Daughterhood the Podcast
Episode #62
Caregiver-Doctor Communication: What Matters with Cheryl Phillips

1:06:19

Resources:

The Guide Program

Age-Friendly Health Systems

Senior Community Centers

Aging Life Care Managers

AARP

Age-Friendly Health Systems Guide for Older Adults and Caregivers: My Health Checklist

Patient Priorities Care

Christopher MacLellan 00:00
This is the whole care network helping you tell your story one podcast at a time. Content presented in the following podcast is for information purposes only. Views and opinions expressed in this podcast are solely those of the hosts and guests and may not represent the views and opinions of the Whole Care Network. Always consult with your physician for any medical advice, and always consult with your attorney for any legal advice. And thank you for listening To the Whole Care Network.

Rosanne 01:06
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 health care 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.

Rosanne 01:56
Cheryl Phillips, MD, AGSF, is the immediate past president and CEO of the special needs plan Alliance and currently a Senior Program Consultant with the John A Hartford Foundation. She has extensive experience in health policy, Medicare Advantage and the program of all inclusive care for the elderly pace. As a fellowship trained geriatrician, her clinical practice focused on the long term care continuum. Dr Phillips served as a primary care health policy fellow Under Secretary Tommy Thompson, and currently chairs the SCAN Foundation Board of Directors and serves as a director on the scan health plan and group boards. Today, we discuss the four M's that will help you prepare for each appointment, the burden of being the connector and care coordinator with specialists, dealing with assumptions and expectations, the danger of anesthesia and falls and much more. I hope you enjoy our conversation.

Rosanne 02:52
Cheryl, you had addressed in a commentary you wrote back in 2016 for leading age entitled care coordination for primary care practice in it, you said, successful care coordination, therefore, must go beyond a pure quote medical model end quote of managing referrals, coordinating diagnostic studies and reviewing medications, it must include the integration of medical and social needs and provide supportive services identified by risk assessment, which are often outside the realm of the primary care office. Now that's our expectation as care partners, but that isn't what we receive. So what do we do?

Dr Cheryl Phillips 03:30
Well, let's start a little bit back okay, when I was talking about that, and I still hold true to those are such key elements of successful care coordination. And care coordination is a term that is tossed around a lot, but there's not a whole lot of definition, except when you're on the other end, when you are the care partner for someone, a family member, a loved one, whatever, you have a good sense of what care coordination is, and that is, my life is crazy. I don't know where to go. I've got 16 different appointments. Nobody is explaining to me what's happening, and I want somebody to manage that. And to me,

that's care coordination, yeah. And when I use that broader definition, very few physician offices. Let's start with the primary care offices are really in a mindset, or have the capabilities or resources or even understanding of how to make that happen, and so the gaps that we see right now are that, and this is not disparaging primary care doctors, sure, but most of them do not know any community resources. They don't know where to send people. They don't know how to even assess for the big picture. So when I say, How is the person doing? If I'm a Doctor, I'm thinking about it. Okay, do they have shortness of breath? Can they walk? Are they having pain? But if I'm thinking about it in the broader care management sense, I want to know how they're doing in their setting, where they live with the resources they do or don't have, and how are you doing as the care partner, trying to coordinate all of that? Right? That's a reasonable ask, but I'm going to say that's a big ask. Now some offices are starting to have linkages. So one of the large health systems that I worked at several years ago, we started a care coordination program, um we called it Cheryl's frail elder program, which was not a good marketing tool, I'll just say. But what we recognized was we needed other expertise, social workers, a nurse who understood Community Health, someone who could help navigate the person and their family care partner to the needed services that were above and beyond the medical I don't know if that answers your question, but right now, the gaps are there. What do family members do? Because it's a big lift, I think starting with an open ended question of we've talked about my mom's, let's say, medical stuff. I also need help with these other things. Do you have a suggestion of how I might get assistance in managing that? That's the most open ended way to say that. And then we can talk a little bit later. What happens when they say, I have no idea.

Rosanne 06:48
Well, that that was my next, yeah, because, because, you know, we go in there, we've got 10 minutes. We have our questions. They do their thing, they're typing away on their computer, and then that's it. You're done. I've asked it, you've asked an answer to and you're done, and you're you're going on, but you're left with more questions than what you came in with, especially if, if there's more than one problem, right? If there's and most likely people have more than just one issue, the comorbidities, meaning, you know, there's more than one condition, one more than one disease, adds more specialists, it's adds more tests, and trying to manage all of that while still being in on in contact with the primary care physician where you started, is also just overwhelming. And how do we what? What is it? You know, are there magic words, or is it the way the

system is set up that there are no magic words. It's just you have to try to find your way through. How do we do it?

Dr Cheryl Phillips 07:46
So how do you start that conversation you walked into the physician office? My suggestion is, is have a list of where you see the current gaps or needs are, so that at least you're organized that the provider, the clinician, the nurse practitioner, physician, whomever you're seeing, may have all the answers, but you have an organized list, and I would even prioritize them. You know, my biggest problem right now is and outline that most offices will have at least an access to a referral for some kind of social work or case management that's becoming increasingly prominent. Okay, so not having the expectation that that office visit is going to solve the problem, but utilizing that list to help start the problem discussion, because that list, you will probably come back to many, many times we can then talk about so the office visit didn't give you any answers. What do you look for outside of the office visit? And I'm going to be a little bit tangential here. A lot of times I went through this experience. My mother just passed away with advanced dementia in January, excuse me, in June, and I had the daughter role I also had in the background the geriatrician role, but I realized I was her daughter first, not her doctor, but I went to all those appointments. I went to all of those things trying to get resources, and realized that my expectation was that her primary care team would provide those solutions, and they didn't. So I had to realize, what was I using the primary care team for? What was an expectation that they could actually provide? And then how do I step back and say, Okay, now I need to navigate some other resources, right? So what are those? Other resources, and they vary by the community that you may be in, and I am sure that your listeners have heard this before, so I'm not thinking that I'm coming up with a list that nobody has ever talked about, or they've never thought about, for those who can afford it. And I put that caveat because much of the care that is needed for an older adult who has dependency needs ends up being out of pocket. Yeah, it just does. If there are care coordinators or senior care managers that are in the community, and some of them are superb, some of them are okay, and you can start with an interview of what your needs are. So that's why your list becomes really important, because as you start to reach out, that list of how people can address those needs or ideas or suggestions become so critical senior community centers, there may be even AARP offices that may have resources. Your healthcare system may have a help call line I would use it, not that I would expect they have all the answers, but they may have some ideas of referrals. And every time you get a referral, I

make a list of this is, these are my problems. These are my potential go tos. So that I start creating a map for myself.

Rosanne 11:33
I love that. I love that. And you're right, the expectation of we're going to get to the doctor and they're going to give me a, b, c and d, and I'm going to be able to move forward with that, and then we leave there, and we don't have it, and it's it kind of adds to our struggles while caregiving.

Dr Cheryl Phillips 11:51
I will add another emotional struggle, and this is a criticism of primary care. So you bring your loved one in, and you know, something isn't right, kind of what it is. Dad has been he always walks to the neighbor's house, but now he's getting lost, or at least he's taking a long time getting back. You know, you may notice some, and I'll use the word behaviors, not like they're inappropriate, but just some actions, some behaviors that you know just don't fit. And you bring this to the primary care physician who says, Well, you know, that's just aging. Don't worry about it, right? One of the big gaps that we have is that many, many primary care providers are not tuned in to understanding cognitive changes dementia and dementia may take on very many forms, and sometimes the first step as this journey of how do I get help, is Finding someone who will take those symptoms, those behaviors, seriously, and so I would often start or recommend that people would start with so these, just like you have your list of your needs, these are the list of the things that I'm seeing that I don't have an explanation for. If you're not able to help me with that, who can I see to help me get a bigger picture, it may be a neurologist, it may be a psychologist, because psychologists can do a mental status and neuropsychiatric testing. It may be a social worker who's skilled in it, but there may also be very good community resources outside of your primary care network that evaluate for early signs of dementia, and I'm going to just give a plug for a new program that's offered by Medicare called guide G, U, I, D, E, and your listeners can just plug in guide dementia care. You will get resources in your area. There are now several of them that are online so you can communicate with primary care physicians, neurologists, social workers, nurses who are trained in dementia care to start that journey of what is this? What's happening? How do I understand it? They also, within the guide model, have resources for families and caregivers. They're not exhaustive. They won't solve all your problems, but they're a starting point. And so if you're not getting where you need with the primary care team that you have, I would encourage people to look at the guide resources online. They are free, they are

available, and they're in a variety of communities, including rural communities and with digital access. So I don't have any vested stock in that. It's free. It's by it's operated by Medicare, but it's recognizing that there is a huge gap, and it's getting worse in this country.

Rosanne 15:09
Yes, and I applaud the effort. I applaud the attempt, because it is the hardest thing to try to get a dementia diagnosis. And I know that you have said before, you know doctors have what one class on dementia?

Dr Cheryl Phillips 15:23
Yeah, maybe they've gone to a couple of webinars, and there's a bias. I remember when I was teaching this is actually heartbreaking to me. I was teaching medical residents on how do you recognize early dementia changes in an older adult, including the interactions in talking with the family, and the response I got from one, which I think is the saying The quiet power out loud is, why would we want to evaluate for dementia when we can't do anything for it? To which I said, you have one exhausted spouse here. They don't know what's going on. They're lost, they're stressed, if for nothing else, even if you don't believe in any of the treatments you need to help this family unit in their path of being a care partner, which to me, is frankly, even more important than the medications and the treatments, which we have yet to see, be wildly successful. So you know, there's no magic bullet. So we start with, how do we help that family unit in making this work.

Rosanne 16:38
So important I love that, and I love that you said that because the the pressure and the anxiety and the worry and the stress that go along with, Oh, my goodness, what am I seeing? And then you can't get anybody to say, Yeah, I think so. I mean, and believe me, I it was years before somebody said the word dementia, and it was years of my watching my mother and being like, wait, I can't be the only one that's seen this. Like, I know something's wrong, yes, and to not have that, but you're right, it then empowers you, because then it's, it's like, okay, now I know. Now we can try to put things into place, even just as guardrails, even if, if you can't do anything, it's a guardrail.

Dr Cheryl Phillips 17:19
Yes, it's recognition, and I will. So now I'll put my geriatrician hat on. Okay, when the individual is going through the stages of dementia early on, it's scary for them to Yes,

it's it's unnerving. It's disorienting. The world doesn't seem right. They may be terrified, they may be confused, and sometimes being able to talk through that with some words that fit is not. People don't want to use the word dementia or Alzheimer's, or whatever words we may be using, but actually, when you start to talk through and the recognition and telling your loved one, you know what, we're seeing this together, and we're in this together. And I know it's scary, but let's find some answers. And the most important thing is that we're here to make a plan and but in order to make a plan, you have to know what the it is, exactly, exactly, and without it, you don't. You're just, you're you're spinning absolutely and that that spinning place is terrifying for the individual, but it's also terrifying for the family members. And again, I'm speaking to your audiences know this way better than I do, because they're in that spin. It's a wash and dry cycle that just doesn't end. And every you know, few weeks, few months, then there's a new thing added to this wash and dry cycle that is a new thing to cope with. So I'll go back to that list. Yeah, what are my problems? What? What are the things that I'm concerned about? Is it transportation? Is it safety? Is it driving? Is it is it guns in the house? I just found a in a family member. I won't give too many details, but helping a family cousin in the care of her mother and a family member, and we found a loaded 45 in her underwear drawer. Now, you know, so I'm going to put some of those safety things out there. Is just real. It's medication management, it's falls, it's getting lost, disorientation, my mother didn't remember very many things, but she remembered her birthdate and her social security number, and she was very happy to tell everyone on the phone those two bits of information. So it's watching for fraudulent abuse, and all of a sudden the family caregiver is thinking. Of all of these Gremlins that are surrounding so starting with the list of priorities, and also starting with the list of what am I seeing, what am I observing? What are the changes? And then starting your list of resources as they are offered to you. Now, some of them may not be very helpful, and we go through a lot of goose chases trying to track things down, but keeping those three elements organized, I think me personally helped me in managing that care path with my own mother.

Rosanne 20:33
Yeah, I I fully agree. I fully agree. And and there's nothing as frustrating as keeping that list and then going into the doctor and having the doctor be like, just aging and and when you know better.

Dr Cheryl Phillips 20:45
Yeah. And so there are times I think that we all struggle with, because I've been on both sides, yes, we all struggle with, I don't want to be that difficult daughter, yes. And I don't

want to be that pain in the you know what? Yep. But there are ways of being clear, respectful, but assertive. I know that you see this as normal aging, but I will tell you my mother's peers are the same age, and they are not having these problems. There is something distinctly different about my mother now than there was two years ago, and then there was three years ago. So if you tell me, this is normal aging, we still have a problem. How are we going to address the problem? And if you're not able to do that, and I understand this may be out of your scope of of specialty, where can I go and where can my mother go? To get both answers and to help start with some planning for solutions. I love that, and I think just being that clear, so you know what, I now I'm going to I actually loved difficult daughters.

Rosanne 21:59
Okay, why?

Dr Cheryl Phillips 22:01
I did I did because they would come in really angry and revved because they weren't angry at me. Maybe they just met me. They were angry at a year and a half of being sent in a million different places and nobody listening to them and getting patted on the head and and telling them that they were overly worried and yada yada yada. And so the first thing was that I got to do with them was say, Wow, this is overwhelming, isn't it? Let's take a deep breath, because I know you're angry and I don't even understand all the reasons why. I just totally accept that, and I want to commit to you that even if I don't always have the answers, I want to be on your team here, because we both want what's best for your mom. So let's step back and let's pick the top one or two things that are overwhelming you right now, because trying to deal with 20 of them may make you feel even more overwhelmed. So let's pick a couple and start sorting through and that would de escalate even the angriest of sons and daughters. Because what is needed, and I wish there was a way to make sure this happened in every care visit, but what is needed is somebody to pause say what you are going through. Sucks. This is hard. How do we help? Yes, I will put in a little bit of plug. And I'm doing this because I really want listeners to start to demand these things in a respectful but insistent way. And one of the organizations that I'm consulting with is rolling out what is called Age Friendly healthcare, and it's based on four simple precepts called the Four M's, what matters medications, mentation, including cognitive and memory changes and mobility, which also includes fall risk, but starting with what matters, sometimes even with the family member, usually the daughter, starting first with, you know, let's put everything else aside. We can talk about meds, we can talk about vaccines, we can talk about

mammograms. But let's start with right now what matters to you and your loved one, and that changes the tone of everything. And then you can start talking about the other things, amazing. Well, I think so. Age Friendly health systems is now a movement, is it? And like all movements, so it's about oh, and 400 hospitals and 700 nursing homes. And let's be honest, that's a starting point. Yes, but I, what I think is empowering is when people learn that this is an expectation, they can demand it, right? And there is, if. Um, you Google Age Friendly health systems. It's through the Institute of Healthcare Improvement IHI, but you just put in Age Friendly health systems. There are family and caregiver resources. So there are tools that somebody can download and say, You know what? I need to start with, what matters with my mom. And then I've got these three other broad areas that we need to talk about.

Rosanne 25:25
That's fantastic and and the fact that you have those areas, you can still take what matters, the medication, the mentation and the mobility, and go in there and use it as a as a starting point.

Dr Cheryl Phillips 25:37
As a starting point. And I even like now, there's a lot of issues that fall out of those four M's, I realize, but many of the problems that we're trying to grapple with will fall under those four M's, right? And even under what matters. I mean, that starts to be things like, I'm battling with my dad about driving so to me, the what matters question is his independence must be very, very important to him, and driving represents independence. How are there some ways that you can support that independence and recognize that his independent driving is no longer safe? So we, we've reframe it back to dad. You can't drive to dad, I know your independence is important. You want to go where you want to go when you want to go. How can we make that happen that doesn't involve you driving? And that's just an example of how you can use those 4m to redirect the conversations back to getting the answers and solutions that you need.

Rosanne 26:40
You know, it's really hard when they're combative. And of course, they're going to be combative. Of course they are, because nobody wants to lose what they're doing. It's it's it may be the natural course of change, but it's hard to accept that. It's hard to say I can't drive anymore. It's hard to say I have to sell my house because it's too big for me, or I have too many steps, whatever. But it feels like this can address some of that.

Dr Cheryl Phillips 27:07
Yeah, if you get to me, and I know there's not simple answers, and I am so respectful that you know one podcast from a geriatrician who you know that it doesn't solve everything right, but reframing these conflicts into what is the underlying what matters this home matters a lot to you. Let's talk a little bit about why. It's where you raised your kids. It has where all your things are, and it's hard to let go with things. It's it's where your friends and neighbors are. Let's talk about that and then talk about ways to think about reframing that in and managing what matters in a different context. Yeah, and it's hard. It is. It is hard. I'm not being trivial, no, but, but it's it's hard, but it's the fact of where you are, and it's also hard. So I have often used this example. I had been up all night on a red eye flight to another country where I didn't speak the language, and I got off, I couldn't read the signs. I didn't know where I was. People were bumping into me. People were giving me instructions that I didn't understand. I was tired, and I kind of had an outburst, and I paused and said, You know what? That's just what it's like to have cognitive impairment, because you are now in a new world with a new language. You're not always understanding people. You don't know what your choices are. Things are being bombarded at you and and when I paused and said, Okay, what did I need right now? I mean, one, I needed some sleep, I needed some space, I needed to calm and I needed single questions that I could respond to in a context that that I could relate to. And I do the same thing when I'm starting to approach individuals with memory impairment that are so genuinely frustrated. These are not because they're inherently bad people. These are just core frustrations, because the whole world is is upside down, yes, because we often bombard with a lot of problems, even to the individual that we're caring for, yeah, and and then we get in rational and sometimes irrational debates, yeah, about why they need to do something or not do something. And this is that I gotta take your keys away, and you need to move out of this house. And house. And this is not safe, and there is no way you can stay here and and so a suggestion is to think about being in another country where you don't speak the language. How would you need to step back and have a one piece of information to get you started?

AD 29:58
I want more daughterhood. We are more than the podcast. We are a community that offers free, nationwide virtual support groups we call circles. These circles allow you to connect, learn and support one another through your caregiving journey. You can find more information@daughterhood.org where you can register for a circle, sign up for our newsletter and find other resources for additional support. REMEMBER to also follow us on Instagram and Facebook at Daughterhood,

Rosanne 30:36
And you can use that as you move through whatever doctor you see next, yeah, so you can use that at every it's like every port in the storm. You can use that.

Dr Cheryl Phillips 30:46
Yes, okay. And you may see multiple doctors. That's the unfortunate. The other thing you may see and realize, even when, and I won't pick any health care system, but they have electronic medical records, they may or may not have read the previous note. I will even tell you that many of the previous notes are auto filled, and so there's often errors. They rarely capture all of the issues that you have raised. So that's why keeping your problem list and your observation of what's happening list is so important because oftentimes we go to the next ologist and assume that they have all the information that we have done the last 20 times, yes, and we're starting from scratch, and that adds to the frustration. So keeping your own map is so important and sharing it.

Rosanne 31:44
Yeah, talk to me about that a little bit, because we are all in all of these systems. Sometimes you're in the same system, sometimes you're in a different one. And we all have our portals, and we do, we assume that our last results got there. What? How do we you know, I'm, I'm an old school I write everything down. I come in with my binder. It makes people very nervous.

Dr Cheryl Phillips 32:09
I love binder families. In fact, I will, I see a binder I will start with. Thank you for bringing that before we even get started. Whats in the binder that you want me to know that I may not know right now? So let's, let's back up and because the reality is, and sometimes, again, I'm not criticize. I am criticizing, but not trying to make them be the bad guys. But the medical system is fragmented, even when they have coordinated information, and each specialist is going to focus on that, I shouldn't say each, but most specialists will focus on that narrow problem that they think you're there for. So the bigger issue is dad has been declining with memory and having emotional outbursts and not managing his meds and getting lost, and we don't think he should drive. But he also has heart problems, and he's on three heart medicines. He has he's past smoker. He has lung problems, and he has two inhalers that I don't think he knows how to use, and and by the way, his knees have been hurting him really badly. And so each of those different specialists, you're going to go to the heart doctor, and they're going to talk

about the heart medicines, and what's often missed is in the context of, I don't even think he's taking his heart medicines, or maybe he's taking them wrong. So before we even talk about needing another heart medicine or doing another heart test. I need to let you know that the underlying issue here is we're trying to manage his big picture, and one of them is his medications, because you'll go straight into, well, we need, you know, it's time for another echo, and let's do an EKG, and, you know, and all of that. And with each of the specialists, that same thing will happen, and the burden, and I recognize it, is not fair, and there's nothing about this. It's fair. But the burden for the family care partner is you are often that connector thread of information between all the specialists. They may not know what medicines he's taking, even though they probably have a list, but it may not be correct. That's another thing to assume. So you are the coordinator of what is my family member actually taking? Now? What are my concerns about what they're taking and if they're not taking it, and that needs to be shared at every different doctor's office, because, again, we assume that everybody has the same information, and maybe they have access to it, but maybe they haven't read it. Yes, and you have a 10 or 15 minute visit, and these problems are two hour problems.

Rosanne 34:58
Right? You're on the clock as soon as you walk in.

Dr Cheryl Phillips 35:02
Oftentimes, before.

Rosanne 35:04
This is true and you you actually put a name to this, which is poly management syndrome.

Dr Cheryl Phillips 35:10
Yes. So I'll go back to, let's say our dad that has the heart problems and the lung problems, and he's also a diabetic and he has arthritis problems. So the heart doctor, the cardiologist, says, I can't manage all of this, but we have a cardiology care manager and the diabetic doctor, the endocrinologist, has a diabetes care manager, and the neurologist may have a neuro you get the picture, and all of a sudden you have these satellite moons that are traveling around you, sometimes getting conflicting information, most often looking at a disease, specific care management solution, which doesn't put into context. This is my dad, who's 88 years old, who has all of these problems, and the most important thing is he's not taking his medicines correctly, and he's falling and he's

not eating. So let's start back in the big picture, and one of the challenges for care partners is managing the poly management syndrome, yes, and you know, again, being respectful but insistent that before we talk about dad's heart medicines, we need to talk about the fact that I need some help in managing his medicines because he's not taking them. I know the way the physician said that he was supposed to so pushing back on the poly management syndrome, and if there is an organization, whether it is even, believe it or not, your insurance plan, which may have a care manager, is the question that I would push back with is, I know each of you are trying to help me, but if I'm talking to The diabetic care manager, I will say, you know, I also have this care manager and this care manager and this care manager, I need to talk to someone who can coordinate the care managers, who would that be in your organization? Okay, sometimes there isn't one, and then that has to be you. But I just I recognize it in our attempts on the medical side to manage care, we sometimes have created an additional burden and mess. And my loved one is not the sum of their diseases Correct. That's a big miss, because in the medical environment, we focus on the diseases and the problem list that we have that's medical. And so the care partner's job is to say, Okay, we know these are all real and they're very important, but I need to put it in the context of this is my dad with the bigger picture of problems.

Rosanne 37:56
Right? And he's a person.

Dr Cheryl Phillips 37:58
He's a person, and these are the things that work well for him, because it's not all about what my dad can't do, right? These are the things he does very well. These are the things that he still enjoys. These are the things that we need help with.

Rosanne 38:10
Yeah, no, I love that. And I think also, when you get into these specialists, each specialist is so concerned on what they're doing, and then you have to, you have to rely on them to be honest with you about what they are treating because, you know, they just keep going.

Dr Cheryl Phillips 38:28
And you know, if, when you're a hammer, everything's a nail. So we're not blaming them. They do what they do. That is where what matters steps in, starting with what matters, because that will frame each one of these specialist conversations, and I'll give

you another anecdote of my mother, but to me, it was so typical of missing what matters. Okay, so my mother was in her early 90s. She was no longer verbal, she was not ambulatory, and she had an ingrown toenail that was infected. I went to the orthopedist in her system, and they had a podiatrist that worked in the clinic, and he said, well, we need to send her for vascular studies, because I don't feel good pulses. And I paused, and I said, I'm going to be the difficult daughter here, but let's ask some questions. What are you going to do with the vascular studies? Because I can tell you right now, she doesn't have very good pulses because her feet are blue. So what are we going to do with the vascular studies? Are we then going to send her to a vascular specialist to stent her? Then, before they stent her, they're going to want to look at her heart arteries, and then they always want to look at the carotids going to her brain. So now we have a series of both invasive and non invasive studies that may or may not give us information for which we are not going to do anything with.

Rosanne 39:56
Right.

Dr Cheryl Phillips 39:57
So can you please remove her toenail?

Rosanne 40:00
Mm, hmm. And what did they say?

Dr Cheryl Phillips 40:03
Well, they said, but our path, you know, our our guidelines are that we shouldn't do it because it may not heal. And I said, Okay, let's step back and I use the what matters right now my mother, who cannot express herself, is in pain because she winces when there's pressure on that toe. So what matters to her is to stop the pain. It may not heal. She may never get another you know, we'll keep it bandaged, right? But we need to stop the pain for her right now. We don't need vascular studies, because we're not going to put her through that. We're not going to do anything with the information. So what matters right now is that the pain in that toenail is relieved. And I will accept that there's a chance that the toenail may not, you know, the toe may not heal. So we he did it. She did find the toenail actually healed beautifully, and she didn't have any more pain. But when you get into there is such a slippery slope of, well, if there's this problem, then we need to do this right. And the what matters question, and why I think it's so important, is that you step back and you say, how will this help the problem that

my mom is having right now? Because we need to know what we're going to do with the information, even lab tests. And I have to say we're also addicted to lab tests. I don't know that docs can can function now without lab tests, and the lab tests themselves may be minimally invasive, but what are we doing with the information? So is it going to help in what matters to my loved one right now, and will it help us plan her care, his care in a way that is meaningful to them?

Rosanne 41:54
Yes, I love that. And the question, what are we doing with the information, I think can be very helpful. Because when you are in front of the doctor and you say, how about this? And they go down that list, like you just said, Well, we have to do the vascular study, and we have to do this, and we have to do this, and you're sitting there thinking, oh my God, how am I going to do this? What does this mean to her? How am I getting her to all of these appointments? Because, you know, it's not like they're going to take you right in, you're looking at weeks between each

Dr Cheryl Phillips 42:23
Weeks and weeks and cancels and scheduling exactly, and explaining to mom why we have to get dressed again to go to another appointment.

Rosanne 42:33
Right. And all of that is going through your mind. And that question, what are we going to do with the information? Is empowerment to the caregiver, because it puts it back on the Doctor. And if they say, Well, you know, we have to, and it's very simple, I need this. This is what's important right now.

Dr Cheryl Phillips 42:51
Yeah. And what do each one of these paths, and I would also add to the burden the time off from work, which is not insignificant for care partners. And sometimes these are difficult, difficult discussions. So I'll use another example, an 88 year old woman whose daughter was very distressed because she was having some blood when she was having a bowel movement. Now it may be something simple, like hemorrhoids. It may be something serious, like colorectal cancer, it may, you know, we don't know. We don't know, right? We start with the we don't know. And these are all of the things that could be so now let's talk about what each one of those would mean, and let's think about a path before we start getting all the tests, right? So maybe the simplest test is and it's not comfortable for her, but I can look and see what if there's anything I can see that's a

start. Maybe we need to do a colonoscopy, but let's talk about that, because that means a rep that's uncomfortable, that's difficult, that may make her very sick. It get, may confuse her. We have to use some sedation, which may make things worse. And then let's say we find a tumor and we biopsy it. Now, the next big question is, what path do you want to go down and where we don't give I know I'm getting a little bit tangential here, but in the what matters, we don't give families a and care partners choices, but informed choices, right? So the worst way to say that is, well, your mom may have cancer, but you probably don't want to do anything about it, which makes a care partner think I'm a monster. This is terrible. Of course, I care about my mom. We want to get rid of the cancer. A better way to put that is these are all the things that it may be. These are all the steps we would have to do to evaluate it. If it were cancer, what does that mean? The likelihood is that, and then I would talk through some of the consequences. But the other reality is that doing a big surgery, doing chemotherapy, if it's indicated, these are also not benign options. And are there choices, going back to what matters, that we can do in stages, realizing that it is okay to say we're not going to the next stage. So maybe the first stage is we do a simple test, and if we get some serious information, that means we have to do something invasive, maybe that's a time to stop and say, Is this what we want to do? Does this align? And the other important thing that families are left with with this guilt is doctors sound like we're not going to do anything. Choosing a comfort path and not being aggressive is not the same as not doing anything. It means you now have a different set of supports and interventions and a focus on comfort, whatever that may mean to the individual and the family care partner. But I know I'm getting off on these. No, you're great that are difficult, but in the context of someone with cognitive impairment, who's unable to share in those decisions, the family and care partners are often left with bad choices, with no information. And so going back to what matters is, how do we talk about the choices, and what do the choices mean, and what is the best option for my loved one right now in the care picture of the whole person that we're looking at. And those are necessary conversations, and sometimes the care partners have to be the ones that start that conversation.

Rosanne 47:00
And it's a conversation nobody wants to have.

Dr Cheryl Phillips 47:03
Nobody wants to have, and they are difficult. Yes, they are very difficult. But you know what? There? There's other resources out there to think about these conversations that

are not medical. Sometimes your faith leader can be a wonderful partner, and more and more are being trained not to be gastroenterologists or cardiologists or any ologists, but they can sit down with you and say, first of all, what matters most to your loved one. What if they were speaking for themselves? What would they say? Not what you want. What would they say? And there's a term called substituted judgment. But what that means, and that relieves some of the burden, so I'll ask the son and daughter in law, tell me about your dad and his how he related to medical care. Oh, he hated doctors. He did not like medications. He didn't want to go and so I would, in that context, say, then let's think about what the next steps are, knowing that if your dad could speak to me right now, he would say, blank, blank, blank, no, I'm not going, which is very different than saying, Well, the next test we need to do is da da da.

Rosanne 48:20
Right, I think, you know, it comes back to not just the expectation, but the acceptance, and the acceptance of where we are and what we're looking at and how this fits in your care partner's life and what they would want.

Dr Cheryl Phillips 48:38
And we need to stop back and reflect, what do I think is going to be like in three years, in five years, and how do I help make that journey as positive as possible, with as much dignity and as much independence as possible for the person that I'm Caring for, and that reframes so much of this other stuff that gets in the way. Yeah, but going back to where we started in our conversation, in order to start that journey, and in order to imagine what things will be like in three years, in five years, I need to know what is the issue right now, what is the it give me a clue. What am I dealing with?

Rosanne 49:24
Yep. And what does this look like from a doctor? So you want to do this today, but what does this look like if we did something and if we didn't do something.

Dr Cheryl Phillips 49:33
Exactly, exactly, which is a very different conversation than we're giving up on your mom. We're not going to do anything for your dad. We don't care about your sister. I often had this conversation in cancer screening, yeah, so you know, I'm my I don't have a sister, but my sister is 76 but she's been struggling with memory changes. For the last five years, and she usually recognizes me, but not always. And you're telling me that it's time for her mammogram To what end should. And I picked 76 in particular because the

cutoff recommendation is 75 but many physicians will still recommend a mammogram, yeah, and they will say, Well, if her life expectancy is 10 years, then we should get a mammogram. And then I would say, Well, maybe her life expectancy is 10 years, but I'm seeing some changes, so we need to talk about what those changes are, because I need to know what the next 10 years will look like. But right now, I have a sister who is agitated, terrified, the idea, and I'll be blunt, of taking her top off and sticking her boobs in a smasher is not something that's going to go well for her. So what are we gaining by that? Let's talk about the options. That's how all of these what matter questions fold into every one of the physician visits, even starting a new medication. Why are we starting the new medication? What is it going to change? How does it impact this person that I love their life, and what are the downsides? Not to mention that they don't like to take medicines and it costs alot.

Rosanne 51:23
Right as it is, yeah, and it's, you know, it's also part of that we're going to do this procedure, great, every procedure, and you know, you correct me if I'm wrong, every procedure, especially if there's anesthesia, There's going to be an effect

Dr Cheryl Phillips 51:39
Absolutely, short term or long term. And anesthesia we know in a vulnerable mind or brain, because we know that the dementia changes our brain changes, anesthesia affects that vulnerable mind in the short term, with delirium, new onset confusion. That's worse than their underlying memory problems, but it also often affects for long term. So none of these, I would even say things as as much as having to hold somebody down to get a blood test. None of these things are without consequences, and are the consequences worth it? Do they get back to what matters to this person that I love.

Rosanne 52:26
It's talked about in such it's and I don't want to say flippant, but that's what it feels like, Oh, it's fine. And it's like, it's not fine. And I mean, obviously for people that have any type of cognitive issues, but is there an age where anesthesia is worse? Is it over 60? Is it over 65 is it over 70? What is it for people that that are cognitively intact?

Dr Cheryl Phillips 52:48
So there's not an inherent cutoff age, but the risk does go up with age, okay, because there are underlying brain changes that may not be apparent. So we certainly know people that in the 80s and went through surgery and came back just fine and had no

problems. So it's not a simple age cutoff, but if you think about any of the forms of dementia as a change in the electrical and chemical and mechanical parts of the brain, anything that directly assaults that, which is, let's face it, that's what anesthesia is. So are many medications is going to affect that process, and I always, particularly if there is going to be long time an anesthesia, or if there is going to be times with low oxygen, like with heart surgery, one of the points that is often not shared with families is the odds are your loved one is going to be much more confused afterwards, And I can't tell you that it's going to come back to baseline. So what does that mean? What does that mean to you and how you're caring for them? What does that mean to them? So if they are marginally independent now, but you're looking at a big surgery, then that what matters comes back and says, How does this big surgery fit with what is the most important thing to them right now? Because if they come back and they have to be in a nursing home level of care that may not be alignment with what matters, if they're having a lot of heart chest pain and they can't function and they're very immobilized, well then maybe the surgery is important, because right now what matters is I can't breathe in my chest hurts. So you put that in the context. And I'm going to be cautious here, because I don't want your listeners to think that you guys now all need to get medical degrees you don't. What you are the expert in is the person that you're a care partner for. You are the specialist of that person. So now you're trying and attempting to have a dialog with the other specialist. They know the heart. You know your mom. How do we figure out a care plan that works for what my mom needs.

Rosanne 55:21
I love that and and the baseline. I love the baseline because No, that's the question.

Dr Cheryl Phillips 55:27
Yeah. And how is this going to change the baseline, and what are the likely outcomes if we do this and if we don't do this? And there are the other thing is to give family and care partners, the freedom to know that as long as a decision is made with love and from the perspective of the person you're caring for, there are no wrong choices. Because that's the scary thing of if I don't know and I don't know what the options are, and what if I make the wrong choice? But if I am coming with an understanding of the person that I'm caring for and with the love, and we use love very broadly, but but their interest, then whatever thoughtful decision, even if I disagree with the physician, there are no wrong choices, right because you're left with that guilt. Oh, absolutely. And what if, and should have I and maybe, and there are no wrong choices, because each one of the choices has consequences, and sometimes your hell handed a pretty ready set of

choices to pick from, and you have to think through and say, which is the least cruddy choice. So back to the 88 year old that had blood when she was having a bowel movement, if there was a cancer, that's a cruddy choice. Now I get to say, Okay, what would Mom? What are the best choices for mom, because I love mom. I know what mom would have wanted, maybe going for surgery is the right choice, but maybe moving to a different, less invasive and there are often less invasive treatments. Sometimes there's less invasive surgery. We can go in and remove the tumor, but not take out the whole bowel. You know, there's lots of steps, but you start with that, that conversation of, What are my choices?

Rosanne 57:28
Why are falls so damaging? You hear somebody falls, and then it's like they fall, and then you they just crash. Why is that?

Dr Cheryl Phillips 57:38
Oh, my goodness, we could spend another hour with your lovely audience on falls, with people with memory impairment who are already frail, a fall has a 20 to 30% mortality rate within the next year. Wow, that's a big deal. Is it the fall that killed them? No. I mean, sometimes it is. They hit their head. They have a head injury, but usually it's a spiral of things. So mom falls, she breaks her hip, and we can even talk about choices right at that point, but right? Mom falls, she breaks her hip. She's in terrible pain. We take her to the emergency room. She's in the ER for six hours waiting. They have tied her down. They stuck a Foley catheter in her because they don't want her to wet herself. She's screaming in pain. They're sedating her, and then, you know, they're labeling her as confused and difficult and all that stuff. She goes off to surgery. She has anesthesia. She now has bed rest. Two days later, she hasn't had a bowel movement in four days. Now, she's confused from the medication. She's in pain. They want to get her out of bed. She's angry, she's combative. So they say, Well, we really can't do rehab. Let's go to a nursing home. She goes to a nursing home. She's now much less mobile, probably on more meds, probably having a persistent delirium because of the spiral that she went through. She may well have another source of infection, including a pneumonia after the surgery, because it put a tube down her throat, and now she's aspirating her own saliva. She may have a urinary tract infection. These are all of the things that start to build this ugly onion that happens after a fall. Now I don't want to create fear, because lots of people fall most of the time. They don't get injured most of the time, even if they have a hip fracture, they may have a good, positive outcome and bounce right back. But this is why we see that spiral of events, and now mom can't live

in her assisted living anymore because she's not mobile, so she's in a wheelchair. She's in a nursing home, and that's starting a whole bunch of stuff. Falls are not insignificant, but the way to address Falls is not to immobilize people we have in this health system including nursing homes, and I use the term a surplus of safety, I will make sure that your mom doesn't fall, because I won't ever let it get out of a wheelchair. That doesn't help your mom, and then when she does get out of the wheelchair, she's more likely to fall. So focusing on mobility, focusing on safe mobility. And there are devices like hip pads. There's devices like, believe it or not, they're even coming out with a mini airbag that you wear, like a belt, nice. And then when you fall, and it protects you from that's great. So I will go back to the 4M's of mobility. If I'm worried about mom falling, or mom has fallen before, I want to look to see where she's fallen. What are the risks? Is it out in the backyard? Is it in the bathroom? Is it on her throw rug? How can I keep her mobile and moving in the safest way possible? Not all falls can be prevented, but we can do a lot to help mitigate the injury and then to avoid that down rapid downhill spiral that happens, particularly with vulnerable older adults, and a fall and they have cognitive impairment, and that's the spiral down.

Rosanne 1:01:13
There's so many things that go with it. And again, it falls on the caregiver to be the point person. And what I'm hearing from you, and I would, I would assume that's it's the 4M's, it's the baseline. It's asking these questions and not being afraid to ask these questions.

Dr Cheryl Phillips 1:01:27
And not being afraid, because these are not questions of not caring. These are not questions of not loving. These are the ultimate loving and caring questions. I need to know what the options are and what they mean, yeah, and what each path will look like. Give me a travel guide. If I do this, what town do we end up in, and what does it look like? And if I do this, what does it look like, and where are the cross sections? Because maybe I go down this path, but we decide it's not the right path. Can I do something else? I want a guidebook. I want a a if I'm going to go to Spain, I'm going to get a travel guide. I want to know where I'm going and what to expect. Yep. And I wish there were good travel guides, just for this kind of care process. And there aren't. There are some out there, and there's resources, but yeah, you want to travel guide that's specific to your mom,

Rosanne 1:02:21

Yeah and honestly, I think the travel guide is you, Cheryl, I really do. I think the travel guide is you. I mean, yeah, totally. What advice would you have to a caregiver going forward to navigate this system and not coming out, you know, broken and feeling guilty and like they they didn't do the right thing?

Dr Cheryl Phillips 1:02:42
Yeah, and you know, dealing with personal guilt is always so hard because you're exhausted and you're doing so many things and you're getting feedback that they're not all right. And put all that aside. I go back to my list. What are my big problems, both for me and as I'm caring for my loved one, what are the things that I am seeing, what are the things that I am being told by various physicians or other health professionals that need to be done and pushing them to get the information of what do these choices represent, and what happens when I choose these for my loved one, and then sitting down and giving yourself space and permission. God, I'm going to sound so zen here, but that calm space of deep breathing and saying, I'm speaking for this person that I am the care partner of, what is their voice to me? What is important to them, what matters, what are the consequences? And also be honest with what am I able to do? Because we can't do everything, and we're not magic, and we're not super. We actually are pretty super, but we are, yeah, yeah, but we don't have miraculous powers. For the most part, what am I able to do? And if I can't do something, then what are my options? And if there are no other options, how does that affect some of these choices? Those are the thought questions that can help calm the being overwhelmed. Because you're prioritizing things, you're creating a plan, even if it's not the plan you wanted. You're creating a plan and then you're realizing that each of the choices that you're making are grounded in what matters, and that, to me, is the best recipe. It's not easy. And there will be nights when you wake up and go, Oh my gosh, did I do the right thing? Oh my gosh. What if I had just done what if only those will happen. But going back to how did I make these choices. How did we approach this care? How did I start with what matters and look for partners to hold your hand along the way. None of us do this alone.

Rosanne 1:05:13
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 subscribe and review us on Apple podcasts or anywhere you listen to your podcasts. You can also connect with us on Facebook and Instagram @Daughterhood, there you can discover our various circles and subscribe to our newsletter for updates, feel free to message me on any of these

sites and let me know what issues you may be facing and would 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, Mama's 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.