

Daughterhood The Podcast Episode #34: Advocating for Your Care Partner with Phyllis Ivey

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SPEAKERS

Rosanne, Phyllis

Rosanne 00:02

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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 Daughterhood. As caregivers, we are often reminded of the importance of being an advocate for our care

partners, asking questions, understanding the situation and being their voice. Today, my guest is Phyllis Ivey, a social worker, consultant and life coach with over 30 years of experience in the mental health field, and a lifelong advocate for her parents. In this wide ranging conversation, we discuss how to advocate throughout the healthcare system, the value you provide, the challenges that arise and the strategies to help you navigate advocacy, no matter the situation. Phyllis also shares the importance of caring for yourself as an advocate. And as a caregiver. I hope you enjoy our conversation. Phyllis, tell me why is it important to have an advocate?

Phyllis 02:14

For several reasons, it's about a loved ones safety, it's also important to help your loved one have a voice. Sometimes they're intimidated to talk to the system, whether it's doctors or nurses, whatever, whoever they're the professional is in their life or the facility that they're in or their family could be all kinds of systems to kind of be a post for that person. So that they're they have someone to hold on to. And it becomes an important with - a partnership of doing it together. And also to help make some really critical decisions that people have a very hard time making on their own as they get older or if they're sick or afraid to make on their own. So this is about reducing not only the isolation, that often happens when people get older, but also becoming a resource for that person. Because also even in today's you know, especially in today's age, computer technology, the elderly generate, you know, the elders in this generation are really not too advanced. And so, you know, a lot of researching goes on online, right. And even in using the phone, the phones have changed, having an advocate help them, you know, walk someone through something that they need help with whatever that might be.

Rosanne 03:38

Well, and it's interesting, because when you when you say it's a partnership, it underscores the importance and the change that's been happening where it is a partnership, it's not, I'm going to do this because you can't, it's I'm going to do this to help you do this better, which is a little more palatable when you're trying to help somebody who doesn't want to feel like they're losing their independence, because let's be honest, nobody wants to lose their independence. So it's, it's a softer transition, if you will.

Phyllis 04:07

Right. Right. Absolutely. And also, if you think about it, two heads are better than one. There are times where you know, don't we all need somebody to not only bounce things off of but to am I doing this right and also have somebody in their life that they're not afraid to ask for help? Yes. Not to say that there are more than you know, there's more than one advocate in somebody's life, but there's usually a one there's one solid one and that's their person who they can go to that they can be themselves with and be be true to themselves in and talk about their fears and talk about their pain and you know, soup to nuts,

Rosanne 04:47

Right. I call that the person you let behind the curtain. Like you know, the Great and Powerful Oz like it's nobody gets to see behind the curtain while you do when you're their advocate.

Phyllis 04:56

Yes, absolutely. That really resonates on because it's not a relationship that is touted all the time, although you see the value in for that person when they're introducing you,

Rosanne 05:11

Right. Like, this is my person.

Phyllis 05:13

This is my person, this is my daughter

Rosanne 05:15

Right

Phyllis 05:16

This is my granddaughters mother who's done this for me who's here for me, and even with sundowning, or some dementia, that they will remember you being there person because of how that gets in. And that stays in. So they keep on reintroducing you,

Rosanne 05:35

Right, as their person

Phyllis 05:37

As their person and you tell the value of that.

Rosanne 05:40

Yup And then it helps because then whoever you're talking to knows the value of that.

Phyllis 05:45

Absolutely, you bring up a really excellent point. So the advocate is not only important for the person who you're advocating with, and for, but for those around them. And facilities, doctors, nurses, as I said, all kinds of professionals who are the helping professionals and families and even friends, and to have just to have those people know who you are, because that does make a difference. It really does. And it's not only making a difference for better treatment of the elderly and the sick, it's really help. It's help for the helpers.

Rosanne 06:21

In what way?

Phyllis 06:22

Well, you know, the story of the person of who they are, you know, in my case, my mother who's living in a facility, or in her case, also when she each time she goes to the hospital, they don't know they have this gray lump. And I know what that I don't mean to sound disrespectful, but it's really, you know, they see age.

Rosanne 06:46

Yes.

Phyllis 06:47

And there is ageism going on.

Rosanne 06:49

Yes.

Phyllis 06:50

And so when I'll never forget a long time ago, when the doctor said to me, it's really helpful that you just told me your mother's story, because we don't know her baseline. What we know that she's really ill right now and she's unresponsive that you just told us where she was yesterday. And she's up reading the newspaper morning till night. And today, she's unresponsive. So we need to know. And also in terms of someone's ability to communicate, you're helping the you're helping the helpers to understand who that person is what they're capable of intellectually, even emotionally fears

Rosanne 07:30

Right

Phyllis 07:31

I've had doctors say to me, I wish there were more people who, who showed up like this. And not to say that people who consider themselves advocates and maybe some people don't consider themselves because they consider themselves families. But maybe they're not giving themselves enough credit. Right, that it's helpful in the short time that someone is being treated with somebody who doesn't know them at all.

Rosanne 07:56

Right. Well, and like you say, they're seeing this gray lump of sheets in the bed

Phyllis 08:01

Right

Rosanne 08:01

And you're seeing your mother, and especially in today's world where everything is on that computer, and they come in and they check the computer and they enter in the computer and then they leave. They're not they don't know who this person is.

Phyllis 08:15

No

Rosanne 08:15

They don't know. They don't know. And that's your and forgive me for saying it like this, but it's your job to fill in that those blanks because you have to.

Phyllis 08:25

Yeah, I mean, I'd like to also as I feel like it's my obligation and out of love for my person. Because it's not my person one way, I'm doing this because you know, that person who I'm advocating for in this case, my mother used to be both parents because of, you know, always a daughter, and recognizing respecting that relationship. Like, you know, you bring up something about the computer that I just like to add. And it just became so interesting to me, my interest turned into concern, let's just say this way, when I noticed one emergency room visit where the doctor was just recording things on the computer. And the nurses had said, we don't really talk we don't you know, when I had to have some conversations, they just put their information in and there's no communication because they're on a schedule.

Rosanne 09:17

Yes.

Phyllis 09:18

And these systems are so overrun. And with patients, especially now. Yes, but the communication, you know, I've heard of nurses sharing with me that sometimes when they know a doctor is coming into a room and they nurses haven't been told the nurses get wind of it and they run to the room and listen in because they haven't been invited. So if this is not to diminish or to attack, this is this is just they're they're trying to survive, right, but the way the system has been created for them, this is what it's turned into.

Rosanne 09:51

Right. Right. I don't know if anybody had that foresight to say, well, this is what's going to happen if we do all this.

Phyllis 09:58

Right. And so When your person that you're advocating for goes into a hospital or a longer term facility, you're transferring the advocacy to those other people in a different way. And you're hoping that they're there grows a a partnership, and sometimes it happens, and sometimes it doesn't. And so having recognized the way the system is just so overrun and hurting and splitting and at the seams, my advocacy stretches to the nurses to the doctors, and my conversations with them, are about also advocating for them, which is also a game changer for my mother. And for them to recognize, you know, usually those in the helping field or they often just hear what isn't going well. Right. And this is and to give them a chance to know that things that are going well in the gratitude that I as an advocate have that I am enlisting you to care and to protect, right and have interest. Have the time to have the interest but have interest. Because this is their new home, if it's a long term facility, people you know, there's, there's there's a lot of that that I have come to know and feel about that. I don't know if the message is there in terms of people working in other people's homes in a facility that this is in the case of my mother who's living in a facility, all the people that are working there from nurses to AIDS doctors, you whoever's there, they're working in people's homes. Right. And I'm sure they see it the other way around, that these people are living in their workplace.

Rosanne 11:43

Yes. Well, it is and how do you walk that line of being, you know, firm and of advocating for your care partner without being overbearing? How do you straddle that line? Because it's hard, because especially in it in any type of community you're leaving, to, I know, people are afraid of the blowback like, Okay, are you going to do this today? How is this gonna happen? And then you leave. And there's that fear that they're gonna then and I don't want to say take it out on but your part, your care partner is still there. So how does how do you navigate that, Phyllis?

Phyllis 12:20

Well, you actually can say, I don't use it, I want to say take it out on them, there is that fear. And there's fear of the resident that something's going to be taken out on them even in a hospital. And so the advocacy becomes a necessary evil. I've seen it kind of go both ways. But in answering your question, I have one answer in one word, relationship. Advocates relationship with staff is incredibly important. And it winds up being letting them know that they're in extended families, so to speak. So when I leave, I'm making sure I stay in touch by phone, I'm asking to please contact me when dot dot dot when I'm there, and I'm seeing things that they have missed because they're busy, or they don't know how to look on informing, so relationship, informing, staying in touch, you know, consistency, continuity to the point where they expect you there, they have a knowing that you're going to be there be involved. And so in my case, I feel like it's worked really well, in the last few years at a facility that there has grown

this mutual respect. And I think that once you really respect the people who are doing a very hard job, and you acknowledge that hard job, and you show gratitude about that hard job. And you also not only say it's from you know you as an advocate, but also the resident who appreciates it that I don't think that people realize in the working who are working these facilities, understand the appreciation of that. And I do want to add one other thing too, to let them know that they're important. Their job is important. I can't say I can't tell you how many times where I on a regular basis, you know, I make sure that they don't forget that I don't forget their value. Your value, your importance is just as important as mine. In another way. You're keeping my my mother alive, you're protecting her, you're making your the things you do make her happy. And they each have you know, different residents have different personalities and have different needs. And in my case, my mother is a connector. You know, she likes to connect with people. So her relationship with the staff is critical. So that is about informing part of her story, where she came from. So that really when when staff learn something about somebody that is interesting, or even helpful to them, then they're because It kind of helps peeking their curiosity and interest. I've seen that happen many times,

Rosanne 15:06

I'm sure. And this can be adapted across all care platforms, whether it's a primary care physician, whether it's a hospital, whether it's a facility, whatever.

Phyllis 15:16

Right. Talking about the hospital, that's a real short term. Well, not yet, depending right. And that that short term relationship is about speeding up the relationship in a sense of letting nurses know, their value their importance, not I'm trying to think of how not to disrespect by, you know, I don't want I don't want anybody who's working in a hospital thinking that it's all blowing smoke, because it's not,

Rosanne 15:46

No, they're literally sometimes keeping your care partner alive.

Phyllis 15:50

Yes. And there's a timeline. And there's also about quick education about whose education both ways what's going on, let me educate you what you need to be educated on, asked me questions, you know, not just go in asking questions asked me questions that would help you to care for my mother in the hospital right now. And the one thing I want to say is about the ageism, that she's 98.

Rosanne 16:16

Your mother?

Phyllis 16:17

Yes, she's 98.

Rosanne 16:18

God Bless her.

Phyllis 16:20

Right. And why I bring that up? Because there's an automatic decision that people think they need to make over a UTI, let's say, or something that is treatable. multiple things that happen in multiple months in a row or something that there there, there was a question like, well, you know, she's 98, what do you want to do? So what I don't want to do is assign my mother an expiration date.

Rosanne 16:48

Absolutely.

Phyllis 16:49

So that's part of the advocacy. And even seeing that. Yeah, even even stating that, that I'm not maybe her POA. But that's all, you know, that's when she is not, you know, lucid and not able to make decisions. And I were still making decisions with and I'm still empowering her to be a part of everything from deciding about booster shots to, you know,

Rosanne 17:10

Treating a UTI.

Phyllis 17:12

Treating a UTI. Right? Right. So, the communication is really critical, because of the how fast they have done because of insurance, they have to move people out,

Rosanne 17:26

You're on the clock.

Phyllis 17:27

You're on the clock. That's right.

Rosanne 17:29

And I think that puts more pressure on the advocate, it puts much more pressure because you have to know what their motivation is, as well, you have to know where they're coming from, you have to know about your person, you have to know the rules of the game that you're playing. And without knowing all of that you're at a disadvantage.

Phyllis 17:47

Right. And so that's why every time that she's in the hospital, I'm on the phone, and I'm staying, and I'm pretty inert, because I have to be available. And I have to check in. And I have to make sure that the decisions that are being made, and there are decisions that I may need to challenge.

Rosanne 18:07

And I think part of the challenge of being an advocate, a good advocate, is our fear in putting ourselves out there in crossing that line in finding out things we may or may not want to find out. And we have to step into that to to be able to be that good advocate, but I don't know, and I don't know what, what techniques or what suggestions you have in trying to develop that muscle, you know, because you have to you have to there's a lot that goes into it. You have to you know, you're anticipating you're you're trying to think ahead, you're trying you're trying to even standing your ground with the doctor sometimes is intimidating. And that's part of gathering that information and coming forward like, Okay, this is what I think this is what I see, this is what I know.

Phyllis 19:00

Right

Rosanne 19:00

Because, you know, medicine is a puzzle, right? You're just giving as much information as you can to solve this puzzle.

Phyllis 19:06

And sometimes it's an art.

Rosanne 19:08

Absolutely, it absolutely is.

Phyllis 19:11

Right. So that is probably one of the biggest challenges for people, I think, in terms of feeling comfortable. Asserting themselves with a doctor in the hospital and feeling the right to Yes. And also the intimidation of you're a doctor. I'm not. You're a nurse, I'm not. And so it's almost like the people put themselves into this caste system that I'm not. I don't know what I'm talking about. He's a doctor, she's a nurse, you know, he's a neurologist, what do I know how you know, what do I have the right to say to intervene and the bottom line to that is being a part. This is a collaboration that if people realize that I, this is not about permission, this isn't about that you are eligible to be an advocate because you, you have had the experience. It's

because you know, it's really leading with love for your person. Yes. And leading with knowing that advocacy means not letting someone be alone. That anticipating what kind of help they might need. Now, certainly, I'm not going to walk in and be feel the arrogance, or even pretend to, under, you know, know what medical decisions need to be made, but we're learning together, I am learning, each time I ask the question, the more you ask questions, the more you are able to have a dialogue with a, with a physician or with a nurse, you know, the multidisciplinary team, whoever's on board, even the social worker who's placed who has to discharge coming down to what kind of transportation coming down to costs, all kinds of things like that, you know, doctors, in my experience, welcome the relationship of families, they prefer it. And it's a balance. Yeah, you know, we have to recognize they're on a clock, but and it's really about anticipating the time that they can give us and so to be prepared, in some ways to be able to ask, you know, think of the questions that you want to ask that leading with curiosity about what what is making you make that decision, feeling the comfort, feeling the right to ask that. The doctors, in my experience, are not ever thinking you don't have the right as a family member to be involved that you don't have the right to ask a question, even weigh in. And in my experience, I have found that that it's it's not the case, that it's really the there's a welcoming of more information, and help, because then we're really helping doctors make really good decisions aren't we.

Rosanne 22:03

Yeah, I was just gonna say, yep, yep. Because then it is really a team. It's a team approach. And it has to be and when you look at it, I mean, you look at the fact that it is ageism, it is a caste system. It is a health care system that's set up not necessarily for it's not necessarily person centered, its cost, its profit centered, its profit driven. And here we are with our people trying to maneuver through all of that they're like their landmines.

Phyllis 22:32

Yeah, that caste system even I, in my witnessing, I think it's, I think it exists in the hospital systems, and even in the nursing homes, depending on your position, and the decision making that you're afforded because of your degree, because your position that it organically happens. And so even within the systems, I have witnessed people, staff feeling, not sure whether they should push or should challenge and there are times where they've said, Well, you're the family member. And here's where the rubber meets the road, they'll say, Well, it'd be better coming from you. And that what does that tell you in terms of the respect that they feel, or don't feel, or worry about or feel like they don't know if they should challenge? So I think that's always been kind of rampant. But, you know, to empower that there's a WE there's so many we's that an advocate is teaming up with whether it's the a the doctor, the nurse, the director of nursing, the physical therapist, you know, there are chances to advocate there are chances to appeal, but also how you go about it. It's all in the approach. And the gratitude that I walk in with is really not about manipulation. Right. And that's kind of the word that,

Rosanne 23:52

Right? Because you know, it's not like you you're not pretending you're actually thankful that they're doing this.

Phyllis 23:58

Yes It's actually relieving that I feel like I'm I'm giving I'm putting my parent in your hands, which can I like to give you an example. When I was at a, an emergency room in a big hospital, and my mother and I think she had I think she had sprained or broken an ankle. So the so the emergency room, this is when she could walk. So the emergency room doctor said, You know what, we'll boot her up, and she'll be good to go. And he put her in a boot and she sat there and he went to the computer that we talked about, and was listing his notes. And I went over to him and I said, so that's it. Yeah, she's gonna go home and be boot at 80 something years old, and she lives alone say, Well, you know, that good will be able to help her work and be able to walk and I get that I'm not knocking him. And I said, Would you do me a favor? And he said, Sure, I said come over here, then this is where I've gotten to in my advocacy. Come on over, over here. There's a relationship about that, like already, like trying, because when a doctor doesn't, doctor doesn't worry, doesn't see that you're worried about approaching him, there's an ease about that. So he said, Sure, whenever and I said, ask my mom to get up out of the chair. Because I said earlier, I said, I think she needs to be here. And I think she needs to have three days so that you know, at least then she can get into a rehab if you give her three hospital days, right? That's how insurance works.

Rosanne 25:37

Yep, three consecutive days, well, yes, get you to rehab.

Phyllis 25:40

So he asked her to get up. And by the third time, he went back and changed his paperwork. And he admitted her,

Rosanne 25:47

Really

Phyllis 25:48

Right there.

Rosanne 25:49

Because she couldn't get up

Phyllis 25:50

Couldn't get up. And he was sending her home. Now, here's the deal. I had it off some liability with that, too. Sure. They do have to make sure about safety when they're discharging. And that has to be in my mind that was needed to be included in a safety plan. Safety discharge.

Rosanne 26:09

Agreed, agreed. But see, here's the difference. You know, you knew in your, in your heart of hearts, that was not going to work. And you knew it, because you knew she couldn't stand like that. And you weren't afraid to say, Hey, Doc, come on over here and take a look. That's instead of and I think that goes back to the well I can't say that. Well, he doctor knows best. And it's it's trying to hurdle the doctor knows best. And I'm not being disrespectful. I just mean, you know, your mom, and you know how she's behaving. And sometimes it takes that push, like, listen, I know this, and this isn't, this isn't going to work.

Phyllis 26:47

And part of the reason to have that advocacy be even more important at the moment because my mother would have gone home.

Rosanne 26:56

Absolutely, of course she would have.

Phyllis 26:58

And she would not have challenged. And so she relies on me. Because after we she is she she gets scared. She is like you said earlier, she's worried about someone getting mad at her that she's gonna seem disrespectful she worries about challenging, so, yes, you know, but she's always glad when I'm advocating because she worried and I said, Are you worried about going home? So that's an example. And I, you know, they you know, and I didn't? I know, I just said that in a joking way. Come on doctor there was a part of that it will say that I said with I really respected him and I let him know, I really, I really appreciate you came over. Thank you so much. And protected my mother and I just gave him some information. I said, you know, asking her to get up made all the difference to didn't, right. So that may be next time when he is making a decision about another emergency room patient, he might think twice. And he might say try to get up out of the chair.

Rosanne 27:54

Right? Let's see if let's see how you walk on this.

Phyllis 27:55

Right who do you live with? Right? Nobody? Okay, this may not be a good idea that we discharged you today. Right. Right. And part of you know you said how do you how do you go about this? And not worry about how you're how you're you're seeming or,

Rosanne 28:14

Or how you're perceived, or when the staff sees you and they're like, oh, it's your turn to deal with her.

Phyllis 28:19

Yeah, two things. You know, I have been groomed. You know, my advocacy was born a long, long time ago, when I was born. My you know, I had two parents, my father is no longer living. But my father was an ill man. And actually my first week that I came home from the hospital, my story is that my mother had to give me to somebody else because he was hospitalized. So I, my caregiving started at infancy in the sense of, I didn't start caregiving, but I was eventually going to have to be a part of it, because it was, there wasn't going to be a choice about it. So it really, at, 10 years old, I remember having to carry my father down the steps with my mother. He had a severe asthma attack, and he was blue, and I'll never forget that image. And so as a child, not to judge my mother, but she needed help. Right. And I was there it was the only way we're going to at the time, get him downstairs. So that began my story of realizing the value in that the message that I got as a kid, and from there it went. And so I had a sick father who was hospitalized many, many times before he his life ended. He had been hospitalized 75 times in one state.

Rosanne 29:43

Wow, Phyllis.

Phyllis 29:44

Yeah. So that's a lot of growing up in the hospital. Yeah. And the other thing is, you know, I'm fortunate this way that I was trained, you know, my profession is social work. So my professional experience was in systems and understanding systems so I'd have to say I was lucky, I worked in mental health. And still, you know, right now I'm doing coaching, but before, up until recently, you know, working in hospital working with hospitals having to communicate with hospitals. So having that experience enables me, and it makes me in many situations its made me want to empower people to be advocates, because of the value of advocacy and what it can do for not only the resident or the patient, or the staff, but quality of life. Yeah, and future, present, and future. Because what you do now, what you decide now with somebody and your life is about future.

Rosanne 30:40

Yes, quality of life, how they want to live, right. In what way they want to live in the in the life process, it's important to, to understand that and to think about that, and how you want to make the best of your life.

Phyllis 30:54

Yeah, it's an evolution. And it's certainly I'm learning along the way and the the emotional, the transitions that you go through, you know, the rug is pulled out, when we're in transition, it feels, it doesn't feel stable. And sometimes it's not stable when we're in transition. And that's where a lot of the fear happens. And a lot of panic happens. And so understanding the transition of as someone gets older, and helping them to make decisions, big, big decisions, moving out of their house, stopping driving, spending all their money down,

Rosanne 31:29

It all adds to being a caregiver, and why it's so stressful to be a caregiver, and why it's so exhausting, and why you always feel like you're running up a hill. because aside from the practicality of caring, it's all of this, it's almost like the administrative side is being an advocate, right? Because you have to know what you're doing. You have to plan and all of that. And it takes, you know, it takes little pieces of you because of that crossing the line into I'm going to help you but now my helping you means that crossing into that advocacy world. It's not the relationship, it's a different, it's a different almost level of the relationship, you move out of the realm of daughter, or son or spouse, you move out of that realm into caring and being that bridge into that care world.

Phyllis 32:26

Situationally for sure. While trying to maintain the identity of being a daughter, right, you know, this is there's a lot of families that are in the sandwich generation. Absolutely. I'm here, you know, one day, I'm Mother Bear, or that hat and the other day, I'm, daughter, Bear. Yes. And, you know, I was saying you just say that it is an energy, taking experience at times just to be with, you know, the gearing up to making a phone call the gearing up, you know, trying to look at the clock and think well, the doctors make the rounds, the nurses are doing med checks, whatever it is trying to know, you have to learn the system and know where you know, where you can sneak in to advocate. Yes, because you could be the best advocate but if you're, you've got to figure out the timing of it. And the preparation, and it is gearing up and it's not only gearing up on the phone, if you're making a call, it's a gearing up in person. Because here's something else that also happens when systems know that there's an advocate, an advocate, someone that is, you know, really walking that walk, there is an energy about that with staff that sometimes I see no matter how long did they worry about disappointing? And in a sense, you kind of don't we all want to you know, I'm not You're not here to please me. I'm not here to please you. Which I realized as part of my gearing up that I have to recognize that energy change when a staff member sees me that while she's coming, she comes in pretty regularly, she calls pretty regularly. So not to over use my role, because I think that's really important to keep that balance because you don't want to be a nuisance. You don't want to overstep and you don't you know you need to have a balanced and they need to look forward to seeing you as well.

Rosanne 34:34

Right? Well because it's not a sprint. It's a marathon.

Phyllis 34:37

Yeah.

Rosanne 34:39

And you have to you have to try to move that energy like you said, you have to conserve it you've got to expend it you've got to concert like it's it's a whole thing.

Phyllis 34:48

Yeah, it's pretty exhausting at times when in some ways, the exhausts there's a relief when the when you know the care is there. And then when you know that you're loved one is getting ill you worry about the shortage now, especially with COVID. Let's throw that on the table. The systems are just struggling to find staff. Yes. Needs nurses, you know, the nurses are doing the nurses, the CNA work in the hospitals, the nurses are doing the CNA work and the systems, the nurses are not all the people are begging to hire in a system that is fragile to begin with. And it's worrisome to know that by no fault of the people who work there, that they're shortchanged with staff, so then your level of worry goes up because of that, because they can't keep an eye and COVID since COVID. You know, the systems have always been strained in that regard, but not as strained COVID has it's another level of strained. Absolutely. And I went, I wind up making room to talk about that. Because the staff now will confide in me and they'll say we're short today. I'm sorry, I can't do that. And then I have to gear up, you know, like I get it. You know, so how do you advocate? You know, they're short, you know, they can't keep an eye. So then what do I need to do? And what am I limited in doing?

Phyllis 34:50

Well? That's exactly right. Because Can you even get in there? Right? That's the flip side, then, you know, I mean, how many hospitals? How many communities are not allowing caregivers in which

Phyllis 36:25

Not at all.

Rosanne 36:26

I mean, I don't? Yeah, I mean, how do you I wish that there was a way that they could change and have somebody go in there to be with this person that's that needs care.

Phyllis 36:39

Yeah, there needs to be another set of eyes. For especially now to come in and assess, there has to be assessment, yes, here's another area of advocacy, when people are missing things, because they're so short staffed. That is not to judge. And that and this is where the advocacy comes, becomes even more important because of the strain systems that you, you plural, you can't take the place of the nurse, you can't assume a different role or position that you shouldn't, because there is a shouldn't about that. Right. You got to stay in your lane. And you know, you said earlier about, you know how to have that role. But you know, your your identity, you know, there needs to be to keep the relationship intact, you know, to respect your loved one, especially if they're lucid, and they're cognitively well enough that they understand everything that you want to respect that. How do you be a daughter and make decisions? The decisions have to be with and informing with and let your loved one know, you know, I see this as a problem. This is what I would like to do to help you to ensure that you dot dot dot dot,

Rosanne 37:54

Right, right. Alright, Phyllis, so you're advocating right? And you're doing your best, and you still feel like you're not being heard? Or the care isn't where you think it should be? What do you suggest?

Phyllis 38:08

Well, I think it's really important to use the proper channels. If you can't resolve it yourself, if you can't get something to change that needs to change, something to improve that needs to improve. Because it's always safety, first, quality of life it all goes hand in hand. You find out how the system works, ask who you talk to, you know, do what you need to do, to get your loved one the care that they need. Because being aware of something and feeling like that there's nothing to do about it is not true. There's always something to do about it. And often the people who you have available to go to you want to do something about it, right. Because if they're the whether it's the social worker, often the social worker, whatever system is someone whose set up to help escalate a situation to resolve it and solve it. Also to ask for a care conference, whether it's someone's in a conference with somebody, whether it's in a hospital, in a facility that you could ask for the care conference, if someone says you already have one scheduled in a month, you need to stress how important it is to give it a level of importance I guess I know but this is too urgent now to wait that long. What do I need to do to make someone like to have someone listen to me and make someone listen is getting urgent and to anticipate how urgent something can become. And so it not to feel like you've tried something and it failed. What's the plan B what's going to be your plan to make sure that progress, movement, action, whatever it is so not be afraid to escalate it and by you doing that you're stressing the level of importance to them right and sometimes it is about this is not working. This is this is not getting my loved one what they need you. Need to sound the alarm when you find out that your parent isn't telling your loved one isn't telling the staff that they haven't eaten everything. So they're starting to dehydrate, you sometimes need to say, hey, you know, if this

doesn't get fixed tonight, tomorrow, this is what I can see happening. And this is a liability sometimes, and I will say there have been oftentimes I've had to spell it out for people and not to threaten them. You're not there to threaten, you're there to spell it out. That where you see it going and then, you know, sometimes you need to raise a little anxiety. I don't think you I think that if this doesn't get done tonight, that call isn't made tonight. I I'm worried about liability for you, as a as a staff member, because this is beyond you. Right. And that is not not that's not me being their boss. That's me saying, You know what, I see that this is going to get worse, because I'm seeing signs of this getting worse now.

Rosanne 41:07

Yep, this is going to go into something else.

Phyllis 41:09

This is going to go into something that's exactly spelling it out like that this is gonna go into something else. And if I were you,

Rosanne 41:15

Yeah, don't let me tell you how to do your job. But if I was you,

Phyllis 41:19

Yeah, yeah. So let's, let's do this together. This is the language, we need to do this together. And please let me know that you've made the call. Yep. And the other thing is supervisors. Generally asking for a care conference, sometimes nurses, they think that it's on them to manage, and to let them know that I really like to have your supervisor involved not to get you in trouble not to say you're not doing your job. This is another level of decision making, and helping them to realize what's in their wheelhouse to do, their pay grade to do, your position to do and they need to bring other people in sometimes like a supervisor, or even an administrator.

Rosanne 42:07

Yep, all part of the team

Phyllis 42:09

All part of the team. The real message is to really know that you're not going in to be adversarial, you're going you're a truth teller, you're you're the reality, you, you really are holding up the picture of reality of the situation, and you're getting the pulse on it, and you're sharing that pulse with them.

Rosanne 42:30

Right, because you know, you know what your person's baseline is, you know, what that looks like, you're the expert to your person.

Phyllis 42:39

Right. That don't worry about escalating it, because think about how you will feel. And this is not about placing guilt, but to feel empowered to take the step necessary. So that action makes us feel like we're moving forward. Right. You know, to develop goals about what needs to happen, and to include the people who are involved in delivering that, that I really can't stress enough to have people not worry about what length that they would go to take care of their loved one. This is about being proactive, and not being reactive, we get more done by being proactive and safer. And I keep on saying quality of life as well. It all goes hand in hand

Rosanne 43:28

And it goes back to that team and the the Care Partnership.

Phyllis 43:32

Yeah, it's a care partnership. Yeah I love that, you know, there is an area that is that we haven't talked about that I think is really important now is where people have to help make decisions about end of life. But in the moment, you're, you can't play doctor. I can't play doctor in the moment. And so this is where that dependency on other relationships come into play. But in facilities such as nursing homes, and they know the age of the person, or they know that they haven't been as well. And they're not they're not as they're not responsive, they're not, something's changed clinically with them. The advocate will be asked, What do you want to do? Right. And that's a heavy burden to carry. And that's where it's really important to remember that you are not, you are not and should not be the only one making a decision right now. So that to bring in the medical professionals to help make a decision. Right, and then there is an ultimate, there is a time and ultimately that it comes naturally that it makes sense that an advocate with family with whoever's involved will collaborate and make a decision that is in the best interest.

Rosanne 44:51

I don't know if you have any thoughts or tips on how caregivers can become better advocates or stray extend their advocacy, you know, top things that they could do to improve that,

Phyllis 45:04

You know, look at the word advocate is not adversarial. Right. I think that's really important that people feel like if they're advocates that they're, you know, historically, that word sometimes is feared, that title is feared. And this is really a valuable title. That helps everybody. You just talked about when somebody is brought to the hospital, you know, how could you best advocate, I started advocating before they get there. I will make the phone call if if you know,

the facility usually will call that there are times where I've had a mate, I've decided I'd better make the call. This is what you have coming in. I'm the daughter I'm the POA I'm your I'm your person.

Phyllis 45:08

I'm your person. Yeah. Yeah, you're gonna know who I am.

Phyllis 45:45

And they, and they will call me every time because they have somebody to make a decision, or they have somebody to ask questions of. So feel like you're a resource, not adversarial. Right. That's what I walk in with feeling.

Rosanne 46:13

Okay, it's not an us versus them.

Phyllis 46:15

No, no, this this role benefits everybody. You know, there are times where I've, I've helped the hos doctors and you know, and there's sometimes are nurses? And I'll say, Well, you don't have to do that. Yes. If it helps you help my mother, and faster. I'll call you right back. I've got that information for you. Today, I think because of the things the emergency rooms are recognizing. They're tightening up, I think. And I just recently had a really excellent experience with the doctor even said he wasn't even sure my mother was going to make it through the night. And he said, I think you should come but drive safe.

Rosanne 47:01

You mean not with my hazards on and my arm out the window? Like move, move, move no don't do that?

Phyllis 47:05

And going through every red light, right? Yeah, yeah. And there's there's a, there's a caring, I just want I want to, I can't say that enough. You know, they're in the business for either not, it's not just a job. That might not have always been a it's not always my usual experience. But that doesn't mean that the doctors don't care and the nurses don't care. And they've been very glad to connect me but you asked me about tips. Can you please let me know if you're keeping her? Can you please let me know if you're admitting her? Can you please let me know what you're coming out with? Can you please let me know when I should come? Or when I or should I come? You know, right hospital that my mother usually goes to is 40 minutes away. So you know, the last time this there was this emergency hospitalization. I came in and the doctor came out and running and said she's turned around and the time it's taken you to drive her I'm sorry, I'm sorry. And it was. That was really, I just, you know, he was really, I just want to speak

of the kindness and the compassion that doctors, those in those positions also have, and probably picking up on the fact that I was involved talking to me the first time, right.

Rosanne 48:17

It's across the board with everything with homecare, with facility care with hospital care with primary doctors. It's it's that we can have a conversation. The stress on caregivers sometimes, and sometimes it doesn't hit until the incident is over. And I don't know if there is a way and I don't you know, it's it's transitions, like you said, and it's resilience, really, because you have to find that within yourself to keep getting up to do it. Because it does take a lot. How would you say to tap into that resiliency to continue down that path?

Phyllis 48:52

Yeah. Well, you know, you talk about the energy. And there's another word that we can sometimes feel and that's guilt if we're not there. Right. And to know your limits in the moment and figure out ways to advocate where you have, you know, think about your own options, so that you recognize when you're starting to feel the effects because you know, like the captain on the plane says,

Rosanne 49:24

Put your oxygen mask on first.

Phyllis 49:26

You're no good to your kids, if you're not reading and I say that as the, you know, the one who's the advocate for my mother, I'm no good to my mother, if I'm not breathing if I'm so worn out. And so it's been a process for me to sometimes recognize when you know what if I'm not there every single day, it's okay to allow yourself that ability to say you're not saying no, you're not saying I don't care. You're saying I need to take care of me so I could maintain the strength and energy that it takes to continue being there. Because you're not just there as an advocate, you're there as a, as a daughter, or a son, or whatever the role is, because you're seeing you're the emotion that you can't avoid. So it's not a job. It's a combination of, you know how to compartmentalize. And that is something where I sometimes have to compartmentalize the emotion and figure out what is the task at hand that I have to make sure of so that I can manage the real emotions that happen, the real worry,

Rosanne 50:35

Right and the stress and the guilt and everything and the panic, and all of that.

Phyllis 50:42

Right. Yeah. I mean, it's and just being true to yourself about knowing that this isn't, again, you're not clocking in and you're not clocking out you're not getting, you know, this isn't not

seeing it as a job. It's multifaceted. And to be able to to recognize when you are feeling stress, there is going to be stress to it, but to recognize when you're overstressed when you're starting to really lose energy to where you're not functioning, because that can really happen because it follows you and often people have panic attacks at night when they're asleep. Because they're that's there, they're not

Rosanne 51:18

It's the only time they stopped.

Phyllis 51:19

It' the only time they stopped. And notice a time where I have experienced depression, I've experienced the aftermath of talking on the phone every single day, for a year with a family member to keep it going was about eight months, every single day. And when she was placed after, it's felt like it was coming out of nowhere. But it was coming out of somewhere that I didn't recognize that you have to link it, there are some times you can't avoid the the things that you have to do. But to be aware of the toll and be okay, and know that you're human. And the self care is really important. Self-Care also comes in the way of taking a break, having other people in your family making a schedule, if you have family there, whoever that it could be a friend, it could be an extended family member could be whoever it is. Can you when is the next time you're going. I can't go in today recognize your cants, because that's the time where you need to, you know, your battery needs recharging.

Phyllis 51:22

I love recognize your cants. Yeah, I love that. Well, because, yeah, we're only human. And yet, sometimes what we're doing is superhuman, right. Trying to do everything at the highest ability, at the highest level, with the highest level of stress. So to step back then and say, alright, I can't do this, and not feel that guilt about not doing it. Right. Where do you where do you put that? How do you deal with that?

Phyllis 52:55

I was gonna say how that is also challenged when your loved one says, are you coming today? You're not. So lead with when you are, what I what I think is really important, rather than lead with no, I can't lead with when you can when I can, so that I can come tomorrow. And I'll look forward to seeing you tomorrow. We have each other on the phone right now. Or there are times when you have a person who can't talk on the phone, especially if they have hearing aids and they can't. You can ask the nurse to give a message so they don't feel alone. So to you know, and being mindful of the level of toll and to give yourself the human humaneness of being able to feeling like I can't but it's not I can't altogether. I can't right now. And to be able to stretch, you know who there other family members involved who can be helpful and if there aren't, ask the staff to check in. So that they're not alone.

Rosanne 54:03

Right. Well, self-care is a big word. It's a big it's a poke in the eye sometimes. What, and I fully agree with you at the at the end of the night is when those you know, things come out. What can you do? What do you advise to do for either moments of self-care or at you know, one in the morning when your mind is just racing and you can't seem to settle?

Phyllis 54:30

Breathe. Meditation to remind yourself meditation isn't always an easy practice to remind yourself of. Not everybody can do it in a routinized kind of way. But in when you begin to recognize your signals, first of all recognize the signals of stress that they're your clues to know that it's even happening because we don't sometimes know to take care of ourselves until we know that we are starting to show signs and so getting in touch with your body signals getting in touch with you Your energy and thinking in terms of any mindfulness, even a breathing, a little breathing intervention. I always like to say stop breath and be, which is a meditation intervention where you're kind of stopping in the moment, because you're not in that next moment yet, you're breathing in, and you are being just in that moment. But to be able to stop and be present in that moment to get in touch with what you are experiencing. When you breathe in through your nose deeply. And you can even do a 4-7-8 breathing. Breathe in for for the count of four, hold for the count of seven, exhale for the count of eight. You know, the science behind breathing is that it really reverses the nervous system, from a sympathetic nervous response to a parasympathetic, which basically means stress to more calm, right. And so that's one thing in the moment, because sometimes we need to settle our brain because we're in a panic mode, or we're in a worry mode. Also plans for what you need, what you know yourself, what is, is your downtime choice that gives you that energy, whether it's walking, moving. You know, the pendulum can swing, we can go into this place of all care, and nothing for ourselves, right. And that's not helpful. Been there, done that and understand, you know, full transparency. It's not easy, but to recognize when that pendulum has swung, and I need to pull it back. So I need to, for example, last week, before I started to feel stress, I started to feel like I was gearing up, okay, listen to those signals. The line, why is this happening to me? What can I learn from it? Instead, you know, think of what I can do about it. So I decided I wasn't going to go spend time with my mom who I knew needed me. Not medically, but there was an emotional need. I decided I wasn't going to be any good to her or myself if I didn't walk. So I walked before I went and that made a world of difference. I knew I did something for myself. Some people can you know, some people like to run some people like whatever your way of discharging that stress is, yep. Whether it's putting a candle on reading, whether it's talking to a friend releasing a discharging in some way, but to discharge it, so that you're making space, space first for yourself, so that you can share, give that space to your loved one.

Rosanne 57:31

I love that. I think what gets lost sometimes is that self-care doesn't have to be a big thing. It doesn't have to be a, I'm waving a flag, I'm doing self-care. It doesn't have to be this big event, it can be these little pockets that you can carve out.

Phyllis 57:47

That's right. And it really to tell you the truth, I knew that I wasn't going to get to the facility until 8:30 at night, but I let her know, I'm coming. But it's not now. It's gonna be soon. So when I walked and let her know, I walked well, then she could be happy as a mother that I'm taking care of myself. Right. Right. That transition of being the caretaker caregiver of your parent, it's a transition is a transformation. It's, you know that when that starts to happen in life, but to keep intact, that relationship is really important to your loved one and to you, you plural to us. Because I think that the value of that relationship is also uplifting. To maintain it's all about identity to maintain identity,

Rosanne 58:43

identity of both you as the caregiver, and of your care partner. And part of advocacy is advocating for them as a person as an individual.

Phyllis 58:55

Yeah. Because you're not all of a sudden, just a resident in a facility, you're still a mother, you're still intelligent, you still have preferences, you still have Love Languages of food and family and need those needs met. And how as a family, you transfer, spending time as a family from when you can't bring that person out to how you go in and maintain that feeling of family. Right. And that is really important, you know, as I'm sitting here listening to myself, so that not really maintain the assemblance in your mind of family. You're still family. You're not a role, your family, there are times where you're taking the role and recognizing the time and space for that.

Rosanne 59:43

Right well and it's hard because that's what happens. You become caregiver, the scales change. So you're more caregiver than your daughter, you're more caregiver than your son, then your spouse then you are whoever because all of your energy is going there and it's hard to then keep The reins on yourself as a person, because you're all these other things and we're, listen, we're always all these other things. That's that's part of life. But the caregiving responsibility is so great that it kind of permeates into your being while you're doing it.

Phyllis 1:00:16

Yeah. And I think there's one thing when I'm talking about family that I think is really important to say. If you have children, no matter what age children, you are modeling that for them, yeah.

You know, having communication with your family, and they see what it takes to caregiver, but they're also watching you with trying to balance and they're, you know, they're seeing the level of they're seeing that pendulum swing, they're saying the the energy that it takes, and the other piece of it is let your family take care of you, and even worry about you. If maybe you're maybe you're not seeing something that they are, the scale starts to tip, right when your family starts to notice.

Rosanne 1:01:00

Right? Because they give you those eyes like, hmm, what are you doing?

Phyllis 1:01:05

Right and you're willing to listen, that you're not letting somebody you're not letting your loved one down by letting your other loved ones who are your children or your spouses or whoever your spouse is, you know, Letting them notice, because they're caring for the caregiver, and they're becoming caregivers themselves. Right. They're learning to care give by watching and by caregiving. And that, and I will say that my family is very aware of that. And they talk about it, I think it's important to communicate about that in your family, and be able to have that conversation that this is not just on you. But also to know not where to where you don't want to put it in terms of the boundary of your children, no matter what age, right, you know?

Rosanne 1:01:53

Well, because it is and it is it's it affects the whole family.

Phyllis 1:01:57

Yeah. So giving your family the right to notice that your you might be a little out of whack. You look stressed, he sounds chess or if not, you know, thinking about what you're about to do? Let's think that through,

Rosanne 1:02:11

Right, and let them care for you.

Phyllis 1:02:13

And let them care for you. Because what's, how can they feel valuable is your family that they're noticing, and they're taking steps and taking steps but also wanting to take that initiative as your as your family, right. To worry, that makes you on it together in different ways.

Rosanne 1:02:34

So you don't feel like you're the Lone Ranger?

Phyllis 1:02:36

Yeah, yeah. I mean, there's nothing, you know, we need to make sure to as a caregiver, there's nothing to prove. If we walk around, say I got this, how realistic are we being. For ourselves, when that scale is tipping, and we're starting to get really stressed out or don't have as much energy, or we're not sleeping as much and we're missing meals. You know, those are the kinds of things that happen because, you know, running, feeding the cats first and running out, because you have on this timeframe. Knowing your own knowing, you know, kind of going back to that space, where do you stand in that space for yourself? What is that space that you need to be giving to you as much as you give to others?

Phyllis 1:03:18

Knowing your own knowing, you know, kind of going back to that space? Where do you stand in that space for yourself? What is that space that you need to be giving to you as much as you give to others?

Rosanne 1:03:32

Because you have to because you're going to run yourself into the ground?

Phyllis 1:03:34

Yeah. Yeah, I mean, really not making sure that you don't isolate yourself. I think it's fabulous that Daughterhood organization has that available as a as a major resource in all different kinds of ways of the meaning of caregiving and the rest. So it's really, really is using your strength of creativity, and perspective and judgment and often self regulating, you know, when really being able to regulate your emotion throughout the whole experience. Yeah. And so having someone to talk to and through as you're that advocate for somebody else, you're that person who who's there for you? Who's your go to and, go to, go to go to encourage people to really go to their to their people.

Rosanne 1:04:34

Right? Whoever that may be. Yes.

Phyllis 1:04:38

Yeah, and you know as women, women often will....

Rosanne 1:04:41

Go down with the ship

Phyllis 1:04:43

Go down with the yeah I got this you know, yeah, maybe on the back baby and the friend Holly bags and they're saying I got I got the door. You don't have to open it.

Rosanne 1:04:52

No, no agreed.

Phyllis 1:04:54

Be able to say thank you when someone offers to help rather than saying that's okay, I got this and not feel like you don't got this has nothing to do with you don't got. Has to do with the allowance of letting someone take care of you in the moment. So practice saying to say thank you. Thank you for helping. Thank you for listening. Thank you for being there for me.

Absolutely. And thank you sometimes for letting me cry with you. You know, sometimes it comes down to that because you know, we there are some really deep, hard moments that we're trying to manage and having a safe a safe place for somebody to go for, you know, to be able to release that.

Rosanne 1:05:36

Make space.

Phyllis 1:05:37

Yeah.

Rosanne 1:05:37

Phyllis, you've given us such great information today. Is there anything else you'd like to add?

Phyllis 1:05:42

I guess one other thing that I want to add is that, to allow yourself to feel the confidence in what you know, and feel the confidence to be who you need to be to your loved one, and not worry about what somebody's thinking of you. To feel confident in what you're wanting to accomplish and make sure of and feel confident in the knowledge that you have and be okay with not knowing and not worrying about who you aren't. You don't have to worry about not being in the medical field. Sometimes you have more to offer that is really helpful. That is a game changer. So being confident in your role, and feel okay to show up in that role. And people will see that passion and compassion you lead with that, it shows. It shows, and even staff will notice relationships, they will they have noticed my relationship with my mother out of the way they see me interact with her. So this is the real thing. She's just not coming in here to tell me what to do this relationship to her matters, right. And then therefore, there are times where I've been referred to as family to the nurses, and I say your family to us, but the confidence in knowing that. You don't need to prove why you're doing what you're doing. And there's no as I said, no eligibility requirements to do what you're doing, but just to allow yourself to feel that confidence in the sense of not worrying what someone will think of you.

Rosanne 1:07:31

A big thank you to Phyllis Ivey for being my guest today. If you would like to reach Phyllis, If you would like to speak with Phyllis about advocacy you can do so at her website intendforwardcoaching.com 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.