Episode #44: Siblings and Caregiving with Dr Barry Jacobs

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Rosanne 00:44

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. Daughter hood 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. Barry Jacobs is a clinical psychologist, medical educator and writer fostering the well being of families coping with serious and chronic medical illnesses. Barry is the author of the emotional Survival Guide for caregivers, and has co authored with his wife, Julia L. Mayer, AARP meditations for caregivers and AARP lovin meaning after 50. Since 2013, he has been a blogger on family caregiving and relationships for aarp.org. In today's podcast, Barry and I discuss the challenges of caregiving with siblings. He offers strategies on dealing with those who don't or won't help the micromanagers how past family dynamics play a part in the sibling friction animosity, and how to continue on after caregiving ends. I hope you enjoyed our conversation. Barry, you have written some of the most insightful articles about sibling relationships and caregiving, can you shed some light on what it is about this specific dynamic that causes so much stress?

Barry Jacobs 02:35

I think Rosanne because people feel close to their siblings, they have a lot of they go way back with your siblings, right? There's been rivalries over the years, there often is a strong bond amongst siblings, and when a parent in common is ill. And there's the expectation that everybody is going to step up and pitch in, there maybe even be the belief that they're going to pitch an equally but in reality, that's not what happens. Not everybody steps up. And even when everyone does, it's certainly not equal is

extremely unusual for it to be equal. And people have feelings about that they you know, everybody remembers who was there in moms our need, and who wasn't. And that has a permanent impact and sibling relationships. And there are lots of dynamics as to who steps up and why they step up and, and who doesn't step up. But you know, there's this, what I find in my work, as a counselor for family caregivers is that this is the one issue that gets people most upset or having a sibling who they feel is has let them down. Yes. And the dynamics that happen in that not just in birth order. Because, you know, I was the youngest I was the primary caregiver. Normally, you hear the oldest is a family caregiver. But then you get, you know, while you were the favorite, so you should be there, or you're the closest, so you should have that responsibility or whatever. There's those excuses that come up. And when you're in the midst of caregiving and you're struggling, it's almost like you want to say, can we just put all of this aside and get on the same page, but those family dynamics continue? And that is a big precursor of all of this stress? How do we deal with that?

Barry Jacobs 04:22

So you said a very important phrase just now Rosanne, and that is get everybody on the same page. And that's extremely difficult. I mean, you know, you may have siblings who have never been on the same page about anything, right? They can't even end up on the same page about their favorite ice cream flavor, right? Right. But when it comes to a parent, they all really need to pull in the same direction. And so what often happens is particularly early in a parent's illness, or when the parent is developing dementia siblings have very different opinions as to what's going on with parents. That may be if you have four siblings, or four children, children within the sibling group then to them they say Mom Mom is really failing. She we think she needs to be evaluated for dementia, but then the other two almost inevitably say, No, you're picking on Mom, you're trying to take over life, leave mom alone. And so you get everybody on the same page about what mom's condition is, what mom's needs are, takes a lot of work. And then there has to be, ah sometimes it can't be done within the sibling group. Sometimes you'd need kind of outside authorities, like a medical authority to provide a diagnosis that everyone can react to. But but but not just dismiss.

Rosanne 05:33

Right well, and is that the way to go forward, because, you know, sometimes parents don't want to even acknowledge that there is an issue. So then to try to get everybody at the same appointment to hear the same words, you don't know then how they hear, you know, what said, and what is heard sometimes can be two totally different things. Is that the way forward, though, to do it that way?

Barry Jacobs 05:58

So there are a number of steps here. So the first one is to try to get people on the same page, to whatever degree is possible, knowing that not everyone is going to be in perfect agreement. And so the first thing that you're alluding to is everybody needs access to the same information. So if one of the children goes to the medical appointment, or that person then to take not just get on the phone and play, you know telephone, you know, going from person to person giving them a report, to send everybody the same write up of the visit, you know, the lot of times people will get a summary of the visit on the way out the door, the parent was in hospital to get the discharge summary, problem list and medication list everyone, everyone gets the same information, the email, the task text, and then we're there to be some sort of forum where the siblings talk together to try to process what this information

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says with what it means and what the implications are going to be over time. And sometimes, it's helpful to have a primary care provider involved in those discussions, sometimes not. But for everyone to begin with some of the same information, what they do with information is not gonna be the same but But to start with the same medical information. And then to do that on an ongoing basis. It's not usually a one time event, especially with a slowly progressing disorder like dementia. So you know, there's going to be multiple medical visits, maybe there's multiple ER visits needed multiple hospitalizations, the more information accrues and then it's harder for people to dismiss what the what the medical system is saying and harder for them to dismiss what their siblings are saying everyone has to come to grips with what, what they're hearing what they're seeing, and then do the responsible thing and begin to think about what what what does mom need to live as well as you can, or however long she has with with this disabling condition.

Rosanne 07:57

Right. And, and that's part of the, that's part of the stress. Because if you are the primary caregiver, and you're the one that's going to the appointments, and you know, this one's working, and that one's in a different state or whatever. And you come out of there with the information and you report that information. And then they go on as business as usual, or they want more information, or they go okay, great. Let me know how it works out. As the primary caregiver, we have to then balance all of that emotion, and that disappointment and that resentment, and go forward. And when how is it that we it's almost like you have to accept it, but you still have to push for it. But you have to accept it. But you have to say, Okay, well, this is what's going on, like how many times do you go to that well, after I've told you, you don't want to listen to what what the report is, or you don't want to help? How many times do you keep going to that? And I know that's I know that's the \$64,000 question. I know.

Barry Jacobs 09:06

So I may share a little bit of my experience with Roseanne because I took care of my mom and stepfather. My stepfather had Alzheimer's disease. My mom had vascular dementia for about seven years between the two of them. When in 2010, my wife and I decided to move them up from Florida where they were living to live in an apartment mile from our house north here that then my my brother, who's in a different field than I am, he's not a psychologist. He doesn't work with with caregivers. He's he beat when I said to him, this is what's going on. This is we're playing to move, mom and stepdad up. I really could use your help with whatever their needs are going to be going forward. He his first reaction was well, this is on you, you move them up. This is your field of expertise. Good luck, buddy.

Barry Jacobs 09:58

Yeah, that didn't go over well. And it took him with my providing information for him with him and coming down to visiting MC for himself what was going on, probably took him a year to two years before he kind of got it. And I wasn't happy with him during this year to year and a half, two years when he was absent, or mostly absent. But I also understood that this was this was new territory for him. He just I was familiar with dementia because I work with individuals with dementia for my whole career, I was familiar with the stresses of caregiving when nobody knew what it entailed. This was for him, it was kind of brand new. And to get his head around, it took a while. And that's not unusual, especially for something is is sad is dementia, people don't want to put their get their head around, or they don't want to see mom declining or think that she's going to get worse with time. So caregivers and that

situations, such as my situation or your situation, had to be patient, if they kind of just wait for people to catch up. And they do. The problem is when caregivers are kind of hold it down before it kind of waiting, they get very frustrated. And there may even be the temptation to lash out at a sibling, especially a sibling who maybe you've ever previous history with where they haven't come through and other things. But the lashing out doesn't tend to bring them closer, it's not like you, it's not like you forcefully drag them into caregiving, that doesn't happen. Most of the time people dig their heels in and don't and will hold their position and justify their position. So they have to kind of invite them in slowly, and just provide increased evidence of what's going on. And that's all part of what I mentioned is step one step, step two is at a certain point, when it's really time to everyone to make a commitment to contributing. What I do as a psychologist working with with siblings in that situation is I basically say to everybody. sometimes as a group, sometimes individually, I say, it's time for everyone to contribute in some form or fashion, I don't think everyone's going to contribute equally, because not everybody has the same ability to contribute equally or has the same availability. But everyone has to contribute. Because you're not all just looking at what mom needs. Right now you're all looking at one another and the decisions that you're each individually making, and people are not configured those decisions. And you have the opportunity now to strengthen your relationships with your siblings, by really coming through for one another, we have the relationship you have the opportunity to weaken, and if not, if not just destroy those, those relationships, because people will remember what the choices are and how people acted from now till forever till maybe get 30 years and everyone will still remember. And so I put it that starkly by way of saying, you know, you may not maybe had a bad relationship with Mom, you don't want to help mom. But if you had any kind of relationship with your care about having a relationship with your siblings going forward, what you do now matters. And so the stakes are high. And usually that gets everybody's attention sometimes, sometimes when I advise clients of taking their kind of position with with their siblings, they get kind of squeamish, they don't want to ruffle people. But truthfully, that this is what it's about. And then it has to be placed that squarely before them for everyone to see like, this is not business as usual. This is like something's happened. We have to we have to step up. Because it matters now. And that is now to our parent, and that is now to our siblings. If we don't, then there is going to be a cost to that.

Rosanne 09:58

It's your choice.

Rosanne 13:35

I think that's wonderful. I think everybody should should hear that going forward. Because you're right. You never forget what happened. You just don't. That's really great. Barry. That advice is, is so powerful, because it can make the difference.

Barry Jacobs 13:56

And you know, I will say Rosanne that that having given advice like that for a long time, sometimes it makes a difference. Sometimes it doesn't make a difference. Sometimes there are siblings that even even when when it's placed in that high stakes context, they'll say, Nope, I'm focusing on my own family. I'm focusing on my career. You guys are you know, if you want to do this, it's up to you. I am I am, I'll pay what pay the cost, it means that we're not going to need to send Christmas cards to one

another anymore. Okay, I'll do it. And that's so that's extremely sad because then for the other siblings, it's not just a loss of the parent eventually, but it's a loss of some some of the sibling relationships.

Rosanne 14:35

Yes. And and what do you tell? What do you tell the people that are left with that rubble? What do you tell the people when when that other care when that other sibling stands up and says, You know what, good luck to you. I'll see ya. How does how does the caregiver that's caring deal with that?

Barry Jacobs 14:53

Um it's usually very painful for them. And they feel betrayed. And they usually hearken back to their relationship with that sibling northings. They differ that sibling over time. And I basically say to them, you know, this is the Serenity Prayer and action here and you got to accept the things you cannot change. And ultimately, you have to make a decision whether you have any kind of relationship with that sibling again. But you're basically accepting that this person has limitations, they're making choices on the basis of those limitations. You accept them warts and all with with those sorts of limitations, knowing that they, they may not have the same commitment to the parent or to their family of origin, then you have. I have seen clients over the years, basically never had a relationship again with with a sibling who let them down. And then I've had others who decide, it's more important for me to have that relationship and forgive them. Not to forget what they did, but to forgive them for what they did. Because I, my family, is that important to me, and I want to I want to have some relationship with his brother, for instance, even if he was if he acted like a jerk, right?

Rosanne 15:59

Well, when you are caring together, and you have the siblings that say, Okay, I'm going to I am going to take part in this. How do you handle when you get micromanaged as a primary?

Barry Jacobs 16:09

Okay, you're on to stage three here. So stage three is when the people who have committed to helping mom in some form or fashion at dinner, figure out how to kind of work together, because you have siblings who may have squabbled all through childhood, and then went off their separate ways. They didn't, or they haven't, maybe they got along pretty well in childhood, but they, they haven't really had to work together on anything for decades. And so now, they're not children anymore. They're adults with different capabilities and different, maybe their personalities are different. They're fitting their own individual family situations are different. So they've got to learn to work together. And that that has to be a very intentional process. So that means getting together. And like I said, setting some ground rules like how are we going to make decisions together? How are we going to share information together? How are we going to going to adjust the caregiving plan as our parents condition changes, or as our life circumstances change? I remember working with a caregiver years ago, who was, you know, who was one of 10 siblings caring for a father who had a stroke, but then her own husband developed very significant cancer. And so she had to go to her nine siblings and basically say, I really do want to help dad, but right at this time, I gotta turn my attention to my husband, right? And everybody understood. Because there was a process in place there where people talk together, they had a level of trust, listen to one another. They all understood that everybody wanted to help. But there were things that occurred, that may mean that for a time, one or another sibling is not able to help. And everybody, everybody got

that. And at the end of the day, those were siblings who came out of caregiving with strong relationships, not weaker relationships. So what I recommend to sibling groups is that they have ongoing communication, writing, sharing, medical documents, etc, in writing. So there's a there's a, no one's going to mistake what was said everything, everything was not going to be legal. But everyone is, you know, having in writing is helpful for developing a record. And that there needs to be a meeting every quarter at least. And at that meeting, we talked about various mom now, what does she need? Now? How do we provide that for her? Are we going to do it as we've always done it? Or are we going to change the plan, a little bit of justice have different people are doing different things than they were the previous quarter. And so that's that all that creates a level of communication and cooperation. So to get back to your question about micromanaging. There are many instances where the primary caregiver feels like they understand things, they are on the line there, they know what's best, and everyone should just kind of defer them. And that that rankles siblings who may have not liked that, you know, this maybe let's say this is the oldest sibling who was always kind of bossy, and and now they're, they're being bossy again, well, I mean, that pushes lots of old buttons for people. And in those meetings, it would be very important to say, this is not just your parent, this is my parent, you're, you're dictating in a way, which feels like the way you used to tell me when I was your little brother, you would bossing me around. I'm not sure I'm not I don't want to be seen as a little brother anymore. I want to be seen as an equal partner this because I had the same degree of love and amount of commitment to caring for a parent. And so if the parent comes to my house for the weekend, I don't want you to be calling and checking that the parent is had their lunch or taking their pills when they're supposed to be but there's got to be a level of trust here where if I'm going to be a partner in this that you trust me, they don't care. I'm going to do the right thing. And if the right thing and my idea of everything isn't exactly the way that you do it, that's okay. Because there's not only does that just one way to do caregiving I think there's lots of ways to do caregiving. So it was a hard conversations, though, for sure.

Rosanne 20:04

They're very hard conversations. And what I'm hearing is what you've always done cannot continue to be how you communicate with each other going forward.

Barry Jacobs 20:15

And I mean, people have to come to a place where they see each other as capable adults, rather than, you know, the whiny brother or the the bratty little brother or the Bossy Big Sister, or, you know, all the ways we pigeonhole or, or siblings based on information we had about them, which is not relevant anymore.

Rosanne 20:34

But it's, I think part of it is that it's so big caregiving, it's so big, and it's so important. And when you're looking at it every day, you're dealing with so many emotions, and then you have people that know where your buttons are, sometimes like to push them for sport. And, you know, you're not, you're not as well rested as you should be or need to be, and, and all of that plays in. And sometimes it's like, you know, being in a pinball machine bouncing around, and it's hard to try to get back to that stability of Okay, everybody, can we just talk about this? Can we just, as adults, talk about this and move forward with it. And there's always that friction that then comes up while you're trying to to make this better? And I don't know how, in the midst of all of this to make that a better process.

Barry Jacobs 21:33

It's really hard Rosanne I mean, I, so two pieces of advice along those lines. So one is, there's always there's always processing content. So the content is what it you know, what does mom need? who's taken mom to the doctor this week? Right? Who's, who's who's picking up her medications from the pharmacy, there's always specific things to decide. But the process is more, you know, how do we make decisions together? How do we adjust what we do? To help mom? Right? How do we make sure that she's as happy as she can be? And that it's important for the conversations among siblings and not just be about who's doing what, when, but also how are we how are we doing? How are we doing working together? Are we are we being as kind and supportive of one another as we can be? Or, you know, when we have friction? And inevitably, we will? How are we resolving the friction in such a way that people don't go away feeling resentful, and that resentment builds up, my expectation is that there's going to be disagreement, there's going to be friction, and that if people can walk, work those things through, just like with any committed relationship, that they will come out the other side with strong relationships and more trust than they ever had. And that, and that matters. You know, that's, I mean, that's what we want. We want to, we don't want to lose our siblings in the process, we want to, we want to draw them closer to us maybe appreciate them more as adults than we ever have understand them better as adults than they ever have. So there is a potential for better sibling relationships in the long run. Unfortunately, that's probably the majority of the time there's too many times one or another sibling relationship is damaged by what has gone on and caregiving.

Rosanne 23:24

Yes, I agree. There's also that part of the it's almost like a holding hostage of care, when we don't need to hire anybody to come in, or we don't need anybody else. We can do it. But then when you asked for certain things to happen, those things don't happen. And then as the primary caregiver, your, your, I don't want to say stuck, but you're stuck. You're the one that's doing it. What do you do in those situations? When time after time? It's like, can you come? Where can you do this? Or can you pick this up? And and it doesn't happen?

Barry Jacobs 23:56

You're only asking hard questions today Rosanne.

Rosanne 24:00

I'm sorry.

Barry Jacobs 24:01

That's alright Well, let's see I would probably because I'm a little more computational and most people are probably say to my sibling, Hey, you said you were gonna do this, and he didn't do it. I understand why you say you didn't do it. But it's hard for me to rely on you. If you don't come through, especially when there's a repeated pattern of this and you can't you know, I don't want you to make promises that you can't keep. I would much rather know that you can't keep them beforehand, and then we'll make them make other arrangements to commit to you know, if you make a commitment to come through. Now, some people won't like that right? Some people become uncomfortable with that. But that's that's, that's what I would say. You know, you also raised it just just reminded me that a lot of this is about

money, unfortunately. So, Mom has X amount of money. If we're spending all of mom's money, on on home health aides, you know that mom's money is going to run out and put mom in a good position or, you know, there won't be any inheritance, right? There will be all things mom was going to get promising to give us one day, she won't be able to give us because we, you know, she spent all the money for care. Well, we've allowed her to spend money for dinner. So money unfortunately, makes the emotions much more intense. And especially, I mean, I have seen situations where a parent is absolutely intent upon giving me their will public that everyone is going to get the same amount. But but all the expenses are coming out of one siblings pocket. And so there's a basic unfairness there. But the parent, the parents still has a control over if they're coaching enough to have control over where the money is there money is used. So money makes all these loving relationships more and more difficult.

Rosanne 26:01

Absolutely. When is it okay to look outside of that? To say, Okay, fine, I accept that you are not going to do this. And I'm going to just, I'm going to put this aside, because a lot of times the, the anger and the back and forth is is toxic to the caregiver. Because especially when you're in, in an in home situation, and you look at everybody that's out there all living their lives, and you're the one that's taking the brunt. And that it's hard burying it, there's a lot of resentment that builds up and when is it that you have to say, okay, for my own health, and my own well being, I'm going to put this aside, I'm going to put this somewhere else, I'm going to let this go. When is that? Is that something that we can do as caregivers?

Barry Jacobs 26:49

Absolutely. I mean, I, you're giving us hard enough, you don't need any more anguish. And so especially to feel like you've beaten the head against the wall, if you're allowed to stop, do you stop and basically say, they're not ready, you know, my siblings are not ready to help me hopefully be ready to help me later on. But I'm not going to beat my head against the wall. Now I'm just going to continue to provide information for them and hoping that that will come around. Or do you say, this person's dead to me, you know, I'm done with them. Either way, you're trying to protect yourself from getting hurt further. And I understand both of those things. The other thing I should mention, and is that sometimes siblings can't work this stuff out on their own, there's just too much emotion, right. And, you know, not everybody has to come to a psychologist I over the years, I've done a fair bit of what I would think of really, as mediation among siblings, was really angry siblings, to try to get everybody on the same page to try to have them, we'll make some sort of commitment of non equal commitment and to have them develop a process for greater cooperation moving forward. But this can be done by a trusted family friend, it could be done by a pastor or Priest. I mean, there's lots of different folks that can can help with this. Because what happens is, we're just talking about the work I do with siblings, when they're in my office, everyone's doing their best behavior, you know, people are screaming and yelling. And if they try to scream and yell, I'm gonna say Stop screaming, yelling, right? This is not a place for that. So people, the idea when you when you lower the emotional temperature, people can hear each other better, and be less reactive. And then there's a much better chance that they'll find a place of greater cooperation with one another. So having a referee, having a mediator is very helpful. Just to get everybody to, to act more humanely, totally.

Rosanne 28:37

I like that, you know, boundaries are hard and caregiving, no matter who you're caring for. And when you're caring for a parent in your house, in your home, and then your siblings are coming into your home, but feel like they're coming into their parents home because they're living there and have no regard for your life, house, family, whatever. How, how can you establish any boundaries around that? Because it's kind of porous?

Barry Jacobs 29:06

Yeah, I've heard I've heard this is not the first time I've heard this situation. I think it's hard. I mean, I you know, you would hope the siblings would come in and into your home and just like open the refrigerator themselves, right? You can sit down and it's something that you would say to yourself what I've seen some families do is they'll have the parent have kind of a room of their own in that and that becomes the parents domain to make decisions about and then when other siblings come in they they can they feel a little freer and mom's domain rather than in the rest of the house. I've also seen where that doesn't happen and where the primary caregiver who's in whose home the parent is whether he has to basically say hey, when you come in and mark in our house people take off the shoes. Please take off your shoes. I know you don't like to take off your shoes but in our you know you're in my house, take off your shoes or, you know, you're welcome to take mom out and, but, but if I'm responsible for giving her dinner, and I'm not sure, when what time you guys are gonna come back, that's, that's, that's inconsiderate. So, you know, please let me know, if I'm getting my own dinner or what time we'll be back so I can plan accordingly. So it's, again, it comes down to as much communication as you can have as much as much cooperation as you can develop, and, hopefully build trust, I mean, all those things are important. I have a client who I see nowadays who's, you know, she has her mom who has dementia, living in a kind of a in law suite that's attached to her house. And her brother who was just was just in for the holidays, and brother came in with a family and, you know, she was able to kind of corral them into mom's part of the house and preserve the part of her house, or husband and her children live. And then certainly these everyone saw one another, but it wasn't, brother didn't just come in and take over. So it having that kind of space that provides provides not just a physical boundary, but providing an emotional, and I was gonna say with holidays, especially it's, it adds a whole nother level of stress, because then you're trying to coordinate everybody's schedules. It is. And holidays are also very difficult. Because if there's been tension among the siblings, or resentment, and now you know, it's a holiday, everybody's supposed to be nice to one another, and maybe put on a happy face, because that's what a parent wants. It makes the holidays doubly hard and probably half as enjoyable as it might be. So those are those real hard things, I recommend to people that they don't have some of these hard discussions during the holidays, you don't wait to Thanksgiving dinner for everyone to kind of blast one another that that of your conversations have to happen, it should happen this separate time for that.

Rosanne 32:00

Absolutely. Well, and you you lead me right to my next question of what happens when you aren't getting along, or you haven't gotten a loan, or you're you just don't get along at this point. And the parent, your parent says, you know, I don't want you all to fight. You know, it's so nice to see you all together. What? How do you manage that? Because that happens more times than not because as a parent, listen, you don't want your kids fighting, you want your kids to get along? You want to be all together. But how do you deal with that?

Barry Jacobs 32:27

I'll have to share how I dealt with it right? Because I was very angry with my brother because he was not coming through. My mom knew I was angry at him. And my mom was, in turn angry at me for being angry, right? And I said, I basically said to her, my relationship with my brother is up to me. And I understand it's upsetting for you that your children are not getting along. But he he and I have to work this out. And this is not something that you can dictate to us. You know, and she didn't like that. But basically, that's what I said. You know, she was already feeling she hated being dependent. And she hated being dependent upon me. And then to think that she was the cause of conflict between her sons and my brother and I had always been very close, made her feel quilty. And she didn't want to be made to feel guilty things were hard enough for her. So for her sake, she wanted me to basically make make it easier for her by not being anywhere my brothers, so she wouldn't have to worry about that. And I basically said, I hear you, mom, and he and I will work it out. But it will take time. And I'm not. I'm not going to just push this under the rug. And maybe we're not having some disagreement. Right. It's that's a hard thing to do. Barry. Yep. It was not it was not. I mean, I'm not. I'm not describing what I did is a kind of shining example of how to do this it just the way I did it. Yeah. And you know, sometimes there, there are people who just opt to keep the peace, for appearance sake. And that's what works best for them. And that's fine. I mean, I'm, it's not my personality, right? My personality a little a little, a little harder than that. So if my mother see, they give another example I have three first cousins, women who are very close to me and their mother to Henry bad dimension. My aunt and they had major disagreements in the care that she was going to receive. But they also decided that for their mother's sake, they were gonna they were gonna defer to one another, but this as the screens aside, behind closed doors, and they vent them but they weren't going to do that in front of their model. And they've managed to kind of keep up a good fit is in front of their mother and cooperations with with one another that they can pull in the same direction.

Rosanne 35:07

It's so hard in in the sibling situation, because it's almost this primal reaction that you have. And to try to stifle that, you know, how are you stifling it, you're eating it away, you're drinking it away, you're smoking it away. You know, I mean, there's, there's such rage that goes with that, because it's your very core, because these are the people that you've known your entire life. And as much as that, I mean, I love the Listen, mom will work it out. Don't worry about it. But then there's guilt that goes with that, unless you can let that go. Right? And then there's the Okay, I'm not going to think about it. Is there a healthy way for caregivers to try to sit with this, either either accept where they are with their siblings, or let it go and be okay with letting go but something that's not detrimental to our own health? While we're doing all of this loaded question I know.

Barry Jacobs 36:03

These are great questions actually.

Rosanne 36:05 Thank you.

Barry Jacobs 36:06

They're making me think a lot. So in psychology, we do one of two things, we either keep people out people change the situations that they're in that are difficult for them. We help them react differently to those situations. So generally, we try to help people change the situation first. So when it comes to adult sibling groups, who are involved in caregiving, we might work first on what are the ways of improving cooperation, communication, getting everybody to contribute more. And we may maximize that. But it's still very unequal, and very dissatisfying. And then the question then becomes, well, if this is reality, then what do you do the reality, right? And I understand those, those primal, those emotional feelings that come into play, and they're very powerful. You can't squeeze blood from a stone, as my mother always used to say, you have to accept the things you cannot change. Is there any proof says, at a certain point, you just have to determine, Okay, what am I going to do with how I'm feeling here? And what am I going to do about this relationship? So, as we were talking before, do I continue to beat my head against the wall to try to change something that's not going to change? Or do I take a different tack. And, you know, ultimately, I didn't want that. So what my relationship is with that person, I think, acceptance is hard. Acceptance is really, really hard. And to feel betrayed by a sibling, is one of the hardest things in the world to accept. And in some ways, it's almost almost as painful if not more painful than watching a parent fade from dementia. And, you know, it makes this kind of caregiving so much, so much harder. It's bad enough to lose a parent, it's needless to lose a sibling in addition, and yet, there are so many things we have to accept through through this whole process. And that may be one of them. And how do we, how do we accept it and come to terms with it's not worth it? Gnaw at us constantly?

Rosanne 38:22

Right? And that's, that is? That's the big question. And it's that acceptance. It's in the acceptance that the freedom is for us. And it's a matter of getting there.

Barry Jacobs 38:33

Oh, for sure, is, it's very, very hard, obviously. And I don't pretend that I that I accept, well, I don't, there's a lot of sadness, and caregiving and a lot of sadness in these situations. Yes, there's always a hope of better, right, there's always a hope of, maybe lose a parent, but you'll, you'll develop a new and better unless you have a sibling in your head. And I try to hold on to the sort of hopes, but I also know that there's always a potential for greater loss, because we can't but help to have expectations in these situations, and our expectations are sometimes just going to be unfulfilled. Which actually brings me to something else, which is, I think, people who are happy as to those who whose expectations are we're going to best tailor to the reality in this one, there are expectations and the reality are, are at a sink that people suffer. I mean, one thing I tell people right up front is that this is not going to be an equal opportunity endeavor here, you know, there's gonna be some people do a lot of caregiving, and others are going to do very little. And that's just the way it is. And it doesn't make sense to chafe at that every day, because that's not that's not normal. It's not normal to expect. So you want you don't want your expectations to be so high. You want them to be tailored to what the likely reality is going to be as unfair as it seems. And try to avoid that. I mean, that's the other thing is the expectation that this is going to be fair is just not realistic either, it's just not going to be. So how do we have, again, how do we accept unfairness and not necessarily swallow it, I mean, we may, we may decide that we can tolerate it, but not, but not have a strong emotional reaction to it either. This is unfair, like my brother is so wrapped up in himself in his life, as he always has been, I'm not gonna have a good relationship with

him, that's the way it is, you know, I can't change him, by trying to change him, he just gets his back up, I, you know, I will I can do is invite him into this into the caregiving team, if he doesn't choose to, to join us, I have the choice of, of not reaching out further or having a relationship with in the future, as long as say this and that, but better than better for me to do that than to feel steamed up about it all the time, and, and then scream and yell and everything, we talked with him.

Rosanne 40:48

Because we're only hurting ourselves with that.

Barry Jacobs 40:51

I think so.

Rosanne 40:52

Well, and it's, it's one more thing to carry along the road. You know, we get things all day that we're carrying as caregivers, right, we're carrying the managing of medications, we're carrying, the being a psychologist to the people that were caring for I mean, you know, there's, there's 1000 things that that go with caregiving, and then those feelings that just sit with us. It's heavy, and it weighs us down even more. And to be able to let that go, is that piece and I like what you were just saying about expectations. And the flip side of that is yes, but I've given up my life to do this. I've given up pieces of my life in my life with my own family to do this. And when you're looking at your sibling who chooses to say, I'm going to concentrate on my family, and you're there saying, and this has become my life. How do you bridge that? How do you let that go?

Barry Jacobs 41:51

Boy you're really, you're really coming after me, aren't you? I mean, there isn't an easy answer, I have another client who's been living, her mom has severe chronic pain is basically bed downed. And your mom doesn't really want to get out of bed, you know, she doesn't want to, she doesn't want to try to function at all, she wants to be catered to my client in her family live, live with a mom take care of her. There are three other siblings of the three others, one comes by regularly to help the other two, don't they? The other three, the other two that don't basically say to her, you, when you when you moved in with mom to take care of her, you made this choice. We respect you for that choice. But it doesn't oblige us to make the same choice. That's really hard for my client to hear. In our work together, we've had to we've talked about exactly what we're talking about today. How do you accept diminished expectations of them? How do you know we talked about whether she wanted to have relationships with those two siblings or not. And she decided that she does want a relationship with him. But she has to understand that she doesn't set the terms of those relationships, she can continue to invite them she can continue to inform them. She thinks in the hope that they come through but not in her. Her well sense of well being and whether they come through or not. I think she with time she has come to better accept and move in part by grieving that, that her expectations are these two siblings. It's interesting that the brother who's helping her is older than her. And then the two that are not helping her are younger than her and she she was the oldest daughter in the family and she always took care of her of her younger siblings who were I think they're like five and seven years younger than her so there's an age gap. So she you know, she comes into this with this feeling of like, I took care of you I looked after

you. You know I was there for you when you were a kid you should be there for me now and I need this help.

Rosanne 44:07

Right.

Barry Jacobs 44:09

But her siblings just don't look at it that way and she isn't a way she can make them look at it that way. And so again, she's it's he left with a choice. The way accept them as they are where do we not have a relationship with them? And she she's opted to accept them as they are. The parent paradoxical thing is when she would push them and push them really hard. They would stay away. When she stopped pushing them. They have they are more apt to come around.

Rosanne 44:41

Yup, I believe that.

Barry Jacobs 44:45

So I'm feeling very sad as we're talking about this because

Rosanne 44:47

I know I agree. It's umm it's because it's it's so hard and it's such a big piece of caregiving and it's such a big stressor. And we don't talk about it a lot because you know, people have this idea that well, you just ask them to help. And they'll come. And it's like, no, there's way more than this. There's more to this than that. And it's, and then when you're in it, you're trying to deal with it. And you can't figure out how to get out of these patterns in these roles. And all the while you're caring for your parent who is deteriorating in front of you. I mean, we can't forget about that, because that's all part of this as well. And then everybody's reaction to that, because nobody wants to acknowledge that, yes, this parent is, in fact deteriorating, and we're getting down further down the road. And all of that adds together. And it's just this big emotional stew. And it's hard to how do you there isn't a magic wand of this? Well, if you do this, it'll fix this. It doesn't work that way.

Barry Jacobs 45:53

No, it doesn't. The one, you know, there is good, I keep bringing up that there is good that could come out of it. And one of the other good things that could come out of this is that that the siblings can commiserate together and comfort one another, while a parent is declining, and then after parent dies better than anybody can.

Rosanne 46:15

Right.

Barry Jacobs 46:16

And that matters.

Rosanne 46:18

Yes.

Barry Jacobs 46:19

And that matters a lot. And even if there's resentment about the way the caregiving proceeded, it's still a loss, for everyone in the family has a shared loss in the shared history there is probably shared love for that parent. You know, the love is not always exactly the same, but

Rosanne 46:40

Right.

Barry Jacobs 46:40

But you know, people could stand together the funeral on or the memorial service or go to Mass, you know, say and ask for a parent. I mean, grieving together as a sibling group afterwards is really important, I believe.

Rosanne 46:54

When there's so much water under the bridge, and you can't do that. It leaves you more isolated, I think. And then you have to find your way back again. And you still have to answer those questions of do I want to make this? Do I want to have this relationship going forward? Or do I not? And I would think, and I don't know you, I mean, you, you would know this? How do you rebuild those relationships, when caregiving ends?

Barry Jacobs 47:24

If you decide that you want to rebuild the relationship, you know, you again, it's always choices, you have the choice of basically saying well let's let bygones be bygones. We can make believe the last five years didn't happen. And we can go back to where we were. I frankly, think that's pretty unrealistic. So then it becomes a question of do you do have some open acknowledgment of the fact that there may have been a rupture in the relationship because of disagreement about how a parent was cared for? And do the siblings want to intentionally try to repair that rupture? To not rather than make believe it doesn't exist, but basically said, you know, we haven't had a nice conversation with one another in a long time. And that's not really what either of us wants. So how do we find a way together to work towards a better relationship? And I do think, frankly, that for the, with a sibling that maybe hurt the other, the primary caregiver, then it feels important for them to not gonna say express remorse, because they don't believe that they did anything wrong. But to acknowledge that there were a lot of the rupture in the relationship has existed, that they've contributed to that rupture, and that they take some responsibility for repairing that rupture. It's not all about, you know, well, you've been throwing hissy fits now for years. And when you start throwing hissy fits, we'll be fine.

Rosanne 48:52

Right.

Barry Jacobs 48:53

That's not realistic.

Rosanne 48:54

No. Okay. Well, I, I think I got you off track of what was number four?

Barry Jacobs 49:04

Number four was really actually what we're talking about. How do how, at the end of the day, do siblings grieve together and decide what the relationships are going to be?

Rosanne 49:15

Okay.

Barry Jacobs 49:16

Because the relationships are, they're changed, they're not the same. And so they could then do I keep saying this, that there is a potential that relationships are better.

Rosanne 49:31

Talk to me about that a little bit, because that hurt is so deep, because it's almost like if you if you can't support me, and caring for our parent, how do we get past that memory? And that realization that wow, if you can't do it, then how are you going to do it any other time?

Barry Jacobs 49:55

So I think, as hard as it is because of how hurt we feel, I think we have to start with trying to turn toward our sibling with empathy. Try to understand kind of who they are, why they made it the choices that they made. So, again, let me refer to my situation as my brother. You know what was brewing my stepfather's dementia was really evident for a while before. My wife and I moved them up from Florida. So it wasn't news. And our brother knew we were going to move them up. What happened, unfortunately, is probably three months, four months before we moved them up. His wife died suddenly burst aneurysm.

Rosanne 50:42

Oh, wow.

Barry Jacobs 50:43

So he was grieving very severely.

Rosanne 50:45

Yeah.

Barry Jacobs 50:46

So early on, in my caring for my mom and my stepfather, I didn't, I didn't ask him for anything. Because I knew he was hurting. After a year, I said, okay, but you know, I gave you a year to grieve, I need to do more. And that's when I got pushback from him. I felt justified at that point, to have him too. But he also felt that he wasn't ready, that he was still grieving. For me to accept the choices that he made, required me and still requires me to kind of try to understand what he was going through at that time, that he was not ready to give that he was he was still hurting. And that's, I mean, what I've just described as a

kind of extreme situation, or sibling situation is going to happen like that. But people are not completely irrational and make the choices that they make for reasons. So whatever the reasons, even if they're not reasons we agree with, I mean, a very typical reason is they have a spouse, who doesn't like the family or doesn't, who's recovered this person's time. And for the good of maintaining relationship with that spouse, they can't give as freely as they might, to, to their family of origin or to the parent. That's really hard, because because then that, but but for the primary caregiver to have empathy that the sibling is not coming through is, is in a bind, they don't want to sacrifice their their relationship, and that they really can't find an easy balance. So there are extenuating, emotional, relational circumstances that we have to take into account as a way of trying to find our way to empathy and greater acceptance and understanding.

Rosanne 52:32

So it's, it's expectation, it's understanding, it's letting go of what you can't control, and empathy.

Barry Jacobs 52:42

And it sounds like sounds like all our things. I mean, all things that we're all taught, right? It's all about love.

Rosanne 52:49

Yeah, at the end of the day, that's what it is.

Barry Jacobs 52:52

Yeah. But none of it's easy. Especially when we're already in pain when we're tired, when we're already feeling that we lost control over our lives. It's just hard.

Rosanne 53:05

Can I ask how your relationship with your brother is now?

Barry Jacobs 53:08

So my mom died? April of 2017.

Rosanne 53:14

I'm sorry.

Barry Jacobs 53:14

So we had some time to recover. It's better. But it's not. It's not nearly as close as it was prior to my mom and stepfather getting ill. So I think slowly, and I was a gradually we're working our way back. So we have a relationship, but it's not, it's not ideal for either of us.

Rosanne 53:41

Takes time.

Barry Jacobs 53:42

Takes time takes effort. Like anything else. My brother and I live in different parts of the country, which makes it harder. Sure. So it would mean making a very concerted effort to repairing some of this. When we see each other, we make that effort. We talk on the phone, we make that effort, but we probably don't do it as often as we need to. I think about it a lot. Because it it, it does represent another loss.

Rosanne 54:10

Yes.

Barry Jacobs 54:12

So

Rosanne 54:13

Well as as a psychologist, as a former caregiver, going forward. For anyone who's listening, what would your advice be? Is it to have a therapist? Is it to have an outlet for these feelings? Or like, you know, to have a mediator, what would what would the best thing when you're dealing with your siblings in caregiving be?

Barry Jacobs 54:38

I mean I, as much as I'd love everyone to be in therapy. I don't know if anybody should do that or wants to do that, or can afford to do that. I think I mean, to put it as simply as possible Rosanne I think for people to be kind to themselves, and to be kind and understanding the best of their nobody's with with their siblings, knowing that no group of siblings is going to do this right? Right off the bat, that is going to evolve over time there's going to be struggling, that all that is normal, that it's never going to be completely fair or equal. But that at the end of the day, the stakes are high. You know, you're losing your parent. What, what do you do? What can you do within your power to bring your siblings closer to you if that's what you want? So I don't I don't have I mean, all that, as we've unpacked in the last hour is a lot more complicated than what I just said. And as you brought up a number of times, because of the emotions run high, but it's a, it's a challenge that is worth thinking about is worth not just reacting to one siblings, but really thinking about, okay, who is this person? Why are they choosing where they're choosing? What do I What kind of relationship do I want to have with? Or can I not allow the past relationship to dictate how we're going to relate to one another now? How can we meet on a new ground as adults rather than as maybe contentious children. We're not contentious children anymore.

56:18

A big thank you to Barry Jacobs for being my guest today. To find out more about Barry, check out his website, loveandmeaning.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 Daughterhoodthepodcast.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

or today, information, inspiration or even just a little company. This is Rosanne Corcoran. I hope you'll bin me next time in Daughterhood.	