

Daughterhood the Podcast

Episode #40:

Floating in the Deep End with Patti Davis

43:31

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SPEAKERS

Rosanne, Patti Davis, Whole Care Network

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Rosanne 00:43

Hello, and welcome to Daughterhood the podcast. I am your host Rosanne Corcoran Daughterhood circle leader and primary caregiver. Daughterhood is the creation of Anne Tumlinson who has worked on the front lines in the healthcare field for many years and has seen the multitude of challenges caregivers face. Our mission is to support and build confidence in women who are managing their parents care. Daughterhood is what happens when we put our lives on hold to take care of our parents. We recognize this care is too much for one person to handle alone. We want to help you see your efforts are not only good enough, they are actually heroic. Our podcast goal is to bring you some insight into navigating the healthcare system provide resources for you as a caregiver as well as for you as a person and help you know that you don't have to endure this on your own. Join me in daughter. Patti Davis is an author, activist, advocate and daughter of the 40th President of the United States Ronald Reagan. She is a frequent contributor to media outlets, including the New York Times and The Washington Post, and has written several works of both fiction and nonfiction. She is the founder of Beyond Alzheimer's a support group program for caregivers of people living with dementia. Her latest book Floating in the Deep End How Caregivers Can See Beyond Alzheimer's, recently released in paperback, is an extension of that support group. Part handbook part memoir, Patti offers practical and important strategies for every stage of the disease. I believe this book is a must read for Dementia

Caregivers. Patti and I discussed the book and the many ways your life changes as a caregiver, the power of showing up and the importance of support. I hope you enjoy our conversation. This is your 13th book. Yes. And one one that is written specifically for caregivers. Why was this important to you to share your experience through this lens.

Patti Davis 02:33

So in 2011, I started my support group Beyond Alzheimer's for for caregivers of people with dementia, and I ran it for six years, twice a week. The way I structured the group is I ran it with a co facilitator, I had several people rotated in as co-facilitators from the medical field either neuro psychologists or neurologists, because I wanted to medical questions that people had to be able to to be answered. And, you know, even if I actually had answers for some of those legally, I'm not allowed to give them. So that's how I created that group. And after I ran it at UCLA Medical Center for five years, then when there was an administrative change there and well, there was a change there. I moved it to St. John's Hospital and ran it for a year there. And after six years running it, I realized that my my life as an author was really being sort of eaten into I had a couple of unfinished novels that I started. And you know, it's not just about showing up twice a week to run a group. There's a lot more involved than that. So I really needed to get back to my life as an author also, quite frankly, in 2016, many times when I wrote journalistic pieces that were political at all, as most of my pieces are, I was getting some threats, including one death threat that was serious enough, I contacted the FBI. And I was really haunted by you know, there, obviously are mass shootings all the time, I was really haunted by the fact that the idea that I was putting other people at risk. Sure. And I mean, anybody could walk into the group. I mean, you're supposed to have a relative with dementia, but I mean, anybody could physically walk in. Sure. And so I came up with another idea. I thought, Okay, I'm going to shut this group down, but I'm going to license Beyond Alzheimer's to hospitals. And I embarked on that. And two hospitals said yes, Geisinger in Pennsylvania and Cleveland Clinic in Las Vegas, I went to both and gave a talk to the licensing and a number of other hospitals said no, that it wasn't in their budget, which was odd because the cost of running the script is very small for a hospital. So when they said it's not in our budget, what I heard was we don't care enough. Yes. So I almost this book really was almost created out of frustration and a little bit of anger. I thought, Okay, fine. You know, if you're not going to let this group be everywhere and help people, then I'm gonna put it in books so people can have it everywhere and be helped and have it at their fingertips. And that's how it came about Oh, wow. And it's, you know, it is it is a handbook for caregivers, but it is also part memoir. Because if I'm giving you advice, you need to know how I came up with that. That's how I ran my support group. And, you know, I think that's important. Otherwise, I could just be making stuff up, you know?

Rosanne 05:18

Exactly, exactly. No. And when I read it, quite frankly, it was it was so gripping. And it was so real. And it felt like you were speaking right to me, because you were Yeah. And you understood what you understood everything of how it feels to be to be in this position and experience everything because you covered everything. Yeah, you, you. You covered. It was fantastic, Patti. It was absolutely fantastic.

Patti Davis 05:46

I wanted to cover things that you know, I mean, people still tell me, I mean, I still you know, help. I don't have run a group now. But I still help people whenever I can privately, and I'm still appalled at the way

that people are treated by doctors. What doctors don't tell them. The lack of information that they're given. It's just It shouldn't shock me anymore. I don't know if it shocks me, but it does still appall me?

Rosanne 06:12

Yes. It I always say it's not surprising. But it's still shocking.

Patti Davis 06:16

Yeah.

Rosanne 06:17

And it is. It absolutely is, because and especially you would think like you said, you go to the hospital. And they say it's not in their budget. It's not in their budget. But yet we're doing all of this. We are doing the heavy lifting. Yeah. Yeah. And it's it's mind numbing to me how they can't see that their the support and training is is so helpful. Support for a caregiver that feels like they're drowning is everything.

Patti Davis 06:43

Well, it's also preventative care, because it's well known in the medical establishment that caregivers of people with dementia are statistically very likely to get illnesses and even die before the person they're caring for the person with dementia doesn't have any stress. Every moment is new. Right? Yes. caregiver who accumulates stress and develops health problems, sometimes very serious health problems as a result. Yes. So it's not like they don't know that.

Rosanne 07:14

No. And then, you know, and it's, it's always that, you know, you have to take care of yourself. And it's like, Yes, I realized that I realized I do. But how exactly am I supposed to do this when there is no support? Right in that world, right? We have support groups here through daughter hood, and I am always for the support group. Why is it important for people to join a support group, because you know, people are kind of funny, sometimes about they don't want to go and they don't see what the point is, and they don't understand the value of it, there's that there's that self bias, almost.

Patti Davis 07:46

Sure. Well, I think there's something very, very therapeutic and also very surprising for people to, to hear others talk about the same experiences, they they're going through, when they felt so alone, in their experiences, like, you know, wow, other people feel like this, while other people are going through this, right, and have the same range of emotions. And, you know, also what's very helpful is that, just by its nature, in a support group, everyone's going to be at different stages along this journey. And people who are farther along, can can give other members of the group insight who are just embarking on this, right. So it's not just the facilitators, who advise people, it's also the interaction of the group members. And I know, you know, for for my support group, there was a lot of laughter in there. I mean, there were a lot of tears also, but there was a lot of laughter. You know, you can people with dementia do funny things. And, you know, you have to be able to laugh at that. And something you might not want to do if you're around even friends who are not familiar with this experience, because they might think you're being cold or, or unfeeling or something. But if if everybody in that room is on that same path, and on that same journey, they all know that spread happens. It's funny. You know?

Rosanne 09:13

No, exactly. No, I agree. And it's hard when you when you try to share with other people that don't fully understand it, because you have to straddle that line between Yes, I know, this is a gift, but I'm exhausted. Yeah, and I don't know what to do with myself and I'm out of my head, because then you get that there's a long range between toxic positivity and no judgment. Do you know there's that? And in that, you have to find those people that understand that you're not saying you don't love your person, right. It's just that you know, it's hard.

Patti Davis 09:46

Well, I think you have to be very careful about who you confide in. Totally agree. You know, when you have when you're a caregiver and you have an you have a loved one with any any kind of dementia. You really have to share This doesn't mean you have to banish your friends. But you do have to look at other people's situations and go, You know what, they're my friend, but they're very likely to not understand this. So I'm just not going to talk to them about it. And I think you've got to be really discerning about that. And I gave, you know, I gave examples in in here, people who said things to me that, you know, were really cold and really inappropriate. And, you know, they had no business saying it, but that doesn't stop people from saying it.

Rosanne 10:32

No, no. And the the one that sticks out in my head was after you returned from your father's funeral, when your friend called you to see if you were over at all, yeah. And could you watch your cat?

Patti Davis 10:44

Yeah. And she was someone I considered a really good friend to. That kind of ended that friendship. I yeah,

Rosanne 10:54

I would think that it would. Yeah, I would think that it would, yeah, it's so removed. I mean, your stories through all of this are touching and real. Was it difficult for you to share such intimate details? You know, you're a public figure whether, no matter what, you're a public figure, how do you come to terms with that when you're sharing your story?

Patti Davis 11:18

Well, I'm pretty comfortable with that. Because, you know, early on, I sort of started telling the truth publicly. And I, I wish I had told less truths publicly, I have learned over the years that not every truth has to be told to the entire world. You can hold a few things back. So I have learned that. But I do have a comfort level with you know, sort of letting letting people in. But I think you I think the key is you have to know why you are telling a particular story. If you're telling something to make someone look bad, or you're telling something to embarrass someone, then you should keep your mouth shut. So I anything that I any sort of intimate story that I tell them, I always have in the back of my mind. Okay, what is the purpose here? And the purpose in every story that I told and flooding in the deep end, was to be instructive to other people to give people insight into a particular aspect of a disease or a particular aspect of, you know, family situations or something like that. Right. I mean, there are people you know,

who are not happy about some of the stories I told, by the way. Really? Yeah, the Reagan Library won't carry this book.

Rosanne 12:40

You're kidding. Oh, really? Yeah.

Patti Davis 12:43

Oh, my goodness. Yeah. Yeah. They told me that I revealed too much.

Rosanne 12:48

Wow. Wow. Really? Yeah. That's fascinating.

Patti Davis 12:55

Mmm hmm. My response was, Well, I think my father would be very proud of this book. I mean, what else we're gonna say, you know,

Rosanne 13:02

Well exactly. And it's not. I didn't feel that there was anything. You know, when you when you care for someone who has dementia, you're very protective. Yeah. Because they're not choosing to share what you're choosing to share? Yes. You are the representative. Right. You are their advocate you are there everything across the board. Yeah. And I didn't feel in anything that you wrote. Oh, oh, she shouldn't have said that. Not once. I felt like you. You were very respectful.

Patti Davis 13:34

Yeah, I think I think I was, I think I was but you know, people. People have their opinions. And I think, to be honest, I think if I hadn't been respectful, and there was any truth to that, you know, some some reviewer or some journalist, somewhere would have pounced on me, given my history. So they were the only ones who said that is like, Okay, well, whatever. Didn't put too much thought after that.

Rosanne 14:02

Gosh, well, and even when you spoke about your family, and how you were all kind of around your parents, that they were there, they were their little circle, and you guys were all around them. Talk to me about that. And in the because people think, well, we're all going to care for our parent and everything, or we're all going to care for whoever we're caring for. And everything is going to be great. And all of the baggage and the issues that we had are going to go away because we're all going to be on the same team. And that doesn't always happen.

Patti Davis 14:32

I have never seen that does not it might happen sometime. I have never seen that happen, actually, in six years of running a support group and a lot of people you know, coming in and out through that, that group. I have never seen that happen. I think what happens is the homeostasis of a family remains the same and actually intensifies. So if there are fractures, those fractures are going to real revealed themselves and maybe even widen. In fact, I can only think of about three families in all those six years, who were very cohesive from the beginning came to the group, family members together, shared in that

experience together. It's not that they didn't have disagreements, it's not that they didn't, you know, argue about care and whatever else. Of course they did. But there was there was a foundational bond between them, that was really unbreakable. And everyone else that came either had siblings who didn't show up for the, for the experience of their, with their parent or whatever the dynamic, you know, I'm the only one who's caring for and then, you know, you would go well, how were things before dementia entered the picture? Well, they never take any responsibility than either. Okay, so where's the surprise here, you know, people, people revert to who they are, and who they have always been, and my family had always been fractured. So, you know, I had an idea to at the very beginning of the disease that oh, maybe this will, you know, bring us all together. I mean, that's a great story in Lifetime movies, but in real life, it just doesn't happen. You know, it just doesn't maybe if you all agreed to go to therapy, you could make it happen. But how do you all agree to go to therapy if you've been broken for decades? Right? Right. So so it's a matter of accepting that. And because if you're going to sit there and separate on the idea that, you know, my sister doesn't show up, or my brother doesn't show up, or, you know, whatever your family dynamic is, or, you know, my sibling is judging me for everything I do, as the as the caregiver, when this is how it's always been, you're just wasting your energy. This, this takes enough caregiving takes enough energy, don't waste it on something, it's always been there. Just accept it. And if and if somebody doesn't want to show up for for this experience, you know what, that's their loss. Because there are a lot of, there's so many profound things that you can learn from this experience. And there's so many gifts folded into this grief and this sorrowful experience, that I'm sorry for people who don't show up for it, I told the story of went on a date with somebody, you know, sort of in the midst of my father's illness, and he was using tossing that vodkas telling me that his father had to mention he, you know, he just doesn't, he doesn't want to see him. He doesn't want to deal with any. So I think I'm handling it really well. Yeah, I don't think so. Think this is not gonna be we're not gonna another day here.

Rosanne 17:47

Yeah, no, I, I fully agree. And it's, you're right. You can't you can't spend your energy on that. Yeah. You just can't, you have to move forward. And if you don't have those people in your life, then you have to find those people. Because it's hard enough as it is, and then you can't you just can't be in that space all the time.

Patti Davis 18:06

Right. Right. I think you know, you I think you find your family where you can, and your family is not always people related to you. Yeah, you know, so I think if you if you come at it like that. I mean, there were there were people in my support group who formed lasting friendships, met in that support group and formed, you know, really strong friendships and became like family.

Rosanne 18:34

No, I believe that because you're, you're experiencing this together. And that's the other part of why it's so sad when you can't do it with your family. Because then it does become that unit, it becomes that I can depend on you. You can depend on me. And then we can go forward instead of when caregiving ends. And it always ends. There is no contact, there is no, there are no relationships anymore. And that's another victim of this. It's another byproduct of this. Yeah. I love the way you speak about dignity. With the person living with dementia. Yeah. Because it's so important. And I think people forget,

especially when they say they don't understand anyway. Yeah. Makes me makes my blood boil. Yeah, you had a couple instances like that. The one that sticks out in my head is when the doctor came to visit your father and the people in your support group.

Patti Davis 19:29

You know, when I was I will mention this to examples, but, you know, when I was running my support group I, I tried to never say to people, tell people like what they should or shouldn't do or what they should or shouldn't say, but I made exceptions in that. And if someone said, Well, you know, they just don't understand anything or they're gone. You know, they're not here anymore. I absolutely would try to stop them in their tracks and go okay, wait, hold on here. You know, this is a human being. They have a heart they have a soul. still hear they have emotions. And you don't know what, what intrudes in their in their brain, you have no idea. No. So it's, it is inhumane really to, to speak to them like that. And it's not healthy for even if they're not present when you're speaking, you're speaking like that your attitude translates what you're saying in this group translates I know, to how you treat them. I mean, it doesn't just exist in here. So the examples you mentioned, or when my father was in the early stages of dementia, and I was still living in New York, and I was flying back here as often as I could, before I moved back. His doctor was visiting him one afternoon and I was there, my mother was not in room, and he was speaking about my father in third person, my father was sitting right there. And he was saying to me, Well, you know, you don't see him all the time, because you look New York, but you know, have you noticed any decline in him? Have you noticed any difference in him since last time you were here. And my father was sitting kind of directly across from me, in this arm, Sharon, and he was looking straight at me, he was giving me this really direct look. And I thought, She is waiting to see how I'm gonna handle this. I just knew it. And I said to the doctor, my father sitting right here, you're talking about him in third person, and he kind of like, laughed a little bit, you know, he went, he doesn't understand what we're talking about. Cognitively. He doesn't get it. I mean, emotionally, he's still there. But cognitively, he took off. And I said something about, well, he has a soul in there, and his soul isn't second year. And the man looked at me, like I was saying, you know, he wasn't my doctor for too long after that. I did tell my mother about that. But, um, I don't know if that's the specific reason that he no longer was my father's doctor. I think it also had to do with the fact that my mother called him and he didn't return her call for a day. He was like, oh, yeah, that replaced, I think it was two of the things, but the phone call was part of it, too. Um, and then, and then when I was years later, when I was running my support group, it was made very clear. And on the website, and everything that it was a support group for caregivers, she did not bring your loved one with you. But you know, a couple of times people got it wrong, not often. But this woman came in this older couple came in, and they were a little bit late, and we'd already started and I I looked at her husband, and I was pretty sure that he had dementia. And anyway, I let whoever was talking finish in, address them. And she started talking about him in third person, you know, well, he doesn't know anything anymore. I mean, I can't even know start conversation with him. And I looked at my, my co facilitator, and we were both about to say something. And before we could someone from the group jumped in and said, we're very uncomfortable with, like, shut her down. And wow, when we explained that her husband shouldn't even be there. So my co facilitator took him out the hall and sat with him while we tried to explain to her that we just didn't do we didn't get through to her at all. She never came back.

Rosanne 23:19

I'm sure because it was like you weren't getting it. Not that she wasn't Yeah, you weren't.

Patti Davis 23:25

Very, I mean, I tried as as gently and, and I think a couple other people in the group tried also to explain this to her, but it was she was just sort of impenetrable amount. And he was lovely. I mean, he was dressed very dapper in his suit. And he was he was, you could just tell he was really sweet man.

Rosanne 23:45

It just it makes you feel sad. Yeah. Because it's like, it doesn't have to be that. And you talk about that as well, where we come with our preconceived needs, and our expectations, and they're changing. Yeah. And I don't know, you know, as caregivers, we have to realize we have to change, we have to say that. Yes, we do. We have to and you the the line that you said that stuck out to me was that dementia can teach you, but not if you're still locked inside of your own history.

Patti Davis 24:20

Right? Right. So when I started my support group, I did not want to just do a group that was focused on what do I do? When this happens, or if this happens, that's part of it. And as part of this book, also, I give very specific suggestions what to do, how to get the car keys away what to do if they're wondering what to do if they're repeating themselves I that's very, very important. But what's more important and when I started my group, I really wanted to dig deeper and say, and I did say to people in the group before you ask yourself, what do I do and in a situation ask yourself, Who am I right now in this situation, because if You're still a resentful, 17 year old or an angry 20 year old or whatever. If you're dragging along the baggage of your family history with you, you're not going to do very well. And no matter what you do, it's probably not going to work. Because you're leading with that reality form will always follow content. And just because someone can't think cognitively doesn't mean they're not picking up on your, on the emotions that you're in fact, they're pulling, they're, they're picking up on your emotions even more, because they don't have that cognition in the way they can't rationalize and say, Oh, I know why she's acting like this, they can't do that. So all they're getting is the emotions that you're sending out and the kind of persona that you are bringing into the room. So you owe it to yourself, and you owe it to them to grow up. I mean, that's what I told myself at the beginning of this disease, it is time you have to grow up now. You know, you've had, you've had the life you've had, you know, how the relationship and fractures that you have in this family grow up, you know, if you're going to show up for this experience, and I really wanted to show up for it, then you're gonna have to show up wholly as an adult?

Rosanne 26:09

Yes. And it makes a difference,

Patti Davis 26:11

Right, because, you know, a grown up way of looking at things is okay, what is looking at the whole picture, you know, standing back and looking at the whole picture with some maturity. And that's how you figure out what to do. Right. Right, your adolescent responses with blinders on and thinking that you know, what's going on.

Rosanne 26:30

And how does this affect me? Right? Not, that's not it. That's not it's not about you. It's about them. Right. It's hard in that vein, because you have to be able to sit with uncomfortable feelings. Yes. And you have to be able to sit with, you know, things are changing. I can't stop it. And it's uncomfortable. And the elephant in the room, which is grief. Yes. That just it's it's all part of the journey. Yeah. Yeah. And, and it's hard to look at that, because nobody wants to look at grief. I mean, nobody wants to look at grief when they when somebody dies, let alone. Right, right. Yeah. So how do you advise people when it comes to that, to be open, to that uncomfortable feeling, and, and to the grief that comes through and to go with it and not try to fight that.

Patti Davis 27:24

We all want to run away from grief, it hurts, and it scares us. And we think that will drown there. But we won't, we will get to the other side, we'll feel like we're drowning sometimes. But we will get to the other side. And I think the common perception, as I've written about in this book, is that if we push grief aside and we send it far enough away, it will disintegrate. And what I said was grief is not biodegradable, it will wait for you and it will come find you. And if it has to come find you, it is going to bring you to your knees, it is going to bring you to a standstill until you deal with it, it will you'll get an illness, you'll have an accident, something will happen where you have to just sit there with it, you're going to be in a lot better shape. If you kind of take a deep breath at the beginning and say, Okay, I'm willing to go on this ride, you know, and kind of surrender to it. And, you know, there are a lot of colors on that on that palette of grief. It's not all sorrow. It's not all tears. And it's a very instructive passage in in life. And it's a very necessary passage in life. And we grieve because we loved, you know, we went that's why we grieve over people because we loved them.

Rosanne 28:46

Yes. And it's all part of the process. The hard part with all of this is that it all happens at the same time. So you're trying to pay attention, and you're trying to put your own stuff aside, and you're trying to deal with the grief and you're trying and you're trying and you're trying. And it just feels so overwhelming.

Patti Davis 29:05

Yeah. So I think, you know, you have to compartmentalize things, and you have to deliberately take time for yourself deliberately take time to sit quietly, you know, meditation is a great tool. You know, actually when I, when I was running my support group, UCLA, UCLA was doing a study on meditation, and how meditation helped caregivers and several people in my support group participated in the study. Really? Yeah, I mean, I didn't because it involved MRIs and very claustrophobic so I didn't but um, but several people did. And I and I think I lost sight a little bit of the results of it, but I think they it was documented that it was helpful, you know, that it helped the stress levels and you know, they could, I don't know somehow see that on the MRIs or whatever I don't quite understand Then the medical end of it. But um, yeah.

Rosanne 30:02

We hear these things over and over again, meditation and breathing, breathing. I swear, I don't think I took a deep breath for 10 years, I swear, you know. And it's important, and we don't think about that. And then when we think about self care, we think of this, you know, you have to go on a trip for self

care. And it's like, that's not what self care is. And that's not what self care has to be for you. Like, you have to find this time in your day. Yeah. And, you know, to give that self to give that back to yourself, I should say.

Patti Davis 30:33

Yeah, I mean, going on a trip is fine, as long as you really go on a trip and don't think constantly about what's going on at home and call 50 times a day. Right? Nothing wrong with going on a trip, but it's like, no, are you really gonna be on a trip? Or are you going to be checking in with the caregiver? All the time?

Rosanne 30:54

Right? Agreed. When I always say to people, when your caregiving journey ends, it's like, you have superpowers. And they look at me like I'm absolutely insane. Yeah, but you through this, your explanation of caregiving, giving you the opportunity to be who you were meant to be. I love that. I love that. Because it's like, you've it's like, you've re you've redesigned yourself.

Patti Davis 31:21

Yeah, I think, you know, you have to, it brings you to if you really sort of turn yourself over to this and say, what can I learn from this? How can I grow from this? You shared the things that that don't work, you know, that aren't productive. I remember somebody in my support group, talking about finally getting an in home caregiver. And and they were saying, but I, you know, I don't like this because now I have to monitor them. And I said, Well, why do they not know what they're doing? No, they seem to know what they're doing. And I said, Well, okay, either you got the wrong caregiver, and they don't know what they're doing. Or you're just still trying to control everything. And this person said, Well, I mean, that's just who I am. I'm just a controlling person. And I said, Well, there's who we are. And then there's who we're meant to be, you know, God didn't put people on this earth and go, Okay, you, you're going to be really controlling, and then you you're going to, like nitpick over everything. And you're going to run away from everything, right? That's not where you're supposed to be fully formed human beings. But that takes some work. And it starts with a decision, okay, I'm a controlling person, I'm going to not do that anymore, I'm going to, you know, there's that great line in in a, it's easier to act your way into a new way of thinking than it is to think your way into a new way of acting. So if you're a controlling person, just act like you're not, and your emotions will, your whole being will catch up to that event, rather than going, I can't be controlling a champion. I mean, that's kind of controlling to tell yourself that right? I'm not gonna get very far doing that. Right? It just just act like it, you know, but But you have to make a decision that this is a change that I want to make, you know, it's like my decision I'm gonna have to grow up here. And, you know, every time when I walked into my parents house to see my father before I walked in, I went, I don't know what I'm walking into here. I don't know what's going to happen. Those three words became like, my mantra, I don't know. And it gave me the openness to hopefully handle whatever did come at me, because I hadn't already made a decision about it. And I think that, you know, that also translates to how you're going to feel as the disease progresses like people, people hold up the the eventuality of someone not no longer remembering your name is this huge thing. Almost everybody does that, you know, I'll get a caregiver. When they no longer remember my name. We'll discuss putting them in a facility when they no longer remember my name. When they no longer remember my name, I'm going to be devastated. How about if you don't make a decision

based on that first of all, to time, something to that is ridiculous. Because they could be the person could be burning the house down and still remember your name. I mean, you don't know the sequence of things in this disease. Ultimately, they will forget your name, but you don't know when. Right terrible things could be happening and they could still know your name. So that's fun, but think that there's a chronological reality here to that, right. But also, you don't know how you're going to feel the moment that I was sure that my father didn't really know I was his daughter actually was very, very beautiful. And I hadn't made any decision about it. And that's why I was able to see it as beautiful. I was leaving my parents house and I suspected he didn't know is his daughter. I was familiar to him because I was there cognitively. I was Pretty sure it didn't. And I was leaving. And I said, my dad, I love you. And he looked kind of startled. And he said, Oh, thank you. Thank you very much. And I thought, Wow, what a sweet person. He doesn't know. As I said, cognitively right now, I think his soul knows everything. But cognitively, that I'm his daughter, I'm saying, This person who's sort of kind of familiar, is saying, I love you to him. And his reaction is gratitude and to say, thank you. I mean, I don't know about you, but if someone who was sort of kind of familiar to me said, I love you, to me, that would not be my reaction. Right? Right, I would have a much harsher. So it was actually a really, it was a lovely moment. But if I had decided ahead of time, this is gonna be terrible than it would have been terrible.

Rosanne 35:58

Right. You're right. It's, you can't you can't plan for you try to plan abstractly. But you can't plan for that.

Patti Davis 36:07

Right.

Rosanne 36:07

You can't plan for the, for these relationship issues that come up.

Patti Davis 36:11

Right. You, you, it's, you know, this is a balancing act, you have to make plans, you have to plan for, you know, financial stuff, I mean, and I would suggest doing that early on, you know, you can't give someone autonomy over their checking account, because God knows where the money is gonna go. So you have to plan for, if you can afford in home care plan for that, you might want to talk early on about what did we do down the line, maybe we should start looking at facilities. Now. If that's something that you that you want to do. So there is there's a lot of planning that that has to go on, you don't have to do it all at once. But you do have to do it. Along with that, you can't plan for how this disease is going to unfold. Alzheimer's is running the show. It's going to go where it goes when it goes, and you have no control over it. So it's two completely sort of divergent paths that have to run parallel to one another. And it takes some reconfiguring in in all of us, because, you know, most of us like to know what, what the plans are and how things are going to unfold. Right?

Rosanne 37:29

No, absolutely.

Patti Davis 37:30

But the truth about life is that we don't any way

Rosanne 37:33

We don't know. Exactly. We like to think

Patti Davis 37:36

We like to think we don't know, what we don't know.

Rosanne 37:40

No, but in this instance, it's like, well, if I do this, this, this and this, then it will turn out this way. And it's like, no, no, no. No good luck to you.

Patti Davis 37:51

Yeah. I mean, you try things that feel right. And maybe they work and maybe they don't I mean, you know, I've given a lot of suggestions in here. And and there's a good chance that they might work. But not i I can't guarantee that they're going to work.

Rosanne 38:06

Right. No, but through your whole journey with your dad, you treated his soul. You knew that he was still in there. Yes. Hit his soul was not sick. Right. And everything that was changing from the from the outside was changing, but his being are still there. Right? And that's who you don't, that's who you concentrated on.

Patti Davis 38:29

That's who I was always looking for. And which is not to say that I was just regarding the disease. I was not know, but I was always that's why I called my support group beyond Alzheimer's. I wanted to to instill that idea into people. And you know, there are there are moments of lucidity even deep into the disease, that that are stunning. Yes. But if you don't, if you don't at least consider the possibility that there is an intact soul. And there, you will miss those moments because they're very quick. And they're very fleeting. And it's a gift when you when you see them. I mean, my father had one I wrote about the moment before he died. I mean, he showed up the moment before he died, his eyes opened. They hadn't been open in a week. They were blue again, they hadn't been blue in probably a year. And he looked at my mother with total cognition, total awareness. He was there. And then he died. So he proved to me the belief that I had hung on to all those years.

Rosanne 39:40

I fully agree with that. And I I mean, I've seen it and I absolutely believe it because it's it's it's very true. And if you're if you're so removed, you you miss it all. Yeah. And that is heartbreaking. Because they're right there. Yeah. In that moment, they're right there. And then they're gone.

Patti Davis 40:00

Yeah. Yeah. And it could just be a look in their eyes. But you know, which you are open that. I don't know that. What's here, but I might, I'm gonna be open to whatever it is.

Rosanne 40:15

I love that. I don't know. I love that. I don't know what I'm gonna get. I don't know what anything is going to be what I'm willing to be present and see.

Patti Davis 40:23

Yeah. Yeah.

Rosanne 40:25

I love your other your other line is the only way through this is through it.

Patti Davis 40:29

Yup. Yeah,

Rosanne 40:31

That's it. Yeah.

Patti Davis 40:32

Yeah you can't bypass you know you can't as I said you can't bypass grief you can't bypass any of your emotions in here, you know some of them are messy, some of them are more sort of elevated and you have to accept each stage of it. And that's how you move. That's how you move through it. Yes, even the anger. I mean, there's anger to you know, and there's frustration. We listen, it's it's frustrating to be with someone who repeats themselves 55 times and asked you the same question again and again. Yes. You know, doesn't know where they are. It's it's frustrating. I mean, I think, you know, Gandhi would have been frustrated. Yeah, I think. Yeah, it's exhausting. It's exhausting. Yeah.

Rosanne 41:26

Yeah. Yeah. Physically, emotionally, spiritually. It's exhausting the whole thing when it comes to trying to say that to a caregiver, listen, if you could tell somebody, the thing that will carry them through all of this, what would you what would you tell them? What would you share with them? As a, you know, just try to remember this?

Patti Davis 41:48

Well, I think what we're talking about is that consider that they're sold as not sick. So you know, there's the disease, there's how that surrounding their brain, but we are more than our brain. And, you know, I'm very aware that that might fly in the face of some people's beliefs or lack of beliefs. And my response to that as always, okay, but your belief system is none of my business. Consider it as a possibility because it will change how you deal with that person. It will change you and and how you deal with this illness. Just Just consider it.

Rosanne 42:23

A big thank you to Patti Davis for being my guest today. You can find Floating in the Deep End How Caregivers Can See Beyond Alzheimer's now in paperback, anywhere you buy books. I hope you enjoyed our podcast today, head over to Daughterhood.org and click on the podcast section for show notes, including the full transcript and links to any resources and information from today's episode. You can find and review us on Apple podcasts or anywhere you listen to your podcasts. We are also on

Facebook, Twitter, and Instagram, at Daughterhood the Podcast and on my blog, HeyRoe.com. Feel free to leave me a message and let me know what issues you may be facing. And we'd like to hear more about or even if you just want to say hi, I'd love to hear from you. Also a very special thank you to Susan Rowe for our theme music, the instrumental version of her beautiful song Mamas Eyes from her album Lessons in Love. I hope you found what you were looking for today, information, inspiration or even just a little company. This is Rosanne Corcoran. I hope you'll join me next time in Daughterhood.