

Daughterhood the Podcast Episode 18: End of Life Care & Caregiver Burden with Jessica Zitter, MD, MPH

SUMMARY KEYWORDS

people, caregiver, doctor, hospital, family caregiver, hear, dementia, feel, ventilator, important, person, thinking, mother, dying, podcast, patients, caregiving, support, conversation, talk

SPEAKERS

Rosanne, Dr Zitter

RESOURCES MENTIONED

MOVIE: Caregiver: A Love Story - <https://jessicazitter.com/>

MOVIE: Extremis - Currently streaming on Netflix

BOOK: Extreme Measures - Finding A Better Path to the End of Life

BOOK: The Lost Art of Dying: Reviving Forgotten Wisdom by L.S. Dugdale

Vital Talk

<https://www.vitaltalk.org/>

Decisions telephone counseling service for patients with terminal or life limiting conditions

ACP Decisions

ACP Decisions is a non-profit foundation with a mission to empower patients to make informed medical decisions by engaging in shared decision making with their healthcare providers:

<https://acpdecisions.org/>

The Support Study - <https://pubmed.ncbi.nlm.nih.gov/7474243/>

00:02

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Rosanne 00:43

Hello, and welcome to Daughterhood The Podcast. I am your host Rosanne Corcoran Daughterhood circle leader and primary caregiver. Daughter hood is the creation of Anne Tomlinson who has worked on the frontlines in the healthcare field for many years and has seen the multitude of challenges caregivers face. Our mission is to support and build confidence in women who are managing their parents care. Daughterhood is what happens when we put our lives on hold to take care of our parents. We recognize this care is too much for one person to handle alone. We want to help you see your efforts are not only good enough, they are actually heroic. Our podcast goal is to bring you some insight into navigating the healthcare system. provide resources for you as a caregiver as well as for you as a person and help you know that you don't have to endure this on your own. Join me in Daughterhood. Jessica Zitter, M.D., MPH, specializes in Critical Care and Palliative Care Medicine and practices at a public hospital in the San Francisco Bay Area. She is the author of Extreme Measures: Finding a Better Path To The End of Life. Her essays and articles have appeared in The New York Times, The Journal of the American Medical Association and other publications. Her work is featured in the Oscar and Emmy nominated documentary Extremis, as well as her film Caregiver: A Love Story, which you can view virtually. She is a nationally recognized speaker on the topic of dying in America. Dr. zitter is also a fierce advocate for raising awareness of family caregivers and the challenges they face and even turn the tables on me in this interview. I hope you enjoy our conversation. When I was watching extremists, and when I was watching caregiver every time you came on screen, I was like, Oh, thank god, she's here.

Dr Zitter 02:25

Oh, sweet. Ah, that makes me that makes me feel. It's so funny that you say that, you know, because, um, it's a really funny, there's actually just an article that I just clipped out of the New England Journal, two or three days ago. And of course, I haven't had a chance to read it. But it was about being a physician, friend, acting as a as a friend to people or, or a physician, another physician to give consultation. And I haven't read what that article says. But I will say that it's a really rough. It's hard being somebody who has this, you know, who who's an ICU doctor and has a lot of experience with the intensive care unit and with what is illness, what is not illness? What is prognosis here, when so little, so few people are actually getting that information, we doctors don't tend to tell that information people. So, you know, I know a lot of what's happening to my friend's parents when they went when they're in the intensive care unit. And I also have this other hat that I wear as a palliative care doctor, which allows me to have skills that I've cultivated over many years about communicating. And so you know, it's really hard to turn away from that. And what happens is, especially with COVID, and even without COVID, so many people are calling me, my mother's in ICU, my father's in the ICU, what do I do with it, and I can't turn away from that. So in addition to being in the hospital, and having all this work around caregiver, and I feel this constant obligation to be there for friends and family when they call me. I got a call from my friend two days ago, basically saying her mother had just entered the intensive care unit. It's not a COVID related thing, but she's very elderly, and she's got liver and kidney issues, etc, etc, etc. And her blood pressure is going down and what do I do the ICU doctors want me to put in a central line,

they want to do that. And you know, I'm 3000 miles away. And my friend say what do I do? And then I hear her talking to the person on the other end in the ICU at that hospital saying, Well, you know, put the ICU and we use an ultrasound. So it doesn't cause a puncture. It doesn't do this and it won't do that. And but they're not talking about the bigger picture, which is, is this going to help her right. And I heard I'm like, I have to admit I was I got really kind of frustrated. I said, Can you tell me you know that she wasn't talking her anything about the liver and the kidney disease and the height, low blood pressure and the fact that they couldn't keep her blood pressure. Let's talk about this is a nine year old woman. This family needs more than two. Then you're going to sign on a piece of paper whether or not you can put a triple lumen and you have to give them some information about what so I You know, clearly this person wasn't necessarily going to do that. And so I had to sort of dig out and, you know, information. And then I said to my friend, I don't think your mother's going to make it out of this hospitalization. And that allowed her to say, okay, we don't want to intubate, we don't want to do cardiac compressions, you know, but she wouldn't have known to do that, had we not had that conversation. And there are hundreds of those kinds of interactions happen every single day in intensive care units around around the country. So this is a problem.

Rosanne 05:29

Well, it absolutely is. And just this morning, I sent three pages from the back of your book on what to ask the doctor. In the back of extreme measures. There, you have a whole index. And that was what allowed her to talk to the doctor to say, what is the bigger picture? Because it's almost like, it's like, cardiology comes in and goes, Well, the hearts beating? Or what can we do to get the heart back to rhythm, right? And that's their only focus, they're not thinking about, well, you're going to put whatever in and then how is she going to functions?

Dr Zitter 06:01

Right. And the untold suffering that results from this what I call end of life conveyor belt just go wrong churning along with nobody, like revisiting Who is this woman Tell me what's important to her? What would be acceptable to her? I don't think she's gonna survive this. Any doctor looking at their at my friend's mother would have known she was not gonna leave the hospital, anybody, but nobody's willing to say it. And it's why, why is there so many reasons, there's so many reasons, they that include avoiding emotion result, let's start at the top, which is, nobody's expected to do it, you don't get paid to do it. And you don't get dinged if you don't do it. So that's the first thing. People are overwhelmed, exhausted, and they just want to do their jobs and go home. That's part of this sort of physician burnout. So so you know, they're not doing that, you know, but think about why you might not choose to do it, especially if you're not being incentivized to do it. It's exhausting. People are crying, people get angry, people might think you're a bad doctor, because you can't come up with something that doctor wonderful said doctor wonderful said that they have to do but you're not going to do anything. So you know, there's many, many reasons why it's just easier and safer. And then, of course, the fear of being wrong. What if you say something and you're wrong with you tell them what you think is gonna happen, and you're wrong. There's so many reasons why people don't do it. And that's why there's this deficit of information, and there's lack of information transfer. So people are trying to make decisions in intensive care units and hospitals around the country with no information about what the doctors think is gonna happen.

Rosanne 07:31

And you're in that position where you're upset, you're probably sleep deprived, you have no idea what you're doing. And you're you've just met this doctor, right? More, nine times out of 10. You've just met this doctor who happens to be on call and comes in and says, This is what you need. Exactly. Exactly. How are you making this decision?

Dr Zitter 07:47

Exactly. And you're probably filled with guilt. And you've got the sister who flew in from the coast who said, What do you mean, you're gonna tell me you're not gonna put the tube on? There's so many human factors that are playing a role here, you know, that just it's a lot to ask. And we don't we don't support our health care providers by teaching them the skills that they need to do this confidently or, frankly, paying them to do the right thing. We're not doing that.

Rosanne 08:15

No. And, and it's interesting in in your book you referenced, I think it was the woman and Marsha was her daughter. Oh, yeah.

Dr Zitter 08:22

Martha Green or Yeah, yeah.

Rosanne 08:24

And and you reference that and I could see it playing out. What can we do? What can we do? And it's, I feel sometimes, well, first of all, I give you credit for actually because you had a round the residents up like, this is what I'm doing. Like I'm telling this woman that she really like this. This isn't going to work for her. And I feel like there's such a rally against around that fighting. We're fighting. We're fighting. We're fighting. We're gonna fight this.

Dr Zitter 08:46

We're going to war.

Rosanne 08:47

Oh, yeah. And it makes people feel like they're giving up when really they're not they weren't gonna win.

Dr Zitter 08:54

they feel like they're giving up. They feel like they're wimps. They feel like they're bad doctors. They may even feel that they're Dr. Kevorkian. Yep. If they're not rally, you know, so there's all sorts of self shaming talk, that makes the doctor just say, oh, what the heck, let's just do this.

Rosanne 09:10

And and then the flip side, is the family also fighting? Well, what do you mean? What do you mean? Exactly? You know, there's there has to be more to do what you can't can't you do this? Can't you do that?

Dr Zitter 09:20

Exactly. It's Yeah, I almost call it a collusion. It's not a it's not a malicious collusion, but it's sort of a collusion of silence about death. You know, let's just pretend that it's not real. It's not real, you know?

Rosanne 09:33

Yes. And, and that and it's like, well, how, how can we get people to because nobody wants to talk about it, and I don't, there's times that I wonder if it's because they think if they fill out a DNR or if they fill out a living will or a pollster or anything like that, they're still that, well, you know, that guy that woke up from that coma that was in a coma for 30 years, and they were gonna pull the plug and he woke up, like

Dr Zitter 09:56

You're you are so right. You know, I wrote a book called Miracles don't come cheap in the New York Times, which I, which I would love for you to read, because it's exactly about this, it's this idea of like, you know, well, this, this idea that well, we got to try because you know, and the fact is, the downside of going for it is that if you go for it, you could end up in a life that is very, very much what you might want to not want. And people don't think about that side of the coin, they just think about the upside of the coin, which is a shot in a million. Frankly, when someone's really sick, the likelihood you're going to be that lucky person who makes it back to the life you want to live is very, very low. But people don't think about, well, what happens if I don't make it back? If I go for it, but I don't make it back? There, you're you're potentially trapped in a life that is really not what you mean, what you may have wanted, you know what I'm saying?

Rosanne 10:48

I do, I do, and because people don't think that they think they're going to get it done. And then they're going to walk out of the hospital, and they're gonna go back to their lives, and it's gonna be fine. And and I don't know, if that's just human nature, you know, where you think, well, it'll be fine.

Dr Zitter 11:01

Well, you know, it's interesting, there's a great book Go on, what was the name of it? It was about the RS maurienne D, which is the art of dying. That was written in the 1400s, I believe that was to teach people how to die well. And she wrote this, this really interesting passage about what ancient Rome, the generals on the battlefield, used to have these hired people who would come around and follow them around and basically be whispering into their ears all the time, you're mortal, you're gonna die, so that they didn't sort of get this sense of just, you know, that they had a realistic sense of who they were on the battlefield, and not this sort of sense of inflated, you know, likelihood, and it made them just more realistic about what they did. It's just an interesting thing. We don't have anything like that now. All we got is people rooting you on with a serum magic youthful serum, we're going to the cancer center treatment of America is going to fix your cancer. And you know, it's, it's interesting.

Rosanne 12:00

Well, yeah, and then when you're in it, it's you realize that this year, this is not what you thought it was, and that, you know, everything's a hope. There. It's not a definitive, it's not like we're gonna fix this and it's gonna be great. It's, it's, it's a hope. And I mean, listen, I come at it from a dementia viewpoint,

which, you know, here's your hat. What's your hurry? You know, get get your affairs in order. What what other disease? Do you know of that? That's your that's what they write on the paper. Okay. Get your get your affairs in order. Good luck. See ya. Yeah, yeah. I mean, it's just, it's awful. And, and in, in trying to have conversations Well, with dementia, you know, once you pass that window, you're not going to have that conversation. Right. So it's important to have these conversations before Well, before you get to that point. And you also founded what was a vital,

Dr Zitter 12:55

vital talk? Wow, you you really read everything, didn't you? Vita decision, sorry, I thought because I because I'm involved with vital talk now. But vital decisions was the company that we founded in 2004. Yeah.

Rosanne 13:07

But it's amazing to me, because even you, as a doctor said, You thought you would find these scripts to talk to people about and there were no scripts. How is that possible?

Dr Zitter 13:17

Well, that's why I said vital talk. Vital talk is this new educational kind of movement to teach people the scripts, that's exactly what vital talk is. But in the days when we started vital decisions, which is a telephone counseling service for patients with serious and life limiting illness, there were no scripts about how to die, there was nothing. So you know, it wasn't till 2008, that the official palliative care movement was brought into being through the American Board of Internal Medicine. But again, in 2004, there was just nobody knew we were like, how do you talk to people about death and dying? Nothing, we made it up. We made it up based on basic logic, and by principles of bioethics, but now there is much more for people who want to opt in and learn how to communicate with patients and how to transfer information, there are places to go to learn those scripts as a health care provider. But still, unfortunately, a very, very small minority of people actually get that kind of training.

Rosanne 14:10

Well, yeah. And and then you look at it and think, well, if the doctors aren't going to train how people don't pull this stuff off to say, Well, what do we do? And what does this look like? And, you know,

Dr Zitter 14:19

you're right, you know, even the most educated people, PhDs don't have any idea how to navigate these systems. These are this is an inside job. I mean, we we are we're very military in the way that we take care of people in the hospital, and we don't, it doesn't there's a sort of, it's sort of like police or the army with their kind of like, you know, this is, you know, this is Delta Force. I mean, what does that even mean? This is how we do it. Yeah, we need to we don't talk to people in a language that they can understand and really get down and this is what I think and this is how I would recommend based on what you've told is important to you, those that that exchange of what are your preferences? What's important to you? Well, this is what I think based on I went to medical school, you didn't, I'm not asking you to be the person to make decisions about whether or not was put in a line in or a triple lumen or this. And that's not a job for a family member, the job of the family member is to be the expert in the patient. That's not that's a job for the family member. And then the physician can come in and help

them get concoct the plan that makes the most sense, given all the medical things that are happening. And based on that person's preferences and values. That's how that's how we should be helping people, but we're not doing it.

Rosanne 15:36

And how do you think now I know you had, again, in your book you said about ACP decisions. Oh, yeah. Dr. Angelo Valadez has this whole because he you had said, talking to somebody about what the process is in the ICU is different than seeing it, obviously, you go down to the ICU, and you can't get out of there fast enough, right. So in being able to explain it, is one thing, but to actually say, this is a chat, this is a ventilator. This is a bipap. This is whatever, and that there's I went on the website, and it's fascinating, but I've never heard of it.

Dr Zitter 16:15

It's mostly for healthcare providers, to assist them to use to assist them to communicate better with their patients, like the iPad, look at this kind of thing. I think that you know, it's been shown to be effective. It's not necessarily a direct to consumer, although he probably has some kind of direct to consumer application of it.

Rosanne 16:38

There is a patient section that you can Yeah, but I but you couldn't access it, I think you had to have a link of some sort.

Dr Zitter 16:44

It's still, the whole system is still not working. The whole system of communication and decision support and helping people with these big, big decisions and helping hold people through this time. We're not doing it. We're not doing it. Well. We're so disconnected from the patient and the family. You know, this new film that that we may use? Did you see the film caregiver? Do we send you a link?

Rosanne 17:14

No, I went on the Roxy.

Dr Zitter 17:16

Oh, good. Okay, good. Oh, I'm so glad. Yeah, that just I guess it just finished playing at the Roxy yesterday, still playing it the Lemley. But yeah, we have many screening opportunities that people want to go to our website under the settings page. But this moving through this whole world of the ICU is almost impossible. If you don't have a guide, sadly, and it really shouldn't be that way. The same thing goes for Caregiving. You know, we have this opaque system for people going home when you know it, you're living it. We don't help guide people. We don't tell them we don't take their hand and say listen, your situation what's going on right now, given your situation, your work situation, your mother's prognosis, her situation, we need to get you into this resource, that resource in this course. And I'm going to follow up with you and I'm going to do that that's what's needed. Someone's got to be advocating for you absolutely must be out there on your own trying to do caregiving. No. And here's the irony. You know, you've been reading about my stuff for a long time. I if anyone should know about

family caregiver burden, it should be me, right? Yeah, I should know about position. I didn't know about it until I made the movie.

Rosanne 18:21

Mm hmm.

Dr Zitter 18:22

I didn't know about it. I had to watch my own movie to know about family caregiver burden. That's crazy. So focused, even on a palliative care doctor, and I care about holistic approaches to people living and dying. And I wasn't thinking about what happens outside the walls of the hospital. All I was thinking about was inside the hospital. I was being siloed myself. That's not that. That's crazy.

Rosanne 18:46

Well, and and let me tell you, and so it's Caregiver: A Love Story. Fantastic Film, not Hollywood-ized. Not. It wasn't a Hallmark Movie. When you said what about hospice? And he was like, they give me an hour a week. The look on your face. I was like, oh, because you got it. Because you got it because everybody says that about hospice? Well, you have hospice now isn't a great? Yeah, the nurse comes once a week. It's great. But and I can attest to this. You're on the phone with them. And they say, Okay, great. Keep me posted.

Dr Zitter 19:18

That's right. And I was shocked. You saw my mouth hanging open?

Rosanne 19:21

It did. It did. And I was like, Wow, she didn't know

Dr Zitter 19:24

I didn't know. But here's the other thing. You don't want people to blame hospice for this problem, either. No, because hospice did what they're supposed to do. And they did a good job. They weren't you want. People watch this film? They're like, Well, wait a minute. Why wasn't hospice more involved? And the hospice people who watch this film feel guilty. They're like, Oh, my gosh, hospice did a great job in this film. The problem is in hospice. The problem is us. It's our society. It's what we've decided to prioritize, and we need to prioritize family caregivers.

Rosanne 19:55

Yes. Agreed.

Dr Zitter 19:57

So I really think and not only were they both Leaving hospice or wanting to blame hospitals people want an answer. They want to know who is the culprit. They're also like, Well, why did her husband's go away? They should have stayed to help Rick

Rosanne 20:08

Oh, her son

Dr Zitter 20:09

Thank you, her sons they should have saved it. And you know why they went away? Because they both had wives who were about to deliver babies who are overseas. So the answer is not to blame the people in her life and the hospice? The answer is to say, what do we need to do differently as a society, this is this is not working. And we've got to, we've got to, you know, check in with our priorities as a society and figure out if we want to support the sort of fabric of caregivers, by the way, one out of five Americans as a caregiver, it's all of us, and it's gonna, you know, the demographics, keep shifting, so that it's gonna be more and more care caregiver, more and more people needing caregivers and fewer and fewer caregivers. So we have a big problem that's going to impact everybody, except for the very ultra rich, we all better start paying attention.

Rosanne 20:53

But people don't realize it. And and the other the other part to that, is that that, that wavelength of Wow, it's your mother. Yeah, of course, you're gonna take care of her or it's your wife, of course, you're gonna take care of her.

Dr Zitter 21:05

So not only do other people have that, like, what are you complaining about? But the person himself is like, feels like a jerk? Absolutely. And a lot of caregivers don't even identify as caregivers, because they think Well, I know, I'm not a kid. People say, who's your caregiver? So you know, there was this the Care Act? I don't know if you've heard of the Care Act, but yes, so it's this, you know, adopted down 40 states in the United States. 40 states, obviously, and it was started in 2008 2014. And basically, it's like, it's called caregiver advisory record and enable I think it is. And the basic thing is for hospitals in those states have to identify who the caregiver is, and then make sure that they have adequate training. Well, here is the first thing people don't identify as caregivers. So you say, Are you who's your caregiver? I don't have a caregiver. Well, yeah, but you have a wife and who's better questions are who gives you your medication, who helps you get dressed in the morning, like action item things because the word caregiver, people don't identify with it.

Rosanne 22:02

Mm hmm. And they don't want to,

Dr Zitter 22:04

They don't want to, and they don't think they should, and they don't think they deserve any special treatment, except the wife and the husband. And I'm this and I'm that.

Rosanne 22:11

Uh hmmyou know, and it's, it's, you know, the thing in COVID, I think that has shone a light on a lot of things, hopefully, it will re organize the whole skill facility. Everything needs to be reorganized. But but we're not considered essential. We're can considered informal caregivers, and nothing makes the hair on the back of my neck stand up more than informal caregiver,

Dr Zitter 22:35

You've been reading a lot of the same stuff that I have, you're writing a caregiver is has to be a part of the medical team, they have to be essential. They they can't be shut out of the hospital, they can't, you know, we're and COVID, you say as you say, COVID is a stress test on the entire system. And it's showing us where all the weak and breaking points are in on a variety of things, the caregiver issue you see the most vulnerable caregivers are suffering the most right now and to the breaking point. Um, it's also, you know, showing us the breaking points just in our communication about the intensive care unit who wants to be on a ventilator? We have row after row after row of person who's on a ventilator, who's never going to come off from Kota and no one's really had a conversation with them with it before they put the ET tube in or whether or not it should I mean, this is you know, obviously some, it's part of it is that we're broken and exhausted and have no time. And that's the thing that falls by the wayside first. But it's really frightening to think that people so many people are going to spend their last moments on a ventilator when they very well may not have wanted that, you know, so COVID has really shown us these things that are already there problematic. But really, you're getting exposed.

Rosanne 23:44

It's a shame, because people still don't want to have those conversations. And I mean, I know someone on Twitter said they were exposed and they were writing down, they just sent to text to their friends to say this is what I want, because it was never written down anywhere. And that's the scary part of this. But again, you're you're deciding on a dime, instead of thinking about it on a on a good day where you can sit and think and or think about it over a course of a month, whatever. Yeah, but, but there's ways to do this. And I think people are just afraid of not being saved, then

Dr Zitter 24:21

The thing I mean, in all fairness, it's true that advanced care planning and advanced care thinking and trying to think about these things over the course of your life really is important and helps you think about it in the way that's most consistent with what your priorities are. Instead of being driven at the end by emotion and fear. It is also true that sometimes people's feelings change over things change in their health in their health situation, which is fine. It doesn't mean you shouldn't be doing this thinking you know, thinking and having these conversations in advance because it makes everything even if you change your mind, you're always allowed to change your mind but it really does make it easier. It makes you happy. A more informed conversation

Rosanne 25:01

Well, and it also makes it easier for those around you. And, like in extremists, the one girl that said she felt like she was killing her mother if she said don't and, and it and, and I could see that you're not exasperated but like,

Dr Zitter 25:16

No, but actually Yes, I was a little exasperated at that moment. And, and I, I think it's important remember human beings are I mean physicians are human beings too and we have all of our, our own human responses to people. And I think it's really important for us to do our best to check them and be as humane and non judgmental as we can be. But the doctor is also a human being who's tired and exhausted and stressed. And, and so I'm not going to deny that I, you know, probably was a little bit frustrated with her in that moment. It's a tough, a tough human. And it's human to I mean, the fact is,

the people's best sides don't come out necessarily carrying it, people's best sides don't come out when you're at home, and you're a caregiver and you're stressed. I mean, we want to mitigate, we want to do the best that we can for the most people in society to drop the level of stress and despair and suffering and fear that happened in all of those locations. So that we're sort of more prepared for and I do think ultimately may not, it may not help every single case go well, but it'll help more cases go well. And I think what it means is that we I think as a society need to start to think about how we want to drive our conversations. And I do think we can do a lot better. And we've got a lot of work to do, though there's been a lot of progress made a lot of progress made with the work of the palliative care movement, we still have a long way to go. You know, I want to ask you, can I ask can I turn turn to interview you for a second?

Rosanne 26:49

Sure.

Dr Zitter 26:50

Have you? Do you use any kind of technology to help you with your caregiving? I'm just curious.

Rosanne 26:56

I since the day my mother moved in, I bought a camera, because she's an she's an upstairs bedroom, a camera and a baby monitor. So every time she went to get up, I would run up the steps. I should be 115 pounds, but I'm not. So what would happen was I get up the steps and walk in and she'd go, Oh, I was just getting up. And I was like, oh, what can I do for you? Because I didn't want her to think that she couldn't do something. So that's how I played it. So that then evolved into a motion detector that I put under her nightstand so that when she would get up and when she would get up in the middle of the night it would go off. The problem was it kept set her comforter kept setting. And so and it's that bing bong that's like in the state store that makes you have PTSD. Yeah, I then I replaced that with a floor sensor and that sensor out next to her bed. So now when she gets up and steps on the sensor, the sensor goes off another PTSD, but that's how I know she's up and I have an iPad. That's how I watch it. And it's also an app on my phone. So that's what I've been doing for five and a half years. You know,

Dr Zitter 28:04

I I am so appreciate your sharing that because, you know I can sit and read about family caregiver burden. But hearing stories like yours are so important for me. Can I ask you? Are you Are you frustrated and angry?

Rosanne 28:23

At

Dr Zitter 28:24

At everything?

Rosanne 28:26

Yes, absolutely. Absolutely. And I've been and I tried to table that. Because I know I'm not the only person in this position. And it doesn't do me any good. But yeah, I'm on pissed off. And that's part of

why I want to get information out for caregivers because it's like, you know, a tax credits. Great, but a tax credit doesn't help me at three in the morning. Oh, tax credit doesn't help me when I've been up and I can't even function. It just doesn't. Yesterday, when my mom got up, she had to go to the bathroom. So I got her up and she couldn't stand. So I sat her back on the deathbed. I ran and got the wheelchair, got her in the wheelchair, got out of the bathroom, got to the bathroom. She goes to the bathroom and she started doing that she has the she has a few tells that I know before she passes out and I was like Oh crap, I got her up, back in the wheelchair back to her bed because as long as I get her flat, she's not gonna pass out. And I've done this so many times. I can't even tell you I have it down. Pat got her on her bed. Put the fans on the whole thing. So I call I text the the hospital. Okay, keep me posted.

Dr Zitter 29:25

Great. keep you posted. Okay, what would be the most helpful thing for you right now?

Rosanne 29:33

I thought it was the 24 seven hospice number. I thought that would be the most helpful for me. I don't know.

Dr Zitter 29:42

You're always, always vigilant you're always have to work her she's gonna get so what about it? Yeah, like, you know, when people have a baby. And some people who are wealthy enough, can hire an overnight nanny so that they can sleep like would that help you?

Rosanne 29:55

The problem with an overnight person is where do I now in in the world, of course. COVID Yeah, where do I, what do I do with them? Where do I put them?

Dr Zitter 30:03

The world of COVID has made it everything. So you can't even like it. Just it's. So let's pretend there wasn't COVID.

Rosanne 30:14

If there wasn't COVID, I would still I would have somebody coming on a regular basis to give me just so that I can have a little oxygen. Where would where would they stay my my oldest daughter's room, I have a chair in there and a table and the TVs in there. And I always thought, when we got to that time, I would have a caregiver be in that room. So that's where I would put them.

Dr Zitter 30:33

Okay. And so you would at least be able to sleep at night?

Rosanne 30:37

Yeah. Now, yeah. Trying to find a night person is a different game. Yeah, it's a different story. Because, you know, number one, it's hard to find them. And then because I am on 24, seven, and I have the ears of a bat, you know, you know, they're going to get up and I know, I'm going to hear them. So but then there's that part of me. That makes me go, okay. Rosanne, you got to shut it off. Like, you got to pick

yourself here. Because you're going down. And I can I can feel that. I mean, my heart's racing my mind. I'm over 100 more than I'm under 100. And I know it's because of the exhaustion and the stress. And all of that. I know that, you know

Dr Zitter 31:18

Have you been to the doctor to find out why your heart? Do you have any arrhythmia, do you, I mean, what have you?

Rosanne 31:22

I do not. I did call my cardiologist last week and what? No, no, and, and he said, he said you need to, he said, I don't want to give you anything, because it's going to make you sluggish. And it's not going to help you do your work. So you need to get somebody in. He said you need to forego the COVID fear. And have somebody come in and help you is what he said.

Dr Zitter 31:41

I think good advice. Yeah,

Rosanne 31:43

It was good advice. Now, of course, his mother's 99 and lives with his sister. So he was coming at it from you know, just just get a caregiver.

Dr Zitter 31:51

You're, you're amazing. I have to tell you,

Rosanne 31:53

Thank you.

Dr Zitter 31:54

I know you're interviewing me, but I actually really think you're much more interesting than me. And I want to say

Rosanne 32:01

Doctor Zitter I don't think so.

Dr Zitter 32:03

I'm amazed by what you're I just You're amazing. I want to ask you how you're doing it because you're so cheerful right now and you're I'm listening to your story and I want to weep. I do. I really do.

Rosanne 32:18

It's it's hard. And I I just I just do what's in front of me. Honestly, I just do the next thing because I don't know, I don't know what else to do. Like, it's just like, okay, that's next. Let's do it. Okay, she doesn't she can't shower herself. I got it. I mean, I just keep going. She had a thing on her elbow, whatever the one of the beginning and getting going off, they call them. It looked like it looked like an eye. Anyway, the dermatologist wouldn't help me. She had been she had been a patient of hers for 30 years. And I

took a picture and brought it to her. And I just wanted her to tell me, what can I use on this? She wouldn't even look at the picture because I didn't have her with me. So I got castor oil, because I thought that was the least offensive thing that I could do. I put a goal as I put it on there. I wrapped it up, I've cut a sock and put it over there. And I got rid of it. I it took a long time. But I got rid of it. You know it used to flake I used to have to pick the stuff. Oh, it was gross. But I did it. And that's the kind of thing and what happens with me is that doctors will come in here and I have a binder. I have all of her tests I have everything ever happened. And they look at me and they go Oh, wow. That's a great idea. I have to take that. So they wind up leaving with things that I'm doing here. And they say to me, oh, just keep doing what you're doing. You're doing a great job. And that's what I get all the time.

Dr Zitter 33:37

I kind of feel like weeping just listening to this. I it this is breaking my heart and it's really I gotta say it's just really helpful for me to hear your story. Because I you're unusual and your competence. Most people nine I don't think I could do what you're doing. I don't know.

Rosanne 33:59

No,

Dr Zitter 34:00

No, no, no, no, no, I you're you first of all. I don't look, I don't

Rosanne 34:05

Thank you.

Dr Zitter 34:06

I don't know how you're doing it. I mean, five years, more than five years of this

Rosanne 34:10

Five and a half years

Dr Zitter 34:11

Five and a half years of this is I mean well. We have babies we do this for three months or four months with a baby sleeping and sleeping and sleeping. not sleeping at night. Right? Five years of not being able to rest is is crazy, and that we don't have kind of a national policy to support people like you is outrageous. It's outrageous. I'm flabbergasted like I feel like flabbergasted. I mean and I'm and by the way, I'm imagining myself with my own parents like my parents are you know, early 80s are pretty, they're healthy. This is going to be my life to what what what, this is all of our lives. Absolutely everybody Yeah, some people are luckier than others. Some people are serial caregivers they do 10 years with the mother and then they do. I just yesterday, I spoke at a program in the Jewish family children's service at this woman said she started out she did a few years with her brother then she did a few years with her husband. And then she did a few years with her daughter,

Rosanne 35:18

Oh my God,

Dr Zitter 35:19

How many years of a life now? How many women? Are they talking about? COVID? Me COVID is exacerbating all of this stuff, right?

Rosanne 35:27

Yes.

Dr Zitter 35:27

You know that women are leaving the workforce, caregiver caregiver responsibilities during COVID at a rate of four to one over men, I believe that and they're saying there was an article in The New York Times that there's going to be a it's like, they're calling it a she session in the workforce, and that women are going to be set back professionally. 10 years by this. And, you know,

Rosanne 35:51

I believe that

Dr Zitter 35:52

I believe it 100% I mean, I don't know what you, I'm not sure what your employment history is.

Rosanne 35:57

I was, I was a Realtor, and I put my license in escrow, when I saw I saw it coming. And I that's what I did. But I'm sorry, I cut you off.

Dr Zitter 36:05

No, no, it's exactly what I expected you to say. You can't work when you're doing this. No. And, you know, you, I mean, Rick, Rick, you know, was a contractor. So he theoretically could have squeezed something and he couldn't do any work. He went through most of his savings in that time.

Rosanne 36:28

And, and he got sick on top of it,

Dr Zitter 36:31

He got sick. I mean, how, who's going to change this, who's going to make this better? I mean, there's a lot of people who who have the potential, you know, between, obviously the government, the Federal, local state governments figuring out how to provide more resources and make them more accessible for people so that they get real help, not just call me in the morning, but real help, that's going to let you have a night's sleep or whatever it might be that it's going to, then there's the employers, you know, and me a lot of people are employed, they get their health insurance through their employer that they need that health insurance, so that they can, and there's got to be a way to make work more flexible around caregiving, employers are losing tons of money, they, it's a win win situation to fix it, you know

Rosanne 37:15

Well, and you know, that people when they go to work, they still have to make calls, and they still have to do parts of caregiving that they're not doing their job over, because they have to do the caregiving part. So it would it would help them it would help everybody and and I often wonder if maybe the hospitals in their reach back program, you know, their community resources that they have to provide? What about something like that, or at the very least Adult Day centers for people to be able to go to?

Dr Zitter 37:41

Absolutely, and here's the thing that's for, certainly for patients with with dementia, for sure, every single because Adult Day centers really work. But I think hospitals, not only should they have their own reach back resources, but there's so many resources that are in the community already that hospitals, which are essentially caregiver magnets, you'd be working to connect caregivers that they identify in the hospital system, with the community, there should be this sort of weaving together of these systems so that people are falling through the cracks. Right. You know, and, and, and there's got to be navigators, people who are coming to find you, you know, to find you, okay, Rosanne, I see you're a caregiver, guess what, I need to do an inventory on what's going on in your life, I need to figure out what I can do to help you and give you just a little bit more support. Right? Like, nobody's coming.

Rosanne 38:27

It's awful. And it's it's also, you know, like with cancer patients, they get navigators, right? They get nurse navigators or dementia you you don't get you get nothing you get good luck to you.

Dr Zitter 38:40

And and dementia rates, I think that it was supposed to have doubled between 2014 and 2015. Yes, so two to three years, the rate of dementia is doubled, is doubled. So we got to figure out how to take care of caregivers of dementia, and obviously the patients but the caregivers, my goodness, you can't live the way you're living your unusual. Most people couldn't do what you're doing. I don't think I could do what you're doing. I mean, I don't know what you're doing is amazing.

Rosanne 39:05

Thank you. Thank you

Dr Zitter 39:06

Can I can I say is there I just like, first of all, I have tremendous respect for what you're doing. You're amazing. You're taking this incredible, tragic and traumatizing situation of watching your mother deteriorate in front of your eyes without any help with exhaustion and constant stress. I want to know what we can do just to make your life a little bit easier. What can you just give me one thing that you could do?

Rosanne 39:34

I you know, it's I I feel like I'm a cactus, like I don't need much, but that's what's happened over these years. And that's especially what's happened since COVID. I mean, listen, in January, I was going to a gym. I was going to a gym. Like that doesn't happen. But because I was like okay, where's and you got it. You got to do something. You got it. I forced myself

Dr Zitter 40:00

Well, so tell me first two things who was watching her when you went out,

Rosanne 40:03

I hired somebody, I found somebody, I was going to go through an agency. And I called one of my girlfriends and said, you know, anybody and she was like, I do somebody really good, blah, blah, blah. So she came here five days a week.

Dr Zitter 40:14

Okay, my second question, how can it feel free? I mean, we're COVID has thrown everything even that much crazier, but pretend COVID wasn't here for one second. Yes. How was it to go to the gym?

Rosanne 40:25

It was great. It was great.

Dr Zitter 40:27

Because Because I want to say the reason I say this, because I reading all this stuff, what should caregivers do? What can help caregivers blah, blah, take some time out of the day for yourself. And I was like, Ah, that just seems ridiculous. These poor caregivers are scrambling to go to go meditate for 10 minutes. But it's really helpful for me to hear you say that, because so many of the caregiver support groups that are out there really do talk about taking time for yourself. And it's really helpful to hear a real caregiver saying, you know what, it actually does help me to do that, like that's important information for other caregivers.

Rosanne 40:58

But that was when my mother was sleeping. So when COVID started, it was about April where she started not sleeping at night. So it's been a while and from and I wrote everything down. I've slept 26 nights since September 30, that she hasn't gotten up and gotten up. And because she thinks her mother's across the street because she thinks her sisters are downstairs because because because and I looked at that number and I was like, Oh my God, I'm killing myself.

Dr Zitter 41:24

Oh,

Rosanne 41:25

Because what do you do? And and it's like, you're stuck. Now this is COVID. And it's just me. So is it COVID? Or is it the natural course of dementia? Well, you will never know. But you know that it's added to that, you know that this isolation has added to that. So now I get up, I barely get up. And I drag myself downstairs, and I get my coffee, the coffee, my coffee is the highlight of my day. And I bought a frother so that I can make a little show this all of this. Yeah, the coffee. Yes. But all of this has enabled me to be Rosanne, all of this, the podcast, my writing, all of that has enabled me to have a little piece of myself in the midst of the house burning down. You know, if that makes sense. So it gives me a little oxygen. And not to say that I don't love my husband, and I don't love my children. But for me, that's

what has started to feed my soul. And it's it's been the buoy for me. It's it's that it's that buoy in the ocean that I'm holding on to. That's what the creative part is.

Dr Zitter 42:29

I am my deepest like, my heart is so heavy hearing your story. And it makes me all the more motivated to push for us to change this. This is unacceptable. It's unsustainable. It's heartbreaking. It's it's, it's there's so many things wrong about it. And I'm just I feel so honored to hear your story. Your story is the story. But it's important. What I did was just some dumb luck. And I'm so thrilled and lucky that we created a piece of work that speaks to your real lived experience. But your real lived experience is the whole meat of the matter. People need to know about it. I'm glad that Rick and Bambi can help shed light on what's going on and what's happening with people like you and one out of five Americans who's going through this in some way or another. But it's really time for us to pay attention.

Rosanne 43:30

Well, and especially when Rick said he was this was four weeks for Rick, or was it nine weeks for

Dr Zitter 43:35

Nine,

Rosanne 43:36

Nine weeks for Rick. And I remember he said he was less angry after he had his break.

Dr Zitter 43:42

Yeah,

Rosanne 43:42

Because we don't want to take we want to take the break. But then when it comes time to take that break, we freeze. Because then we think, well, what what if something happens? What if this person doesn't do the right thing? What if my my loved one needs me in those moments? And I'm not. And it's the guilt that it's that ever loving guilt that swirls and it doesn't matter what you do. And it's you know, it's it's like the last out of a baseball game, right? Somebody makes an error and they lose the game. Everybody remembers that. They don't remember that the bases were loaded three innings in a row and they didn't score. They remember the last error and that's how it is with caregivers. It's my my mother died and I wasn't there. Okay, but does it mean that you didn't love her? No. I turned around and my father fell and broke his leg. Well, where are you going to carry him to the car, but it's because we are in charge. And we're those people that are we're driving the bus. And then when something happens, it's our fault. But when we do the right things or when we support them, it doesn't matter because that doesn't count.

Dr Zitter 44:45

But but that's why so much of this campaign to improve the lives of family caregivers isn't just about making more resources and guiding people to more resources. It's just as important for people to understand And all of us, the caregivers and the non caregivers, the people peripheral to the caregivers, that this job is a one of the most important jobs that we have in our society. It is completely

under recognized and under appreciated and under supported. And that those of us frankly, who are adjacent to it and don't support it, shame on us. It's time to change that people need to step up and really, really honor the people who are doing this work and support them. And I think that raising awareness piece is so critical.

Rosanne 45:34

A big thank you to Dr. Jessica zitter for being my guest. For more information about doctors that are including all of her work, as well as how to view caregiver a love story, go to Jessica zitter.com. I hope you enjoyed our podcast today, head over to daughter hood.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 also find us on the Whole Care Network as well as anywhere you listen to your podcasts. We are also on Facebook, Twitter, and Instagram at daughter hood the podcast Feel free to leave me a message 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 row for our theme music, the instrumental version of her beautiful song mamas eyes, from her album lessons in love that you can find on the iTunes Store. 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 daughter hood.