things are not created equal.

She passed away, and that was sad and hard. But I'm grateful for the lessons I learned because I do think that one of the things that we can do in life is pay it forward, so that's why I was excited to be on the panel, and I am excited to be a resource for our clients. I did a lot of things right, but I did a few things wrong and we all do so I hope that you know we will always be a resource for you. But that's my mom. She was a fighter until the end and a tough cookie.

## **Kim Insley:**

Yeah, Cook County Hospital, for sure. And she raised a great daughter. Mike Dummer is joining us as well. And Mike, your mother was.

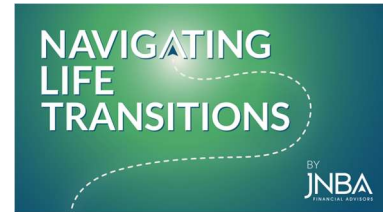
## **Mike Dummer:**

Rosemary.

## **Kim Insley:**

Yeah. Tell us a little bit about Rosemary.

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## **Mike Dummer:**

Yeah, my mother was, again, fiercely independent, very vibrant, outgoing person. Autonomy was her big thing. She wanted that more than anything. She started out as a; my father was a physician. I was a physician as well. So, she transferred to me after my father died. I was the one that she came to, although I had three other siblings who were involved. Two of them were out of state, but the other one that was here and their spouses and my spouse helped with her care as well. But she looked to me to support her the most because like I say, I looked like my dad, but he was better looking.

But anyway, she went back to school to the University of Minnesota at age 40 and got a master's degree and then became a marriage and family therapist and practiced until she was 78. My father died 15 years before she did, she died last year at 97. The big thing about my mother was something she kept hidden from everyone except the family, was she was severely bipolar, which meant in the first, her episode was when she was 20, then 40. So, the first episodes were very spread out, but they were severe, she was hospitalized. The only thing that ever worked was electroshock therapy. No meds ever worked on her, and she became more and more severe as she aged, so she'd have three to four episodes a year where she'd become completely dysfunctional. At some point, we'd have to feed her because she couldn't do anything, and then she'd get her shock treatments and then she'd be back out driving and working and doing stuff.

We had to take over fairly early on, and it was a case of not her asking, we just had to take over because there was no other way to do it. Her living progression was that she lived in a large home for five years after my father died but eventually realized she needed to live in a more structured environment so she moved into a senior apartment in a very nice place that then had assisted living. When she did an attempted suicide at one point was down, and that took her down for a while, and we realized after that she couldn't drive. The driving was the main thing that then said we have to go into assisted living because she couldn't go shopping, she couldn't get to her hairdresser, which she had to do every week at least once a week.

And so, then she went into assisted living for three years. Then ultimately, when she couldn't get her ECTs or shock treatments anymore, then it was just a roller coaster constantly, and she ended up in the nursing home. With that, she also started gradually getting some dementia, couldn't walk. That was the main thing that pushed her into the nursing home. And then as I say, she went into hospice. She graduated from hospice somehow. Supposed to have six months to live, and she lived a year and a half on hospice or something like that but ultimately died last year.

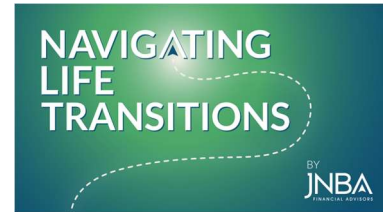
## **Kim Insley:**

Okay. Thank you, Mike. It's a long journey, right?

## **Mike Dummer:**

Long journey.

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## **Kim Insley:**

You made it through. Stephanie and Michael. So, a lot of you, we have spouses here in the room who have been on the journey with their loved ones as well. Stephanie and Michael went through the journey as well, first taking care of Stephanie's mom and then Michael's dad. Stephanie, tell me a little bit about your mom.

## **Stephanie Rossi:**

Yeah, so my mom, I think her picture's up there, you can see how sweet she was. She was always sweet her whole life. My mom was a newspaper reporter for 45 years, so that was back when newspapers were a big thing, and she was so proud of herself because she didn't get to go to college, but she was able to become a newspaper reporter. My dad passed away at 64, so he was very young when he passed away, and my mom did not let that hold her down, I can tell you. She loved life. She loved people. She honestly never said a bad word about anybody, and I can say that I know my husband can vouch for that as well. She loved to travel. When she retired, she traveled internationally with her siblings and just had the best life.

When she started to slow down a little bit, she started to help us with our kids. Our kids were little at the time. We actually had just built a house, and we made sure that she had a room in our home where she could really come and go for the first, well, until actually we moved out here to Minnesota about 13 years ago. It was a natural progression with her. It wasn't that she was living on her own, she was always part of our family and always there. Every vacation she would go on with us; every little travel she would be with us.

When we moved out here to Minnesota, she was about 80 years old and a lot of her friends were passing away unfortunately, she had a lot of friends that were older, and I said, "Mom, I feel like you should come with us."

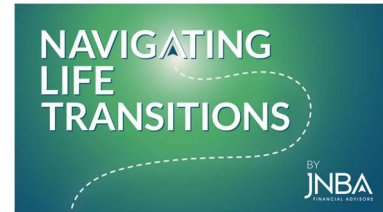
She said, "Okay, I'm up for an adventure. Let's go."

So, she came with us, and then honestly, probably five to six years after being here with us, she started to develop dementia, and it got progressively worse along the way, and it was hard. Dementia is a really hard journey for you to watch somebody go through, especially somebody who was so vibrant and loved life. I did bring this with me. She left me about a hundred of these, believe it or not. My mom, because she was a reporter, she loved to write things down, and she kept this journal, and I'm going through them. It's fun to see. She loves everybody. Nothing bad about anybody ever. I haven't found one yet where I did something wrong, which is great.

My husband and I ended up taking care of her, and we kept her home the whole time. She did not go into a facility, she was with us. My husband's a nurse. He worked on the weekends at nights, and I, of course, was working during the days so one of us was always there. We could not travel together, just the two of us. I mean, I know a lot of the JNBA people will say you never really saw us both at an event for about two years because we couldn't leave her, but my mom died last summer at the age of 92.

We were on our last adventure actually. I'd taken her to see my sister in Pittsburgh, and she got sick, which she had a blockage and got very sick, and that was the end. She passed away within a

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month and a half after that. I was the main caregiver, obviously talking through her living with us. But my brother passed away very young, and my sister had cancer, so we couldn't have the help from them, so we took it on. But it was a blessing. And quite honestly, my sister and I at the end both had about a month with my mom together, and it was probably one of the biggest blessings that we could have had. So, miss her terribly for sure.

**Kim Insley:**

And during all of this, so as your mom was declining, Michael, your dad was starting to, he had had issues, but they became more acute, and you became involved in his care directly?

**Michael Rossi:**

Yes.

**Kim Insley:**

Tell us a little bit about him first.

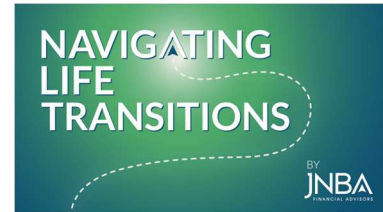
**Michael Rossi:**

My dad? All right. Stephanie's mom was the greatest patient, greatest mother-in-law anybody could ever ask for. My dad, he's a pain in the butt. As a nurse, he was the kind of patient I'd pass off to another nurse, trust me. I didn't have that choice though. My dad was a; it's kind of a funny story. He was basically a gangster from Detroit. He died at 93, but a long time ago, my mom was a small-town homecoming queen and from Pennsylvania and said, "I'm not going to live this lifestyle. You're going to change or we're going to change."

And my dad decided to go with my mom instead of going to Vegas and run a casino and became a barber in a small town in western Pennsylvania and steel country. And some 10 years later, my mom asked my dad, she said, "Frank, you've fallen away from the church. I want you to start coming to mass with me," and for the last 60 years of, probably 50 years of his life, he went to daily mass with my mom. And from the lifestyle he led to what he became, at his funeral, he had two deacons, five priests, one being his grandson, and the bishop showed up for his funeral. So, it was total story of redemption for, yeah, dad, you were a pain in the butt though. That is his story.

But during, yes, my mom passed three summers, three years, three and a half years ago really. And at that time, my dad had to come and stay with us for most of the time. My brother and I, my oldest brother's a physician, and I'm a nurse, so we basically took care of our parents. My brother is, he's a physician, so I'm sorry Mike, but physicians stay with their patients for five minutes, nurses stay with their patients for 12 hours. My brother was really good at fixing the machine, but I was my dad's buddy, so he always wanted to come and stay with me, so he came and lived with us, and he lived with us through the entire journey of Steph's mom and then lived another year longer.

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My brother and I shared his care, and it went really well. We gave him the best care that we possibly could. It was very difficult at times, and I'm sure we'll talk about some of the things that you have to do, giving up car keys and things like that. But yeah, it was a really good experience. Like I said, I would take care of Stephanie's mom over and over again but taking care of my dad was very challenging.

**Kim Insley:**

And a lot of travel between you and your brother.

**Michael Rossi:**

Yes.

**Kim Insley:**

Did he pass at home or in a hospital?

**Michael Rossi:**

He passed at home.

**Kim Insley:**

Okay. So, you've heard a lot of stories. What amazes me is how accomplished everybody's parents were, including a gangster from Detroit. You don't hear that very often, right? I'd love for you to take out your phones one more time and connect with that Slido question, which is what caregiving tasks or responsibilities do you wish you understood better when supporting your aging loved one? Or what do you want to know about if you're not at that point yet? Because not everybody is, and you never know when it's going to happen.

Managing household tasks and safety, yes, because I assure you, none of your parents want to go into assisted living unless they've really planned in advance, which the JNBA people will talk to you about. They all think they're going to stay home, and they all think they're going to be really healthy until they're not. Navigating healthcare systems, we have some experts at that. Lots of questions, lots of things, and I'm now in your way. Coping with caregiver stress. Let's start with the first one. Coordinating in-home care and assisted living. Who had that situation, because a lot of you were very hands-on and the only caregivers? Kim, you're.

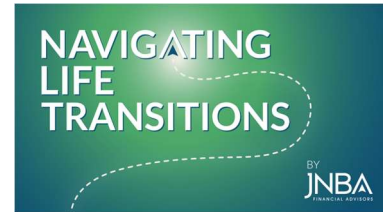
**Kim Brown:**

Yeah. I didn't have at-home care though.

**Kim Insley:**

Okay.

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**Kim Brown:**

My mom lived independently in a facility and then when she got worse, I wanted to be closer to it because she was 45 minutes away from me in Chaska, so I moved her closer to me, but she was still living independently, so we never did bring care into her home.

**Kim Insley:**

You dealt with hospice though, and I know that all of you, not all of you, but most of you did deal with hospice at some point and you had some really strong feelings about that.

**Kim Brown:**

I do.

**Kim Insley:**

And asking questions. You feel like your mom, you think you could have waited a little bit?

**Kim Brown:**

Yeah, I had a really bad experience with hospice personally. I was in New York with my nieces, my mom fell, and thinking back on it, my mom did not have any memory issues at all. She was always very, very with it. She was always, she knew what was going on, she knew everything. And so, I got a call from my sister-in-law and she's like, "The hospice nurse is saying we should start the process."

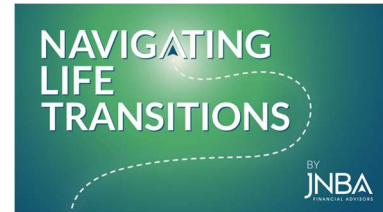
And I said, "Well, she fell. She's probably in pain. She's probably got something going on."

But what I didn't understand is hospice is hospice and they're not going to do things to help you. It's about your comfort only. It's not really about helping you to stay alive longer. And the experience that I had with the physician at the hospice that we used was not very good. My mom had lymphedema severely, and one day I came, and if you're familiar with lymphedema, you can get, I mean, her arm was massive. And so, I called hospice. I said, "We need to get somebody to come and wrap her arm. And they told me no." So, I found it through a friend of mine. I found an independent service and a wonderful lady took care of that and did all that.

But ultimately, for me, the hospice experience was bad. And I guess what I would say is when, this was my experience only so I'm not being judgmental, but if your parent is in a facility and not at home, I asked the facility who, I imagine you work with hospice quite a bit, who do you work with and who do you prefer? I just went with what they told me. And if I were doing it again, I would interview hospice organizations, and we're working right now on a list, and Michael's going to help us, for our clients to be able to ask the right questions.

One of the things that was really horrible is my mom never had the same nurse, so it was a horrible experience, and I actually was able to have a conversation with the head of the hospice, and I do know that my comments and complaints went to their board. I don't know if that would matter, but it's a really important choice because in that moment when that process starts, you are not in a position to really think straight because it's happening. I never had to coordinate

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care. When we signed hospice, we had them for four months, I guess, but they didn't really, again, I didn't really understand the difference between what was the facility going to help with. And the thing I will tell you is once I put my mom on hospice, the facility that she was in just was like, "Okay, well now, she's on hospice and they'll watch her. They'll take care of her. We're going to do not much." I didn't understand that either. So, I was just uneducated and I have so many resources, but I'm a, I don't want to bother people, but I'm just going to tell you, bother people ask a lot of questions because then you won't have any regrets.

**Kim Insley:**

Yeah.

**Mike Dummer:**

I would just like to comment. I was a hospice director for about 15 years of my life out in a rural town, and I would say, and I've had, my father was in hospice, my mother was in hospice. We've had different experiences all along. And I think just like any system that involves people, there are infinite ways to fail. So, hospice itself is a good idea.

**Kim Brown:**

Yes.

**Mike Dummer:**

But you have to remember that you are the advocate, you're the primary advocate for your loved one, and you cannot let that go. You have to be advocating. I always said when patients came to me, and complained about something, I said, "I don't look at you as a squeaky wheel. I look at you as information. You're giving me information. We're doing this as a team, and I need that team member. I need people to tell me what they're seeing that I'm not seeing." Nurses are the absolute, they save my life every day, and patients' loved ones have to be there.

And the trouble is when you hear that no from hospice, you have to be able to say, "No, this is what you're going to do."

For example, when somebody falls and breaks their leg on hospice, hospice, their philosophy is to not hospitalize. But if you break a leg and the bone is ticking out someplace, you do that, and what hospice can do then is just sign you out of hospice-

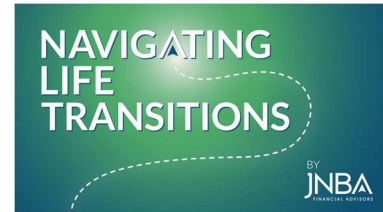
**Kim Brown:**

Right, they sign you out.

**Mike Dummer:**

... because they know they're going to do that, so they have to do some certain things. But otherwise, it's generally a good program. But there are infinite ways to fail.

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**Kim Insley:**

We had a similar experience with my dad. Michael, what's the difference between hospice and other kinds of care? What is that differentiation? And then I want to get in with you, you had some points to make with regards to legal stuff that you should have in line for any of this.

**Michael Rossi:**

Well, I mean, I agree with Kim, I think you should look at the different hospice organizations. I'm involved with one now that I feel goes the extra mile, a lot like JNBA does for their clients as far as financial is concerned. But you definitely should review and interview, and you have a choice as to which hospice organization you want. Steph's mom had a great hospice experience.

**Stephanie Rossi:**

Was amazing.

**Michael Rossi:**

It was absolutely amazing. We were blessed to have it.

**Kim Insley:**

If I may interject, what made it great, Stephanie?

**Stephanie Rossi:**

Yeah, so first of all, it's actually the hospice that Michael works for now. That's the reason why he went to work for them.

**Michael Rossi:**

That's the reason I went to work for them.

**Stephanie Rossi:**

These people were so caring and so amazing with everything that they did. They helped, obviously with my mom wasn't in any pain, but we had all the pain medicines. We had the same nurse all the time, which is, that's a big deal. My mom actually got really used to the nurse and the other team members that she loved them. She just felt really comfortable with them, and they were there all the time. I mean, I feel like somebody was there at least once a day.

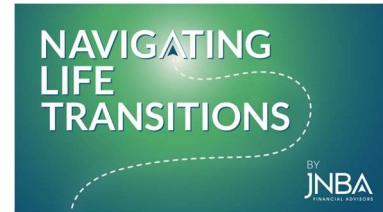
**Michael Rossi:**

Every day.

**Stephanie Rossi:**

Every day. And they were kind, and I just felt like she had a really, really peaceful end of life.

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**Michael Rossi:**

So, some of your hospices, you'll have the corporate mentality, and like Kim said, the facilities will say, "Well, hospice is taking care of you now, so we're done with you," and that is true. It's sad, but the ones that advocate not only for the patient but for the caregivers as well is very important.

Our hospice nurse took a night and said, told me and Stephanie, "When was the last time you guys had gone out to dinner together?"

And we said, "Well, it's been a long time."

And she said, "Well, Saturday, set a date. I'm coming to stay, and I'll watch your mother-in-law and I'll watch grandma." And we went to dinner. So, I mean that's, talk about going the extra mile.

**Kim Insley:**

It's the people. It is the people.

**Michael Rossi:**

It is the people that you're concerned. And the one thing I do regret is they were so good, I wish we would've, and this is something that you might want to think about. I wish we would've started it sooner. When people think of hospice, they're thinking someone's on their deathbed, end of life. And as Mike said, his parent graduated from hospice, and that's fine, that's beautiful. There's nothing wrong with that, but at least they were there, and you do graduate and then you go back in and then you graduate again. I mean, it can happen. That's absolutely fine. There's nothing wrong with that.

And if they get an infection or something goes on, they get discharged, they get treated and then they come back, but it's all about comfort. But not only comfort for the patient, it's comfort for the caregivers as well. There is such thing as caregiver strain. I think that was one of the words on the board. And caregiver strain does exist. It's very hard, and it's very hard for people to experience for long periods of time. And you feel guilty because it is one of your loved ones.

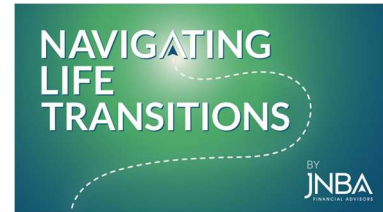
**Kim Insley:**

It is something that everybody needs to be aware of. In the interest of time, I am going to move into something that you brought up, Michael, and Kim, I know you can speak to this as well, but whether your loved one, wherever they are, there's going to come a time where you're making decisions. If you don't have the proper legal documents in place, you're not going to be able to do some things. And you were pretty insistent about that legal end of it. Michael, can you quickly go through some of the things that you believe people should have in place?

**Michael Rossi:**

Well, they should definitely have a healthcare directive. I mean, that's very important. Will.

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**Stephanie Rossi:**

Power of attorney.

**Michael Rossi:**

Power of attorneys are very important.

**Kim Insley:**

Did power of attorney come into play for any of you?

**Stephanie Rossi:**

It did for me.

**Kim Insley:**

It did?

**Stephanie Rossi:**

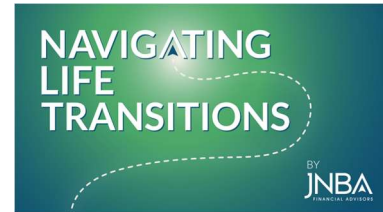
Yes. So, when my mom got sick in Pittsburgh, she was out, so nobody knew who was allowed to act on her behalf. So, I actually called the office, Corinn, if you know Corinn got actually her power of attorney and healthcare directive. They wanted both of them, and I had them within literally two minutes, and everything was smooth after that. But yes, they asked me for those immediately when we got to the emergency room.

**Mike Dummer:**

I think there's a legal difference, a little bit difference between a healthcare directive or advanced directive or a living will, which is supposed to only come into being or into use if you cannot speak for yourself and you have a terminal diagnosis. A legal power of attorney for healthcare needs can come in before you have a terminal diagnosis. For example, with my mother, we had her sign it when she was 50 years old because when she hit her skids, she was completely incapable of making a decision, any decision, and would never sign for her ECTs, her electroshock therapies so we had to direct those ECTs. We had to tell the doctors, "She needs it now," and we had the power of attorney to do that. So that was extremely crucial to have that document.

The other thing I want to say about healthcare directives or advanced directives or living wills is they're not just for old people, they're for young people, everybody should have one because old people are going to die anyway. But young people, let's face it, sorry. But young people are the ones that get a brain injury or something and then can lay and be on food pumps and things like that for years and years, even though they would never have wanted it. So, I think an advanced directive is something we should all fill up. It doesn't come into being, it doesn't mean you're not going to get care. Doesn't say don't do CPR. It doesn't say anything like that usually, unless you

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have a terminal illness. If they know you have a terminal illness, okay, it's a different story. But if they don't know you have a terminal illness, they're going to do CPR.

**Kim Insley:**

Yeah, just give you a second to swallow. Any thoughts on legal documents? Because I know that's something the team talks to every client about.

**Kim Brown:**

No, I agree with all of them, and I think everybody should have every legal document in place that they need to have in place as soon as they can get it done. But I will say the one thing that I think there's unspoken words, I think sometimes between siblings, and I think it's important that every sibling knows where the parent is because like you said, you can take somebody off of hospice, but I'm like, "Mom doesn't want to go to the hospital again."

"Well, I want her to."

"Well, she doesn't want to, and she couldn't tell us."

And so, I just think those conversations are really important because the documents of course give you the power, but there's that emotional thing about, "I didn't know Mom thought that" or, "Did Dad really say that?" So, I just think those family conversations are really important.

**Michael Rossi:**

We had a lot of that in our family. I mean, we have six physicians in my family, and we're sitting there taking care of my dad, and you got six physicians there arguing and each of them has an opinion on what to do.

I'm just like, "Okay, dad, here, come with me. We're going back to Minnesota." They'll figure it out and tell me what they want.

**Kim Brown:**

Actually, this is funny. There's a lot of medical up here because my dad was also, he was a thoracic and vascular surgeon.

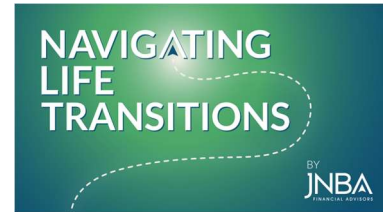
**Kim Insley:**

High-powered group here. Did any of you have difficulty getting? Yes, wills, trust, everything, have it all, okay? Because if you don't have it there, it's not a good situation. I had the hardest time getting my mom, so I was supposed to be the healthcare person. She's like, "Oh, you'll just know when it happens. You'll know what I want."

"What do you want?"

"Oh, you'll know." I had a really hard time getting her to fill out her, she was at the point of where do you want a do not resuscitate? And we had to have the doctor come in and tell her what that process would be. What would CPR be on a 94-year-old woman, and how would that

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look for her and what would the outcome be? Did you have difficulty with your parents getting them to express their wishes so you could have that? No direction at all.

## **Stephanie Rossi:**

Now my mom actually, I mean obviously we're advisors. She has always had her documents in place, and we actually had to redo them when we moved out to Minnesota, so she was good.

## **Mike Dummer:**

My mother, when she was well, not when she was depressed, when she was well, when she moved into the nursing home, she made a statement to the doctor and I told the doctor, "You write that in the chart."

The statement was, "If something comes along that hastens my death, I welcome it."

And I had to refer to that frequently with the nursing staff that this is what she wants. This is not me, it's not my brother's, it's what she wants. And this was when she was good.

Frequently she would say, "Michael," because she was fiercely, she was a very independent person, and she used to take a bath every night and in the nursing home, she got a shower once a week. She hated that. And she just said, "Michael, can't you get me the pill?"

I said, "Mom, it's not legal. I can't get you the pill."

## **Kim Insley:**

She wanted to commit suicide.

## **Mike Dummer:**

Yeah, she wanted to be out of here. I said, "Well, isn't there someplace I can?" And I said, "Well, I think in Portland we can."

"Well, let's move to Portland." She was clear.

## **Kim Insley:**

You find yourself having conversations you never expected, and if you get it done in advance, it makes it a lot easier. I do want to leave some time for questions. So, before we get to that, I'll have each of you, if you would please, give us lessons that you learned. And sadly, it's got to be brief, but what did you learn and is there anything you would do differently, Kim?

## **Kim Brown:**

I think just really simply, just find resources. If you've never been through it, find resources, because everybody learns something through the process. And also, it is a really important decision if you're going to move your parent into a facility. Just make sure it's a really good fit and that they understand the needs of your parent or whoever you're taking care of because not

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all facilities are the same. The head of nursing matters a lot, and I just think the environment is important, and so I just would ask a lot more questions, I guess.

## **Mike Dummer:**

Okay. I think I've already said it, but basically being a squeaky wheel is your job as a loved one. You have to be the squeaky wheel and be advocate because there's nobody else that's going to advocate like you can do.

The other thing is I learned, I didn't know this, there's a patient bill of rights in the hospital. I gave those out a thousand times. I didn't know there was one in the nursing home, but there's a nursing home bill of rights. Get it, read it. For example, in my mother's case, she was doing some choking and had some difficulty with that, and so they wanted to change. They had somebody see her and say, "Oh, she needs to change to a different diet."

She said, "Michael, it looks like somebody threw up on my plate. I don't want to eat this."

I said, "We are not going to do that."

So, they came back and said, "Well, you have to."

I said, "No, here's, in the bill of rights, it says you have the right to refuse specifically changes in diet recommended by the facility. There it is, right there." So, knowing those kinds of things also very helpful.

## **Kim Insley:**

That's a good one. Stephanie?

## **Stephanie Rossi:**

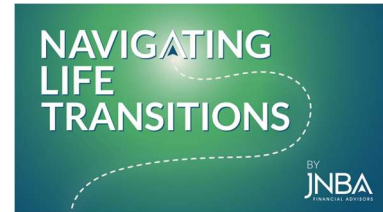
I would say talk to people that are going through similar situations. I can tell you we have a really good support system. My friends from college are all going through these same things with their parents and just sharing and knowing you're not the only one that this is happening to is really, really important.

The other thing that I'm just going to reiterate what they said about advocacy. Remember, you're the one that knows your family member the best and what they need, and you can see what's happening to them as they go downhill. I would say always advocate for them. Don't let them feel like they're alone. They're scared. I saw some of the things on the words up there that scared was one of those for you, but your loved one is scared too. And so, I would just say love on them all you can, that's the most important thing, and be their advocate.

## **Kim Insley:**

Michael?

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**Michael Rossi:**

You're going to make mistakes. You're not perfect no matter how hard you try, but just do the best you can and don't feel guilty in the end. That's all. There's no reason to feel guilt when they do pass that you could have done more or something like that. You did the best that you could, and you love them, and that's all you can do.

**Kim Insley:**

Thank you for that because we all feel guilty 100%. You look back and say, could I have done something different? And yeah, you did the best you could. We have one question that was submitted, and then if you have questions, please raise your hand. And also, Jonathan, can you raise your hand real quick? So, he has a business here in town with Radha, his wife, where they help people choose care for elders. And often people come to him, come to them when it's a crisis, but you can come to him before it's a crisis, and he's a guest on one of our podcasts we'll be talking about.

If one parent has early dementia and the other is taking care of them saying, "I'm good," and they're living in their current home, how do you get them to understand the importance of getting on the list for assisted living? Having that discussion, I mean, everybody thinks they should be the caregiver for their spouse, and they don't want to give that up and they don't want to put that on their kids. And if there's dementia involved, it's even harder. Michael, I'm going to start with you because you had a similar situation.

**Michael Rossi:**

Yeah, we had that situation. My mom had dementia for two or three years prior to her death, and my dad was taking care of her, living near my brother. My brother actually ended up building an apartment onto his house, a separate actual apartment attached to his house so that they could reside there the last few years. But my dad was very adamant that he was going to take care of my mom until the end, and it grew too difficult for him to do. Luckily, we had the resources that we were able to take them in, but we had to definitely keep them closer to us at that time.

**Kim Insley:**

But how did that conversation go?

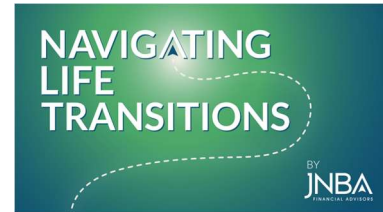
**Michael Rossi:**

It was very difficult.

**Kim Insley:**

How did you navigate that?

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## **Michael Rossi:**

It was very, very difficult. My dad was very stubborn about it. He was independent. "Me and mom are fine. I can take care of her."

And just eventually it was just, "Dad, you can't do this. It's not safe. The best thing for mom is to come and live with, come over to our place now."

And I think in the end, he felt guilty because of the expense my brother put towards building the addition. And he's like, "All right, well, you built this addition for us, we might as well use it."

## **Kim Insley:**

A lot of times there's something that precipitates, if somebody falls, somebody gets hurt and then it becomes apparent. But anybody else have any advice on how to talk to a parent?

## **Kim Brown:**

I didn't have that with my mom, but we had it with Richard's parents. Richard's dad was getting memory issues and was getting to be a lot for Judi, who is still doing great, living independently at 93, but it was just wearing too much on her. And this, I think is the bigger thing. I think that's hard. There is a balance between what they want and what you know is right, and that's the hard thing because it is their life, but it is, but it isn't because now it's part of your life.

And so that was challenging, but we just basically said, "You can't do it anymore, Judi. He's too much for you. We need to move you and we're going to do it," and at first they didn't like it, but then they were glad they did it, and we just made that decision, and that was how it was going to be.

## **Mike Dummer:**

I would just add, I think there's a transition between reasoning with people and then managing. At some point you just have to realize, "I have to manage this. I cannot just reason with them."

## **Kim Brown:**

That's a better way to say it.

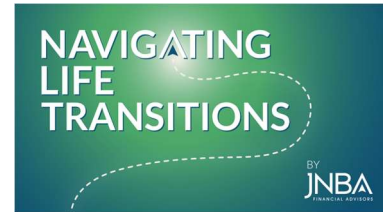
## **Mike Dummer:**

I always said that in my life as a hospitalist, I dealt with a lot of alcoholics and I have to say alcoholics were people I couldn't reason with, I had to manage. And that's what I realized with-

## **Kim Insley:**

Kim is a president of an organization, and so she's speaking from how she does that. Does anybody in the audience have any questions at all? I have a question. In terms of being the caregiver, what were some lessons you learned about being a caregiver, whether it's taking care of yourself or some great trick that you learned? Michael, we'll start on that end of the table.

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**Michael Rossi:**

Well, I mean, I became a nurse because I knew I was going to have to take care of them someday. So I made a change of career 13 years ago, and I'm glad that I did it.

**Kim Insley:**

In terms of being a caregiver, and you spoke about date night, a lot of caregivers, they think they'll go 24/7, and that's not good.

**Michael Rossi:**

No, that's not. You do have to take care of yourself. It's very different. And it's important that you take care of yourself because if you take care of yourself, you take better care of your loved one as well.

**Kim Insley:**

Stephanie?

**Stephanie Rossi:**

Yeah. So, I have to admit one thing here. We're obviously advisors who recommend that people buy long-term care insurance, and my mom did have a long-term care policy that we really didn't use much, and we should have used it more to have people come in and give us a little bit of relief. And we didn't do it because I didn't want to admit that she was in the state that she was I think at that point. But I'll say if you have the policy, use the policy, even if it's for a little bit of R&R for you. I mean, there's a lot of policies that do have times where you can leave for a couple days and they'll take care of them. And I think that especially if it's a situation that's going on for a long time, you need it. You really do need it.

**Kim Insley:**

We have a whole podcast on that, long-term care insurance. Mike, do you have anything to add about taking care of yourself as a caregiver?

**Mike Dummer:**

When you put up that thing with one word that people, or two words or something, I came up with four. I couldn't come up with two, which means I talk too much. But no, the first one was actually second-guessing, the uncertainty. You're always going to second-guess yourself. And the second one is emotional rollercoaster because it goes up and down and that emotional rollercoaster for recognizing that death would be good, but on the other hand, you know you're going to miss them and it's just you swing between one and the other.

The other thing I think I wanted to say back when you brought up, what about in-home things? From my father, we had some in-home things. It was something like Caring Angels or somebody like that that came in. They were great. They came in, they knew him. It was the same person.

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They came in three times a week, and eventually when he couldn't stay there because he kept falling and he was too big, they couldn't pick him up. They said he's got to go someplace. That was very helpful.

Also, palliative care is something that's short of hospice. Hospice, you have to have a terminal diagnosis. Palliative care, you don't. And that's, I think, a Medicare paid for service that you can get on palliative care and have some home health aid come once or twice a week or things like that. That can also help. So, looking into that, that would be a good thing for JNBA to just put together so maybe there's somebody that has a list of resources where they are and how you can get those things.

**Kim Insley:**

Good handoff for you, Kim.

**Mike Dummer:**

Good handoff for Kim.

**Kim Brown:**

Well, so my mom did not want any help from anybody, but pretty much me or my brothers, but they were very busy, she would remind me. My assistant, Marie, she loved Marie. It was crazy. I mean, I did my mom's grocery shopping and then I would do my grocery shopping and my mom needed everything specific. One banana, two tomatoes. Not that brand. Not this brand.

**Kim Insley:**

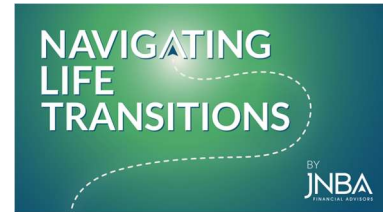
We had the same mom.

**Kim Brown:**

So that was crazy. And then she did not like the food in the facilities, and I think that's a universal comment when you talk to people who live in the facilities. She did not like the food, so she always wanted to go out to eat because food was her life. My mother loved food, so it was always going out to eat. That was interesting.

And then when we moved her closer to me and she was getting a little worse, she wouldn't even let the facility do her laundry. I was doing that and running back and forth, and so I just needed to do that. That was one of those things where I could have probably forced it, but then it was closer to the end, and I didn't want to have arguments. But if you have high-maintenance parents who don't want, I mean, she was a nurse and she did not want those people coming in and doing, the showering was a disaster for her, so I did that. She only wanted me. And then finally we got her to a place where she would use some of the services, but that's a real thing. Not every parent is like, "Oh yeah, thanks. Have them come in. I'd love the help." I had one of those parents that did not want that, so that was a lot of work.

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**Kim Insley:**

I think that that's not uncommon. We had caregivers come into my mom's home, which was the only reason she got to stay there as she very much wanted to do. And they were really helpful, and of course she hated it because she didn't want people in her house, right? So I mean, you just deal with it. But one thing I never had to do was the take the car keys away. Did any of you have to do the take the car keys away talk.

**Mike Dummer:**

My buddy.

**Kim Insley:**

I figure some of you might want to know.

**Mike Dummer:**

My buddy unhooked the transmission or something because they knew they couldn't take the keys away, so they just made the car not work.

**Kim Brown:**

That was a good idea.

**Michael Rossi:**

So yeah, it came down to where when my dad was with me, he couldn't drive because he lived, we were in Minnesota, and he wasn't familiar with Minnesota. "Dad, you want to take the car? Go ahead. You're going to end up in South Dakota." So that was easy.

But when he went back to Pennsylvania and stayed with my brother, it was time to take his car away and he thought he was going to be able to drive again. And I mean, sometimes you got to tell little white lies. "Well dad, the rule in Pennsylvania is once you turn 90, you got to go take your driver's test again and it's on a computer. Can you do that?"

He said, "Well, no, I can't do that. Well, what are you going to do? There's nothing you can do about it." And so, I got a call, "Will you come and get me? They're taking my car away." Actually, so that's how we ended up dealing with that one.

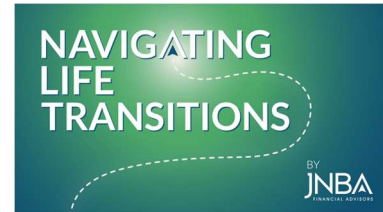
**Kim Insley:**

Subterfuge.

**Stephanie Rossi:**

Yeah. My mom was actually very easy with her car keys. We live in New Prague, so we're out in the middle of the country. And one day she got lost, going two miles. She was coming back, and

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she got lost and she got really scared and she handed me her car keys and said, "I don't think I should be driving anymore."

**Kim Insley:**

Wow.

**Kim Brown:**

Wow.

**Stephanie Rossi:**

And that was it.

**Kim Insley:**

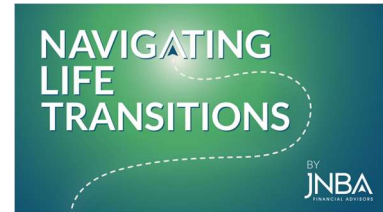
Yeah. My mom was in her mind trying to figure it out. There was a neighbor who had a son that she was going to hire and didn't quite get to that point, but every situation is different. So, you've heard some amazing stories. Really accomplished parents, and then you have to watch them need all of this help, which is hard for you, and it's hard on them, but there are resources. We'll talk about that in just a second. But I really want to thank all of you, Kim, Mike, Stephanie, Michael. Sharing these personal stories, I know is sometimes really hard, but it's really important because the more we talk amongst each other and the more we realize we're all in this boat, maybe in different stories, but we're all in this boat, it helps.

And somebody else who can help, of course, JNBA who hosted this event and its financial planning committee, they've developed a whole library of resources for you. Videos, podcasts, checklists, I encourage you to check them out. There's a podcast on Medicaid and medical assistance. There's a podcast on long-term care insurance. There's a podcast on navigating a dementia diagnosis. These are all with experts who have real information that can help you. Estate documents, power of attorney, important considerations when there is a dementia diagnosis.

And there is a link, you can go to the [jnba.com](http://jnba.com) website and look there, you'll find the information there. And on your table, you'll see a little card that you can take with you that has a QR code that will also get you right to those resources and I highly recommend it. And again, the Navigating Life Transitions podcast, which I get to host and I learn more, I learned so much. It's so helpful, I've taken notes. But check those out.

Have a great day today. Thank you for being here. This will be a podcast, so if you miss anything today, you'll get to hear it again in a few weeks when it gets put up on the website, so thank you all so much, and thank you.

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