

# Daughterhood the Podcast

## Episode #63

### Dementia Tropes and Platitudes with Kitty Norton

• 56:18

<https://www.winewomenanddementia.com/>

<https://www.stumpedtowndementia.com/>

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#### **The Whole Care Network** 00:00

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#### **Rosanne** 01:05

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 health care 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.

#### **Kitty Norton** 01:56

In 2016 Kitty Norton left her job as an NBC assistant editor in Los Angeles, California, for her hometown of Portland, Oregon, to care for her mother living with dementia while

she was caring kitty authored the dementia caregiver blog Stump Town Dementia, writing tales of dementia life, not dementia death, which resonated deeply with readers Around the world after her mother's death in 2021 Kitty took to the road in an RV to produce and direct her cross country documentary film, wine women and dementia. This film honors the journey with her mother as well as spreads awareness of the caregiving side of the equation in dementia. It celebrates family caregivers and lets them know they are not alone and that they are worthy of being seen, heard and celebrated alongside who they are caring for on this difficult road to the end of life. In this episode, we discuss common tropes and platitudes most often heard in dementia, the reality behind them, and how Kitty's caregiving journey led her to create her film. I hope you enjoy our conversation.

**Rosanne** 03:05

Kitty, you and I were on this dementia caregiving journey together. When we were in the throes of it, we emailed, texted and talked to each other, and these were some of the things that used to really bug us, these common dementia tropes, cliches, if you will, and the harm and misinformation they can cause.

**Kitty Norton** 03:22

I am so looking forward to this hour, because I'm so ready to rant and rave, because these things are still driving me greatly. I thought, Rosanne, you and I both don't ever want to pass judgment. We know that this is a rough journey, and whatever's helping you keep doing it, but I did think we should give a little bit of a disclaimer. These were a lot of the tropes and the platitudes that I got, starting in 2016 from doctors, social media, well meaning friends, and almost all of them, to me, align with that pervasive tragedy narrative. And it was exhausting to try and figure out in my journey, why? Sure, we were having tragedy, but that wasn't the only experience we were having. That wasn't the only emotion. And I was like, What am I doing wrong? Why am I not as upset as everybody else is with all these pithy sayings? So I just wanted to say it worked against my mom and I, but if it works for you, you keep it up. But we're taking the hour to bust these things down, and if you want to think a little bit differently about them, we're your girls.

**Rosanne** 04:31

Perfect. Thank you. Thank you

**Kitty Norton** 04:33

And your what's on deck? What's our first one?

**Rosanne** 04:37

Our first one, I think, is the one that makes you the most angry, which is, if you've met one person with dementia, you've met one person with dementia.

**Kitty Norton** 04:46

Oh boy, we're starting out with all the fireworks today, aren't we? Yes indeed. Yeah, this. Did this one drive you nuts? Because it sure make it still makes me crazy.

**Rosanne** 04:56

I saw it both. I saw it two different ways. So you you first.

**Kitty Norton** 05:00

All right, so this one for me also has its evil sister. Well, everybody's different in dementia. Those two came together all the time, and I mostly got them from like medical professionals. And I was trying to get some answers, and instead I'd get back this. Well, if you've met one dementia person, you've met one dementia person, which absolves them from trying to help you, like, one, yeah, yeah. That's how I felt about it. It's like, okay, you don't have any answers, so you're giving me this bull crap, and I'm supposed to just be like, Oh, okay, well, there's nothing that can be done, right, you know? And it made me absolutely crazy the further I got into this, into this journey with mom, I was like, wait a minute, that's not true. Most all people living with dementia are going to go through sundowners. Okay, so there's something that's very common. A lot of people are going to go through their rage stage. I thought we were going to skip that. Turns out we weren't. So there's something that you can kind of, when a caregiver comes to you with a problem, you can say, Hmm, this may be a little bit of that crazy rage that that sometimes comes with the different types of dementia. You know, it just it was like, over and over again, incontinence, everybody's going to be incontinent. If I come to you not understanding what to do, that mom's throwing poop around the house, you can tell me that other people are having these same issues.

**Rosanne** 06:31

Yup, it only leads to your isolation.

**Kitty Norton** 06:35

Yeah, yeah, that's how I felt. So it still drives me nuts. It still drives me crazy. And when I, in fact, I was on a panel a couple of months ago where someone in the community who provides a lot of resources said that, and I just had to bite my tongue because I just wanted to reach over and smack her upside the head, like, no, not on my watch. Lady, you don't get to say that.

**Rosanne 07:03**

What did you do? Did you jus

**Kitty Norton 07:05**

Well, I can't remember. She said something about five minutes earlier that I also got on her about so I finally said, You know what? Okay, just let this one go. Now you're just losing your mind, and it looked like a crazy person,

**Rosanne 07:17**

Right. Well, yeah, and you know, knowing those things and knowing the the food issues that come and all of that is more helpful than simply throwing up your hands and being like, ah, you know, you just That's it. Everybody's different.

**Kitty Norton 07:31**

Right And I would have been so appreciative they just said, You know what? I don't know. I don't know, yes, but here's some ideas of places that might know. Here's some groups you might want to join and ask them about this. Or here's somebody in my office who's going through this also, and they can help you. But no, it was just Well, every dementia person's different. And slam the door.

**Rosanne 07:54**

Yeah, yeah. You can make a let the exit sign and check out

**Kitty Norton 07:58**

Exactly and a couple years later, I'm like, wait a minute. Yeah, not all of this is different.

**Rosanne 08:05**

No, no.

**Kitty Norton 08:06**

So what's one of your biggies? We started out with one of mine.

**Rosanne** 08:09

One of my biggies is it's just like having a child.

**Kitty Norton** 08:13

Oh, yeah.

**Rosanne** 08:15

It makes me redline, because it's not just like having a child on many levels, and I understand that people want something that they can identify with. They want to have something that they can say, okay, it's like this, and I've done this, so I understand what you're feeling. Yeah, I get that. I get that that's, you know, it's very common, but for me, it's, I never saw my mother as a child, as my child, she's my mother. And it is, you know, she's an adult. And when people say, Well, you know, you do what you do when kids take a nap, you go take a nap, it's like, no, this is a fully grown person who is not in a crib. She's fully grown. She can walk around. It doesn't matter if she naps, I can't nap if she gets up, like it's, it's those types of things, and it's the, it's the parenting, your parent, which, you know, is the sister of It's just like having a child. I always found that to be disrespectful. And again, I understand why people say it, because it's that connection, but it's your parent.

**Kitty Norton** 09:21

Right.

**Rosanne** 09:21

You know, I just never sat right with me. And, you know, with children, children are growing and they're learning and they're moving forward, and when we're caring for our parents, they're losing skills. They're losing these things. So it never, it was never on the same playing field for me,

**Kitty Norton** 09:41

I agree. I will have to confess I did use it sometimes, but I would say it is, this is the closest I can get you in just a few minutes. Gotcha, it's a lot like raising a child, except your child isn't learning new things and isn't going on. To bigger, better things, right? This person is actually losing things and moving towards the end of their life, right? But you're right. They're not kids, you know? And that used to frustrate me, too. It's like, you can't simplify it that much, because my mom is an adult, and her brain has a disease,

and the disease isn't turning her back into a child, right? But the disease is doing things in her head that makes her seem more childlike. That's good, but again, she's not two, right? She's 81

**Rosanne 10:33**

Well, exactly and it also that narrative, that cliché, makes you miss what is still there. Because while they're losing things, they're still retaining their intuition, and when, if you're just going to put them in a bucket of well, they're just losing all their skills, no, no, no, no, no, no, no. They're not losing all their skills. They're losing the practical things, but their intuition is still there, and how you interact with them is still there, yeah, so I think it always comes back to, it's not that easy to just say, well, that's what dementia is. It's not that easy.

**Kitty Norton 11:09**

You can absolutely, absolutely, and that's the thing. That's why they're called tropes and platitudes, because they make something seem all one thing, right? And that's not what this is. No, it's very complex. If you want a little trope, just to give you a quick explanation, fine, but don't leave it at that, right? You know, right?

**Rosanne 11:31**

Because it's so much more than that, and it makes it seem simple, and it's not, not at all.

**Kitty Norton 11:37**

And why didn't we ever get to talk about the things that mom gained? I know, sure she forgot my name, but holy God, she developed a love for peanut butter and her throwing arm as she threw garbage out the door and said it in the garbage can, got so much better. We used to look at the banana peels and how far out they got into the yard, and we're like, wow, she's really picking up some skills there.

**Rosanne 12:01**

I think your other one is and I know we've talked about this, you do not like the long goodbye.

**Kitty Norton 12:07**

Oh yeah. I think for both of us, isn't that a hackle raiser, yeah. And part of this, I think for me, stems from the fact that I lost my dad so fast. You know, we went from the

diagnosis of pancreatic cancer to death in three weeks. So I've been through the short goodbye, and it sucks. And as far as calling it the long goodbye, that just seems like it just seems like everything is lost. Yes, instead of okay, it took mom a long time from her diagnosis to get to when dementia actually killed her. But that wasn't a goodbye to me. That was a wow, I finally get to be the daughter I should have been my whole life, you know? And it was also Hello, new parts of mom, right? And I thought that, I think the long goodbye really just puts you dead center in that tragedy narrative. Instead of being like thinking about things a little differently, like my mom was quite timid her whole life. You know, her and my dad had a very traditional marriage. He was the man. She was the woman, she was quite a beautiful woman, and so was your mom, and she was extremely uncomfortable with the amount of attention that garnered her for most of her life. So she, except for her family, she was kind of a wallflower. Well, during this long quote, unquote, Goodbye, mom came out of her shell. She did not have inhibitions anymore. That stopped her from walking up to a tall, handsome stranger in the grocery store and touching him on the arm and smiling up at him. You know, she just there were so many ways that mom kind of blossomed into someone she had not been her entire life, and to go with the long goodbye, oh my gosh, we're saying goodbye to everything about the woman we knew. It's like, come on, you know, yeah, yeah, you miss it, yeah, yes. If you're gonna sit in that head space, you're gonna, you're gonna miss some really cool stuff,

**Rosanne 14:17**

Right because they're still there. And I'm with you, fully with you. My father, same we've talked about this pancreatic cancer two weeks from you have it to dead

**Kitty Norton 14:28**

Yeah,

**Rosanne 14:29**

That is such a shocking. Talk about no preparation and No, no anything. I mean, it's, it's, it's just, it's completely overwhelming. And you know, to look at this, because people think you get it's it's the long goodbye, and then there's that people think you get diagnosed, and then they're dead, and it's and it's not that way. It doesn't happen that way. And. And and all of those things. You know, the moments that I had with my mother were, were precious, and I, of course, I felt awful for how her life changed. But having her with me and being able to see her every day, it was, it was joyful for me. It wasn't so joyful when I wasn't sleeping and she was up for 24 hours. I mean, I'm not

sugar coating this this is not a sugar coat. But there were, it's, you know, it's to say there were parts that were wonderful. And when you get caught in that, that that vortex of sadness, you're not seeing it, you're not experiencing it. And that's the part where you have to be really careful of what you take in and what you accept

**Kitty Norton 15:53**

Right, accept as truth, you know? And that's, I think this was one of the very first ones where I finally rejected it. I'm like, Look, I, I this is not doing me any good. It's not doing mom any good. Now, I'm just feeling like I should be morose, right? You know, every single day, every single minute, it's like, okay, mom finally got what she wanted, her two daughters with her every week. You know, I don't understand. Goodbye is goodbye when she takes her last breath, that's goodbye. That's goodbye. Until then the end of life, journey has a lot of life, and not all of it, you're going to enjoy most of it. You're not, but it's going to be there, right? You know? I yeah, I think this was one of the very first ones where I was finally like, I can't. I don't want to hear this anymore. I want to see it on social media. This just seems preposterous to me. It is if, if this helps you, great, please don't put it in my face again. I can't, I can't go there,

**Rosanne 16:57**

Right because living in that space is harder. It's harder to live in that space every day. If you're getting up and thinking, Oh, it's just another day and it's just one day closer until she dies, that is a hard space to be in on the daily, you know,

**Kitty Norton 17:14**

I guess I won't put on my tiara today.

**Rosanne 17:16**

It's just, it's just hard, I mean, and you know, I mean that end of life is hard enough when you're actually like, death is down the street and making its way that hard. You don't want to be there any sooner than you need to be you want.

**Kitty Norton 17:33**

Yeah, for us, maybe some people do, and maybe that helps you, great, right? But yeah,

**Rosanne 17:39**

And I, I think it's an acceptance thing, don't you? Where it's like, okay, this is the disease. This disease is going to kill them. There are going to be changes through this

disease, accepting that, because sometimes we rail against that, well, there's got to be something I have to do there. There has to be something that I can do to fix this,

**Kitty Norton** 18:00

Especially in the beginning. I think that's pretty common for most of us. In the beginning.

**Rosanne** 18:05

Yes, it's that railing that makes it difficult, and not saying that you don't, of course you're going to, of course you're going to want to do everything that you can. But there has to come that point where you go, Okay, this is what it is, and I have to figure out how to how to live through this.

**Kitty Norton** 18:23

Yeah, that's a really good point. I hadn't thought about it in that way, that it's a part of acceptance. You know, my dad, it took him so long to accept the diagnosis, like he really struggled with this. He looked for every other possibility, and that was so stressful for him. And during that time, my mom, who still, I don't believe, had really accepted it for herself, really felt like she couldn't accept it, you know, really felt like she had to hide it because she could see how stressed it was making my father. There was a really funny little exchange between one of my mom's friends and me, probably about the year after mom after dad died, and this was she had a group of two of her quilting friends that she went walking with every Tuesday and Thursday, and my dad had kept that going up until he died. So my sister and I, of course, we'd take her to the mall every Tuesday and Thursday, and she'd walk with her friends, and they'd bring her back home. And one of her friends actually said to me, You girls have made such a difference in her life, because she's happier now. She seems less guarded. And you know, it's dementia. You don't know if that's just the disease, right, moving a little further ahead, or if it really was being out from under the stress of of my father's anxiety over it, and her stress trying to meet his, you know, trying to keep his anxiety down. Yeah, maybe that was a part of it. Maybe it was both. But I just found that really funny and I and it's kind of hard, like, well, thank you for saying that. After my dad died, things got so much better. And I know she didn't mean it like that, you know, I know she meant to really say, You girls are doing something your father couldn't do for your mom, right? And maybe it was something in their relationship, the way they ran it, that just couldn't allow that to happen anyway,

**Rosanne** 20:27

Rhe other one is, well, it's just memory loss yeah, you know, how hard is that? It's just they just, you know, where are my keys, and I forgot what I was doing, and that type of thing. And it's like, it's not.

**Kitty Norton** 20:41

And I have to tell you, Rosanne did, were you ever stuck in that? Because I was stuck in that for a while.

**Rosanne** 20:46

In what in the

**Kitty Norton** 20:47

in just in thinking the same thing, oh, it's just memory loss.

**Rosanne** 20:51

No.

**Kitty Norton** 20:51

No?

**Rosanne** 20:52

No. Well, I have, you know, my mom's siblings, and I've, I had seen this, I had seen this film before, and I didn't like the ending, yeah, I so I kind of, I was already pretty, pretty well primed.

**Kitty Norton** 21:05

Yeah, I, I definitely got rid of it. But yeah, that I got stuck there for a while. And, you know, I think one of the first things that kind of had me rethinking that was mom couldn't point her foot anymore. And this seems like a really silly thing to to kind of bring give you an epiphany. But do you know how hard it is to help somebody put on their shoes and socks when they can't point their foot?

**Rosanne** 21:34

I would think very difficult

**Kitty Norton** 21:36

When you've got a foot that's like, as it's stepping, you can't maneuver a sock around. You can't get a shoe. And that was the first thing where I was kind of like, okay, it's not that she's forgotten how. It's that her brain isn't making those connections anymore. She might be sitting on top of her bed in her head going, point, point, point, right? But it's just that, yeah, it's not coming down the pipeline.

**Rosanne** 22:03

Isn't that interesting?

**Kitty Norton** 22:04

Yeah, that was, that was, like, a weird epiphany to me. I remember, I know it was weird because I told my sister about it. Like, have you noticed mom can't point her feet anymore, and she's like, why do you why do you talk about these things that's such a what is wrong with you?

**Rosanne** 22:21

Can't we just have a regular conversation? Yeah, no, you know what? Now that you say that I take it back, now that you say that we would be driving in the car, and my mother would say, Oh, I know him. And I'd be like, What? What do you Oh, yeah, no, I know him. And I'd be like, What are you saying? And I remember being thinking, Well, what, what does, what category does this fall in? What is this? Is this?

**Kitty Norton** 22:50

And she didn't know him, then know him?

**Rosanne** 22:53

No.

**Kitty Norton** 22:53

We the random dude on the street,

**Rosanne** 22:55

A random dude that was driving next to us in the car, and where we would go to the grocery store. And she'd be like, Oh, he was here last week. And I'd be like, Okay, maybe it was, I don't know, but it was those types of things. And it was those types of things that fully ignited my hair on fire fully, because then I was like, Wait a minute. Wait a minute. Because while I had witnessed other dementia happenings, they weren't that.

So, yeah, like, well, what is this then? So then, am I on the right track? Am I on the wrong track? What is happening? What's next? How do I support this? Like, it was all that was going through my head, because it was just like, wait, I What? What?

**Kitty Norton** 23:38

So do we do? We need to go say hello? I don't know what to do at this point.

**Rosanne** 23:43

Well, yeah, and I'm and I'd be looking at the person in the grocery store, like, well, I don't, I don't know. Maybe she knew them when she was younger. Or, you know, maybe, you know, how many people do you see that you went to, you know, grade school with, or whatever. If this was a grade school person, I'd have no idea. If, who that person do you know,

**Kitty Norton** 24:00

I would have probably paraded mom a little bit closer to the person and see if they said, Oh, hello, Gloria.

**Rosanne** 24:08

Well, no, because she would go up to them and be like, Hey, how are you? How you doing? And they'd be like, what? Who's this person? You know, most of the people are very open when they see my mother. Because she would just like, Oh, hi. Like, okay, but you know, you get people that are working there that are like, lady, I got it. I got things to do here.

**Kitty Norton** 24:26

I didn't know Rosanne. That was all a mom's dementia career. She just, she just started going up to everybody, but that's a really good example. That's way better than my foot thing to let people understand that this is going to be a lot more. Yeah, sure, there's memory loss, but there's a lot, there's a lot to this that, and there's just these random things that you don't think about you know, like, all of a sudden, your person may just be recognizing a bunch of strangers,

**Rosanne** 24:55

Or think they know them, and they don't right? And those, those are the things. And. That's where it's a disservice when there is this, like, wow, it's just, you know, they can't find their keys. No, it's a disservice because there's more to this. There's the, you know,

buying the same things at the grocery store. There's sleeping late or sleep or sleeping less or not, being social and that kind of thing. And I was looking for pictures the other day, and I came upon a picture of my mother's refrigerator. Oh, because I had taken a picture of it, because it was water, a Brita pitcher, coffee mate, a dozen eggs, four bottles, you know, four pack of champagne. And

**Kitty Norton** 25:39

I love her,

**Rosanne** 25:42

Yep And ketchup, and I was that was it in the refrigerator. That was it. That was it. Wow. Mom did you eat? Yeah, yeah, I had eggs. Okay, there's still 12 in the carton. Ma, did you What did you have for lunch? Oh, I had whatever. She would say something, I'd be like, she didn't eat anything. It's those types of things that you have to observe,

**Kitty Norton** 26:00

Right

**Rosanne** 26:01

That if you didn't, if you know, if you just thought, Oh, well, it's fine. She's remembering where her keys are. She's remembering, you know, whatever, where to get her mail, whatever you miss it, and that's that's the disservice. There's more to this.

**Kitty Norton** 26:16

Yes, there definitely is. And this leads me to one that I'm not sure this is on our list, but this one also really, really gets me is I would always be asked, I think this is still very common. I would always be asked, does she, Does she remember who you are? And I see people on social media like, oh, today's the day my person forgot me. And I'll admit, the first maybe two or three times that happened, that was a huge gut punch. It's awful, but eventually it's like, you know what? There's a lot worse coming. If mom doesn't remember my name, if she doesn't remember how we're related, who cares? It's not her job to remember me anymore. It's my job to remember who she was, to celebrate who she is, and to embrace what's coming. You know, it's like this crap about her not remembering who I am. Who cares, right? You know, that's not that's not on her anymore. Nope, not used to driving nuts too.

**Rosanne** 27:19

Well, because it's almost like that's the tragedy

**Kitty Norton 27:22**

I know,

**Rosanne 27:26**

Right?

**Kitty Norton 27:26**

Like, Oh, apparently mom's life was only valid when she knew who I was.

**Rosanne 27:32**

Exactly right, right? And it's, it's, you know, she may not know who you are, but, man, if she when she smiles, when you come in the door, it's all you need, right? And and again, it goes to the deeper thing. This is a progressive neurological fatal disease. These are the things that happen. It's beyond what we think, right? It's beyond what we think is going on. And we have to, we have to realize that and be like, Okay, this is the next step. I'm not saying it does not hurt. I'm not saying that it doesn't make you, you know, leave the room and be like, oh my goodness, my mother doesn't know who I am anymore. I'm not saying that's not heartbreaking. It is. It is, but in the in the big scheme of things, this is what it is on this journey, right? And be prepared for that, and know that that's coming, and you're still providing something, even though they don't know you, you're still providing that security and that comfort.

**Kitty Norton 28:37**

And man, let it hurt man, because that does hurt. Just don't stay there. It's gonna just, it's gonna knock you out of the running if you're trying to be there and support your person, whether they're long distance, whether you live with them, 24/7, whether they're in, you know you're their advocate in a facility. Get out of that headspace, because there's worse coming. That's the that's the one thing about dementia, whatever you think is terrible today, it's going to be a walk in the park next month, it's about to get really bad.

**Rosanne 29:14**

Well, which brings me to the the next one, which is, you think that every stage is the end stage.

**Kitty Norton 29:19**

Oh, that's true. That's true.

**Rosanne 29:21**

It can't get worse than this. I mean, doesn't want to eat. You know, we're having UTIs every other day. Whatever you think this is it, this is the end stage. It's like, it's not the end stage.

**Kitty Norton 29:31**

I fell for that so many times, and I think it was the hospice people finally, after like, the third time, I'm like, You guys need to come and evaluate her. I think we're six months from the end, they'd be like, sweetie, there's a lot of life left here. Why don't you give it a year or two, give us a call,

**Rosanne 29:52**

But you're but you're in such a panic, you're in such a panic, and no one you know of course, there are those charts. You know, the charts, and then it's like, one to seven, and then there's like, But wait, there's some, there's sub ones, there's a, b, c and d, like, and you're looking at this, and you're like, well, but she's got some of three and some of seven. So what does that is, is this an average? Right? Averaging? What are we doing?

**Kitty Norton 30:17**

Well, you know, every dementia person's different, so we can't answer that question for you. Oh, thank you.

**AD 30:29**

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**Kitty Norton 31:02**

Yeah, that's that's really true to and I think this especially came into play for me looking at the charts and trying to figure out things. When I would have to look at the financials

every year, it's like, where are we? I mean, I don't want to have to do the math for my mother's death, but I also I need to be very, very careful that we don't run out of money, because my sister and I were in no no way able to, you know, help my mom. We had to make her money last to help her. So, yeah, that always trying to gage where things are. And sometimes I would be gaging where things are, because it would have been like a terrible week or a terrible month, and it would be literally, when am I going to be out of this? Right? I'm here for the long haul, but I tell you, if she dies tonight, I would be relieved, you know? And those, those are hard feelings to acknowledge and go, Okay, you know, sit, sit there for a little bit, and then let that go, and let's get back to work.

**Rosanne** 32:05

Right, right. But that's what you have to do because all of this. And I think that's the most important thing, is this is that, you know the end is the end, and you know you have to, you've got to go through all of this to get to the end, and along the way, you have to allow yourself, and it's it's allowing yourself to think these things, to sit with them, and to let them go and get back to work. Yeah, that if, if you're going to be a dementia caregiver, that's all part of it, and it's the hardest part, because there are days you're just like, I just want to get in my car and I'm just going to drive and I'll turn around maybe or I'll just keep going but those are those things that you think.

**Kitty Norton** 32:53

Or maybe McDonald's drive throughs for the next four states.

**Rosanne** 32:56

That's it I mean, it's just, it's, it's hard. You know those times when you pull back up and you're like, I don't know, I don't know, I don't know. And it's, it's always, it's always, you know, for me, it was always, I'm going to see this through to the end. It might kill me. It nearly did. It nearly did.

**Kitty Norton** 33:15

Yeah

**Rosanne** 33:16

But I'm going to see this through the to the end. But how am I going to do this? How am I going to go through each of these stages and still be on my feet? And that's the part that that everybody misses, because everybody thinks it's just memory loss, and it's just, you know, it's just like having a child. You just

**Kitty Norton** 33:36

How hard is that?

**Rosanne** 33:37

How hard is that?

**Kitty Norton** 33:40

You just have to find the keys right.

**Rosanne** 33:41

Right, right that's the thing. It just, it reminded me of the I've never seen it, but The notebook they and when the wife, you know, all of a sudden, is like talking to the husband and and then we all expect that. We expect that, that before they die, they're going to have this we're going to have this conversation with them, yeah, where everything is everything is clear, and everything is resolved, and we expect that, and then when it doesn't happen, we're left with, well, do we do something wrong? Or didn't happen the way it was supposed to happen? And I feel like that adds to our own grief and our own I don't know, feelings of of what did we not do?

**Kitty Norton** 34:30

Yeah, I've never seen that film either, but I do see on the Facebook groups and the forums a lot, it's like, wow, this sure isn't like The Notebook,

**Rosanne** 34:40

Right, right. Yeah.

**Kitty Norton** 34:42

I've never watched it thinking, Well, I'm probably not gonna get any tips from that. Apparently, it's, it's nice and a good cry, but not really very informative,

**Rosanne** 34:51

Right, right? It's, it's not real life. And, you know, those things, they do happen, like, let's honest. Like, you know, and I'm sure, and. You've experienced it, I know I've experienced it, where those things do happen, where all of a sudden my mother was like, hey, and it was like, oh my goodness, she's right there.

**Kitty Norton 35:09**

I would say mom showed up for every day of her dementia journey, not necessarily the mom I knew or the mom I liked, but Gloria Norton was there. Yeah. But you know, that's funny that you mentioned that, because I had kind of forgotten about this. I think I wrote about it in one of my blog posts. It was the month before mom died, and what took mom down was a was a fall, and she broke her hip. But I think it was like a week or two before that, we were sitting on the sofa and she said, my name. Oh, wow, not to me, and not really in any conversational way. She just said it, wow. And then later on, a few days later, she said Lexi's name, my sister. So, you know, that was like, who am I to say? My mom's not there anymore, right? No, right? And then she was dead within the next four weeks. So that's really close to the end of the life, and she still pulled those two things out of somewhere. For some reason she didn't seem to be mad. Shouldn't say, like when I was a kid, Oh, God. Ooh. What I do now hide in the closet, right? But it certainly wasn't a conversation, and she didn't tell me anything about a safe in the backyard that now I'm going to go dig up just in case, just in case there's one out there.

**Rosanne 36:36**

Well, we had that, you know, I think my mother had a stroke, um, two months before she passed and she lost the ability to speak, but I felt like her dementia changed. It was the weirdest thing I've ever seen

**Kitty Norton 36:54**

In what ways?

**Kitty Norton 36:56**

In clarity.

**Kitty Norton 36:57**

Like she became more, she had more clarity? It was very more she had more clarity. Wow.

**Rosanne 37:03**

It was really weird. And I don't know if it's possible, I don't know, I don't know, but it was really strange. It was welcomed, but it was just, I was like, I don't know what I'm seeing, but like dementia caregiving, you go, I don't know what I'm seeing, but I'm going to go with it, right?

**Kitty Norton 37:23**

Yeah, okay, this is the road we're taking now. We're

**Rosanne 37:26**

making a hard left. Okay, that's what I did, um, but it was very fascinating to me, and I don't quite understand it, but you just, kind of, you just go with it, right?

**Kitty Norton 37:40**

Yeah, that's very cool. Yeah. I felt like it was a gift to me to hear my name again. It'd be a long time. Totally, totally Yeah. It was really nice,

**Rosanne 37:52**

Which is the opposite of this one, which is suffering with dementia.

**Kitty Norton 37:57**

Oh yeah, yeah. I think you can suffer with dementia. I think even dementia, people are changing that narrative. You know, I when I first started in 2016 I started following a few there. I think there was three people on Twitter. I believe that I followed that were living with dementia and writing about it and posting about it and blogging about it, and I thought that was really cool, and that for me, that was incredibly informative. You know, it's like, oh, okay, here's here's somebody actually, you know, in the war zone, what can they? What kind of information can I get from them that can help me kind of understand my mom more? Yeah, I feel like that's one that's definitely fallen by the wayside and and more as more and more baby boomers find themselves in this situation, either as caregivers or people living with dementia. You know, they're baby boomers. They're not putting up with this crap. They never have as soon as something affects them, it's going to change for everybody, and the millennials too. You know, the millennials, the Gen z's, we love to get after them, because they never shut up about anything. But, you know, they're not shutting up about dementia, and that's a great thing. They're on Instagram, they're on Tiktok, they're there's so much more information, and we're what, eight years away from when I first started this journey, I would have killed for any of that in the beginning. Instead, I was, you know, reading books like the 36 hour caregiver, which incredibly informative. You guys so incredibly dry. I don't know anybody gets through it.

**Rosanne 39:48**

I remember sitting in my closet reading that book, and I thought, well, I don't like any of this. I'm not. I appreciate the work that was put into it, the information that is in there, but boy, oh, boy. I was like, Yeah, this is not, I'm not a fan. I don't like this.

**Kitty Norton** 40:08

But yeah, you know. And then I remember even some of the films that I found, there's an HBO series that was helpful in a lot of ways. I think it was done in conjunction with Maria Shriver, but it was also just all of the horror. You know, I remember very vividly a woman in a wheelchair in a memory care facility who always thought there were snakes in her wheelchair. Oh, gosh, you know, and these things happen. But when you've watched, like, a six hour series, and it's all that stuff, you know, it's all some husband hitting his wife on the head, just because, just because he has to mention he doesn't know his own strength anymore, and he's like you would tap a kid to say, hey, you know, stop kicking me in the in the chin, and he just hit her. You know, it's just like I, I needed, I needed some hope, and I needed something to more reflect our journey where, yeah, it's hard, but it wasn't continually delusions and violence.

**Rosanne** 41:27

I think, to make a point, they show that like, well, this is what happens, and this is where you're going to wind up, and these are all the horrible things, so that people understand that it's something, so we can get funding for research.

**Kitty Norton** 41:42

So, yeah, I think, and I don't know this to be true, but I would look at absolutely no balance in the media, in the books, in in, you know, the news articles. And I was like, this helps them raise money, but it doesn't help those of us whose dementia is not a normal part of aging, but when you're in this life, whether you're somebody living with it, or somebody helping somebody live with it, you need to find the normalcy. Yes, otherwise, you're not going to be able to help at all. You're going to be one of those people who's like, this is just too hard for me, and I'm going to who cares? They don't remember me anyway. I'm just going to bow out. They won't even know I'm here or I'm not here, you know? And, and I think that's definitely changed. People are showing the balance. People are showing themselves out with their dementia person, and they're at the market and, you know, Dad's gone and done something goofy, but nobody cared. Nobody like, threw a fit. You know, getting over that stigma and that embarrassment with my mom happened pretty fast for me. I'm not sure I may have been one of the faster ones to just like, drop that all together. But yeah, that's not having anybody see

that. There's a balance. This is terribly difficult, but it's not terribly difficult every minute of the day for the next decade.

**Rosanne** 43:09

Correct?

**Kitty Norton** 43:11

Okay, can I get to one of my other pet peeves?

**Rosanne** 43:13

Oh yeah, sure.

**Kitty Norton** 43:16

I still see this one every once in a while, and I still push back when I see it on social media. It's a quote from a woman, I believe, who wrote a book about caregiving after she had gone through it. And the quote is the hardest thing you will ever have to do, my dear, is grieve the loss of a person who is still alive like really, that's the hardest thing. I would change one word in that to say the hardest thing you'll ever have to do is celebrate the loss of somebody you knew and accept somebody who's coming, who is still alive. Give that a shot. Give celebrating that person every day a shot, because that's the hard stuff.

**Rosanne** 44:06

Oh, my goodness, I love that. Yeah,

**Kitty Norton** 44:09

You're ducking dishes because your mom's pissed. You learn to celebrate that. Again her throwing arm had gotten so much better.

**Rosanne** 44:19

Think her aim got better too, exactly, yeah, because they are still people.

**Kitty Norton** 44:25

Exactly.

**Rosanne** 44:27

Gosh, say that again.

**Kitty Norton** 44:29

The hardest thing you will ever have to do is celebrate the loss of a person who is still alive, who is not the same person that you knew. But you need to celebrate and get ready for who's coming and be happy to see them too. Amen, not every day, not every day, because not every day are they going to be somebody you want to live with. Be happy for that person and the journey that you guys are going through. Yeah, there's your challenge.

**Rosanne** 44:54

That is a challenge, and you know, it's, it's very clear to me, why you made your movie. Yeah, yeah, I will say it

**Kitty Norton** 45:05

It wasn't always clear to me when I started it.

**Rosanne** 45:07

Well so for those of you who don't know, Kitty created, produced and directed a movie called Wine Women and Dementia. I am very pleased and honored to be a part of that, and

**Rosanne** 45:22

I'm lucky to have you in it.

**Rosanne** 45:24

Thank you. It was a journey of your heart, a journey of blood, sweat and tears, and I think.

**Kitty Norton** 45:32

It still is.

**Rosanne** 45:33

It still is. Why did you want to make it? Why did you why did you feel compelled to say, I'm going to make this movie after your mother dies and you pack up yourself and Beth and jump in an RV and drive around the country? Why?

**Kitty Norton** 45:51

I'm not sure I can pinpoint just one single reason. I know the idea started before I even started to think about making a movie, and that was that I had written the blog Stump Town Dementia, and I had made such great friends of caregivers around the world and five of you in the US, even before mom died, when she was when we knew we were getting there, I thought, You know what, when, when she's gone, I just want to get in a car and drive away. I need to be out of this house for a while. I want to go meet Rosanne. I want to go meet grace. I want to go meet Veronica, and I want to go meet Matt and Lindsay and just thank them for being there for me. So that was kind of how it started. And then I thought, well, these conversations that we're going to have may be very helpful for other caregivers, because I already knew that we all were kind of on the same page about this journey. We all were using Huber to help us get through the really rough stuff. So I knew we were going to have fun just opening a bottle of wine and talking non stop, which is what happened at every single every single household. And from there, I thought, these are we think differently about this journey than I've seen related in any other media, and I think that's important to get out there. Not everybody's going to go through this like we did, but they may be able to watch a film that is showing a very different side of the dementia lifestyle and say to themselves, I can take that and incorporate it into my journey. I can take that and incorporate it into my journey, and this might make my time with my person better, easier, doable. So and I wanted to celebrate caregivers. I don't I was watching so much of the media and reading so many of the books that just ignored us. You know, we weren't asked questions. We weren't it was all to the person living with dementia's point of view, and those are incredibly important stories, but we weren't represented, and that's been the coolest thing. Having the, you know, the screenings where I get to go in person, or the virtual screenings, and then we have conversations afterwards, is I'm watching caregivers for the very first time, see themselves on screen. They aren't the people up there, but it's their stories, and they're like, Wow, that happened to us. Wow. I felt that same way. Wow. This is I that could verbatim have been my night last night, and it's making a difference. Yes. So some of when I try and think about why I made this movie, some of it's now tainted with seeing other people's reactions. It's like, oh, that's why I made this movie, even though that had nothing to do with that. That's more just the outcome. You know, it's not, it's not for everybody. There's I've had people push back, mean, like, too many naughty words, and I, you know, I don't like some of that humor. I think that was disrespectful. I'm like, God, love you. You feel this is a tough journey. You get through it. How you can get through it, right? But the majority of it has been Thank you. I am so I I can't get through this another day without somebody showing me what community can do. Support can do, finding your people can do, and running with it.

**Rosanne** 49:25

It really does show the importance of community. And I've been fortunate enough to be at a few screenings, and the response is, it's breathtaking to me. It's really just, I mean, because they're like you said you're seen, we're not seen. We're like the other, I feel like the other box. We're just not seen. We're not part of the equation. Yet we are the ones that are holding the entire health care system up. We're holding the entire care economy up.

**Kitty Norton** 49:59

I believe, is why we're not seeing because if they start to see and acknowledge us, then they're going to have to start doing something to support us and pay would be very, very nice. Absolutely, we're losing. Most of us are losing our biggest financial years, our most productive financial years in our lives. So we're about to become a huge problem for Social Security, because I just gave up six years of my life taking care of my mom during the years where I can make the most money and take care of myself later, you know. And this is I'm not, by any means, an exception, so sometimes I think that's why they don't see us, and that's why I'm putting this film out there, which, by the way, it's been accepted for PBS distribution. You know, November's National Family Caregivers Month. So a bunch of programmers all around the country are looking for content, and our film is one of their options.

**Rosanne** 50:52

Any PBS station?

**Kitty Norton** 50:53

Yes, any PBS station. So this is our distribution deal. Is a little different, because it's not like, like a masterpiece or a nova. You know, those are PBS produced programs. So they, you know, on Sunday night all across the country, you're going to see the same programming for these independent films. PBS loves to program those two, but they get slotted in in between the regular programming. So yeah, and it's available for the next three years for any PBS station,

**Rosanne** 51:27

Really? For the next three years?

**Kitty Norton** 51:29

Crazy, right?

**Rosanne 51:30**

That's fantastic It should be

**Kitty Norton 51:34**

In three years, it'll be like, Ah, I've seen it. Ah, so over it.

**Rosanne 51:38**

No, I think it'll be, Oh, good. I didn't miss that part.

**Kitty Norton 51:41**

Yeah, yeah. Oh, and that's another thing. People were also going to release DVD and I believe a Blu ray and VOD sales in November, probably mid November. And I've also heard from people that, where can I watch it again? Because they need to go back. And, you know, remember this part, how that happened, or what you know, just maybe the attitudes are helping them when they're having bad days. To go back and look at caregivers who have also had bad days and can now kind of chuckle about some of that.

**Rosanne 52:13**

Yeah, to find out and to keep up to date, it's winewomenanddementia.com. Yes, sign up newsletter and all the information is there. Yeah. I mean, I think, you know, at Daughterhood, we're all about support and community, and this film shows the importance of both. And you did a wonderful job of capturing everything and even our care partners like I feel like we got to know everybody in this film, and I think it's a testament to your spirit, Kitty, and I appreciate you putting it all together and making it happen.

**Kitty Norton 52:52**

Well thank you. I had an amazing cast, and I had an amazing post production team who corrected everything I wanted to do wrong.

**Rosanne 53:01**

Perfect that's all you need, post production, baby, now that you've been through this and you traveled the country and met your people that you you know, and you continue

to meet new caregivers with every screening and what advice would you give to a dementia family caregiver?

**Kitty Norton 53:21**

Yeah, yeah. I think the biggest thing and, and this is, this is after the fact, because not really understanding how important it was at the time, sometimes thinking, I just don't have time for that. I don't have time to pull that together. It's community, you guys, if you are a caregiver right now and you're isolated, and that happens so easily. You have friends who have kind of dropped away. You have relatives who are giving you the Oh, it's so hard to see the my person this way. Find new people. I don't know how I got through this without you guys. I don't know how I got through this about my sister. We had some family members who were reluctant to be involved, and I just kind of blew through that, you know, just being like, Hey, Mom and I have been driving around. We're in your neighborhood. Can we stop by? You know? And most people were foolish enough to answer the phone so that they couldn't pretend like they couldn't answer the door. Find your people. Man dementia cafes online. Because of the pandemic, so much stuff has gone online. Daughterhood has circles online. I think you guys have at least two or three,

**Rosanne 54:32**

Yep, two or three a week, up to 10 or 12 a month sometimes.

**Kitty Norton 54:35**

There's so many other even your local people, your local organizations that offer support groups. Not all of them have to be in person. If you can't get out. There's so many online options, community, community, community, find people to help man, you need it, even if it's just talking.

**Rosanne 55:00**

A big thank you to Kitty Norton for being my guest today for more information about Wine Women and Dementia, including how to purchase and see the film, visit [winewomenanddementia.com](http://winewomenanddementia.com)

**Rosanne 55:13**

I hope you enjoyed our podcast today. Head over to [Daughterhood.org](http://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 at 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.