

# Daughterhood The Podcast

## Episode 26: Dr Jessica Zitter Q&A What Just Happened? Questions about End of Life

Video of this interview can be viewed at <https://www.daughterhood.org/daughterhood-the-podcast-3/> under the podcast section

Websites referenced during interview:

[jessicazitter.com](http://jessicazitter.com)

[caregiveralovestory.com](http://caregiveralovestory.com)

[vitaldecisions.net](http://vitaldecisions.net)

[inelda.org](http://inelda.org) - end of life doulas

### SUMMARY KEYWORDS

caregivers, people, hospice, support, patient, doctors, hospital, person, conversations, life, morphine, care, decision, jessica, medications, medical, symptoms, important, palliative care, home

### SPEAKERS

Rosanne, Dr Jessica Zitter, Disclaimer

#### **Disclaimer** 00:02

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#### **Rosanne** 00:43

Hello, and welcome to Daughterhood the podcast. I am your host Rosanne Corcoran, Daughterhood circle leader and primary caregiver. Daughterhood is the creation of Anne Tumlinson who has worked on the 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. I'm more than thrilled to have Dr. Jessica Zitter as my guest today. Dr. Zitter is a strong advocate for a new approach to caring for the dying. She specializes in critical care and Palliative Care Medicine and practices at a public a public hospital in Northern California. Dr Zitter's first book Extreme Measures, Finding A Better Path To The End of Life offers an insider's view of intensive care in America and its impact on how we die. Her essays and articles have appeared in The New York Times, The Atlantic Time Magazine, and the Journal of the American Medical Association, among others. She's also been featured on fresh air with Terry Gross, The Doctors, Dr. Oz and CBS This Morning. Her Oscar nominated film Extremis is available to stream on Netflix. And her most recent film caregiver A Love Story challenges viewers to acknowledge the difficult challenges facing family caregivers and to envision a new approach. Her website, Jessica zitter.com is the most comprehensive resource on end of life care. I'm so happy she could join me today to answer your questions. It's always a thrill anytime I'm able to speak to her . Welcome Dr. Jessica Zitter.

**Dr Jessica Zitter** 02:37

Oh it's so good to be here with you, as always,

**Rosanne** 02:41

Always great to see you. Thank you. You know, I've spoken to so many people and you know through personal contacts in groups, even the posts I see online. And when it comes to someone's last minutes, hours days, even that whole process, I haven't seen one person who didn't feel like they had some sort of wrongdoing or misdoing or responsibility for their loved ones death and the death process. The responsibility that's left in the room with the caregivers is just incredibly hard. How do we make that better? How do we how do we try to bring it? Is it education as a training? Do you think people want to know that their loved ones are dying? How do we do this Jess?

**Dr Jessica Zitter** 03:25

Oh, wow. This is this is such a multifactorial problem. You know, we don't, we don't do dying Well, in America, whether it's inside of the hospital or outside of the hospital, we have this sort of process that I call the end of life conveyor belt where most people sort of the default approach to most people who have serious illness or who are approaching the end of life, is to bring them into what I call the end of life conveyor belt just to keep this high level life prolonging intervention system going to try to keep this body alive. And it's people who actively opt out of that system, who have the opportunity to go home and use hospice or to go home and, and have, you know, be with family that requires opting out because it's very hard to get there if you're not actively planning for it. So when you talk about Extremis, these people are the message of that film is think about the ICU as a destination that you may not actually want to go to and if so, like back it up and make some advanced care plans and the same thing for caregiver a love story. The whole system really needs to be planned for in advance But the last thing I'll say it's too long an answer for you. But we don't support caregivers in the out side world to do the job that they need to do. We don't support them financially. We don't support them with training. We don't support them with the kinds of things that that a person needs to do this work as you well know. In the hospital, we don't support physicians and patients and family members to make decisions that are more patient centered around issues in the intensive care unit or in the hospital. So we've got a lot of

supporting to do, whether it's financial teaching training, there's a whole variety of things we need to do differently. long answer, sorry,

**Rosanne** 05:21

No, I, that's great. I love it. And opting out, then becomes feeling like you're giving up because of that, H word, once hospice comes in, everybody thinks, well, we're giving up

**Dr Jessica Zitter** 05:35

Yeah, we've really, really, in America, it's not only the physicians and health care providers who have been trained, that there's always something else to do, there's always some other intervention to reach for. But family members, and patients expect us to be doing that. So this this, almost what I would call like a collusion, this belief that we just have some answers that we often don't have. And so instead of really sitting down, looking at the situation, looking at the prognosis, looking at the reality, we just keep doing things, and we're just avoiding this very, very, very important. Reality is this existential reality that we are all going to die, and we want to do it in a way that works for us.

**Rosanne** 06:19

Right. And I think the, one of the underlying factors is choosing hospice or choosing not doing the intensive treatment, it almost feels like we are doing something to them, when in reality, they're dying. That's when we have to step back and look at the fact that they're dying. And we need to try to help that process.

**Dr Jessica Zitter** 06:42

When I describe hospice to people because there's hospice has a marketing problem. Hospice is, you know, the giving up the death word. The weak, doctors the weak at a no the abandoning of the patient. When I describe hospice to families and patients, I say, Have you ever heard of hospice and a lot of times like, Oh, yeah, you don't want hospice and sit down and actually talk about what hospice really is, which is wrapping an extra layer of support around a family around a patient, to allow them to be in a location that they would want to be in, which is for most people home. It's adding it's it's not, it's the opposite of abandoning, it's adding on all sorts of things. And people most of the time, oh, and often end up choosing hospice, when they understand what it really is. And when it's not, by the way.

**Rosanne** 07:35

Well, I was just gonna say there's there's a certain level of expectation that comes with hospice. So when you choose hospice, and then you're under the impression that somebody is going to be here all the time. That's not what hospice is.

**Dr Jessica Zitter** 07:48

Very true.

**Rosanne** 07:49

And then there are things that you need to do that you didn't realize you signed up for. And then that comfort pack comes to the front door. And when you stop sweating, and thinking about what is in this comfort pack, what do you do? And there's a reason they sent the comfort pack to your house. What is that? How did that come to be? Because there's a lot of drugs in there of Jessica, that make people very uncomfortable. And we can talk about the specifics. But where did the advent of sending this comfort kit home come from?

**Dr Jessica Zitter 08:19**

Well, it's interesting that you say that because I don't actually know what a comfort pack is. And probably many people on this call are hospice people or caregivers who have experience right, but I don't know what it is. I'm assuming it's, it's it's, it's morphine and it's depending on the illness, it might be black towels if someone has the potential to have a bleeding event. You know, I don't know what else is in it, but I

**Rosanne 08:41**

It's morphine, ativan, haldol, Tylenol suppositories, something for nausea. I can't remember the rest but right. So they're, they're pretty, they're pretty heavy hitters, and the morphine alone makes it very uncomfortable.

**Dr Jessica Zitter 08:58**

People have a lot of associations with morphine.

**Rosanne 09:01**

Yes.

**Dr Jessica Zitter 09:01**

So so the thing I think that we really need to be clear about let's just talk about that issue. What is yes, what is hospice not. Hospice is an amazing service that allows people like in our film family to actually be at home when they otherwise might not have been able to be at home. It provides all sorts of durable medical equipment that provides the comfort pack all sorts of medications that might be necessary for somebody who is really having serious and end of life, illness, all the things that that are you would not want to be at home without if you are coming to the end of your life from a chronic or serious illness. What people need to understand is that they are provided this medication. Most of the time, much of the time there will be a nurse who's helping to administer but a lot of the time the family is going to have to step up and administer these things. And that is the way hospice works hospice does not have a 24 seven helping with household duties helping with hygiene and baths and changing diapers, those are things that still fall to the family. And it's not because hospice isn't doing a good job, it's because that's not what Hospice is compensated to do, they don't have the time to do attend to all of the needs of the family caregiver and what I've learned, you know, as we as you know, we in the palliative care movement, you say, oh, Hospice is, you know, once you get, you know, find it, you're going to do hospice, that's the end of the game, we've, you know, gotten everything set up. And the fact is, I've learned through making outside of the hospital, what's happening is not, you know, the Hospice is itself slammed on, you have to really support the caregivers who are doing the bulk of the work, you have to prepare them for the fact that they're going to be doing the bulk of the work, you have to support them. To do that you ideally have a country that has a support system that provides for them to get in home support from other people, professional caregivers, you have professional caregivers who are available in a pool of professional caregivers. But right now that workforce has shrunk. Because it's a very difficult job, which does not get paid very well. So we've got a lot of things that we need to do better to support the caregivers to work alongside hospice to provide the support to the patient, but patient, but caregivers need to understand that hospice does one piece of this and they the family are going to be responsible for another very large piece of it as well.

**Rosanne 11:23**

Right. Which is part of the challenge, because things can change very quickly. When you're at that stage, when you're at an end of life, things can change very quickly. And as caregivers, I'm not trained as a critical care doctor. I mean, you know, so all of that there's, there's anxiety, there's frustration, there's panic, really, and you don't know what's happening,

**Dr Jessica Zitter** 11:48

Right.

**Rosanne** 11:49

Which adds to the stress. And I know, when when the doctor said, you know, give your mother morphine, I, it was a come to Jesus for me, Jess because I thought I'm going to give her this medicine because of everything that I've heard, it's going to kill her. And I'm going to kill her when I give her this.

**Dr Jessica Zitter** 12:07

So let's talk about that.

**Rosanne** 12:09

Yes.

**Dr Jessica Zitter** 12:09

Very important point. That is not true. morphine, opioids, all sorts of other types of pain and symptom related interventions and medications. They This is one of the biggest, most important things for people to understand that if given in the way that we give them, hopefully, it you know, in search of managing the symptoms, managing the high respiratory rate of someone's short of breath, or managing the pain level of someone's having pain, if we give it and titrate it just to bring those numbers down to the person is comfortable. Again, morphine, opioids do not hasten death. And it's really important for people to understand that there's just so many myths around the use of opioids that we need to really disabuse people of.

**Rosanne** 12:48

And I, you know, it becomes that it becomes that pass it along. Well, my friend's mother's brother used it and they died. Yeah. Well, were they dying? Like was that like, do you know, but, but in those moments, you have to decide and, and part of that, you know, on TV, we see people that are at end of death, and they're sitting there having full conversations with their loved ones around them. And that's not how that happens at times. So, you know, you think you can say, Do you want this? Is this good? You're in pain? Would you like this medicine? And a lot of times you don't have that option?

**Dr Jessica Zitter** 13:34

Right? Right.

**Rosanne** 13:35

But the fear is still very real.

**Dr Jessica Zitter** 13:37

Yeah. The caregiver really needs support to do that piece of symptom management, which is a part of being a caregiver with somebody who's having a lot of symptoms on hospice. The reality about death and dying is that death and dying are often not easy. It's not you know, it's not the Disney kind of fall

asleep peacefully, a lot of the time, sometimes it is, and those are, those are gifts. But a lot of times it's hard. And you know, I know, you know, from personal experience, and I know a lot of people on this call probably know that dying can be difficult and the caregiver being that loved one. And frankly, being the surrogate at the bedside in the hospital, it's probably easier because you've got nurses and people all around, but being that caregiver in the home with somebody who's actually having symptoms can be very frightening, especially if you believe the myth that you're hastening their death. And I think what we need to do to combat that is to just be more supportive and provide more training to the caregiver so that they understand what they're doing that they feel confident when they're doing nursing and medical duties, which is a big part of being a caregiver. 60% of caregivers, actually do duties, have things that they do for patients that were once done by a nurse. That's just the reality. And we want to make sure that people are as trained and emotionally support it and physically support with other other types of support in the house, which we don't currently have to do this work with the confidence and the calm that they deserve to have when when doing the sacred work of taking care of a loved one at home, and we're not doing a good enough job of that.

**Rosanne 15:19**

Well, now tell me is dying painful. Is that why this comfort kid comes to the house?

**Dr Jessica Zitter 15:24**

Dying can can can be painful depends on the, you know, so many of these things depend on the condition the the actual diagnosis that a person has, not only the diagnosis, but how it's impacting the different organs. And you know, everybody's different. There's as many ways to die as there are people. And, you know, I think it's really, really important to understand just like in, in caring for patients in the hospital for a while that we're trying to keep them alive, the same thing goes as people are, are dying, we really need to have patient centered care, we need to really know how to assess their symptoms and how to best manage and treat their system symptoms, and how to teach the family members how to, to manage those symptoms and treat those symptoms, each patient's going to have a different set of things happening to them. And we need to really take each of the if hospices involved, which is the minority of cases, but if Hospice is involved, we need to make sure that the family, the patient, understand what their disease trajectory is, what all the things that could go wrong, and how we would manage them are. And we need to really, and by the way, it's not just for people in hospice, we should be doing that in the outpatient clinic, we for people with COPD and people, you know, we should be explaining people, what is your illness? What are the different ways that it can go? What are the different kinds of interventions, we have to try to prolong your life? What are the different interventions, we have to help you manage your symptoms, and really bring them into this conversation that so that they're as aware as they can be about it, and as prepared for it as they can be?

**Rosanne 16:56**

But where do we get that information? I mean, on Jessica zitter.com? But where do we get that information? If if the doctor, you know you're trying to get information about the doctor, they either don't want to say it?

**Dr Jessica Zitter 17:09**

Yeah

**Rosanne 17:10**

They don't want to say, Well, this is what's going to happen. Where do we get it? How do we find this?

**Dr Jessica Zitter** 17:14

That's probably the \$20,000 \$20 million question. Because you know, there is a roadblock, to understanding your reality. And if you are being cared for by a medical team, I'm talking particularly about doctors right now, because they are, we are the rate limiting step to giving you the information that you need. And if you have a doctor who's not comfortable with communication, which, frankly, is a lot, unfortunately, way too many of us, then you may not be getting the information that you need and deserve to make plans that would be that would be in your best interest or what you what you would personally want to have happen if if you just are kind of having groups of doctors taking care of you different, you know, sub specialties, etc. We're going to do this next, we're going to do that next. But you don't have any context. You don't understand the big picture. Well, what happens if we try this, but it doesn't work? Or how do we even know if it's not working? And then when do we kind of move into this mode or that mode, people are really flying blind and they're and that's why this end of life conveyor belt is such a trap, because it's the default approach in the work. I'm in the hospital right now, these four walls of the hospital, the default approach, is to just keep doing things, even if they're not working. So that is very, so I didn't answer your question, because you asked well, so how do you get this explanation?

**Rosanne** 18:35

Right?

**Dr Jessica Zitter** 18:36

You know, I, it's it's the most important question. What I try to do is write articles and write books so people can get more of an insight into what might be going on with their healthcare team so that people are more savvy about how to talk to their healthcare teams in a way that's going to make maybe make the information come out in a more productive way. I try to make films that are thought I tried that that are possibly, you know, thought provoking, not only to general audiences, and kind of providing insight, but also that we can take into teaching medical audiences about how we can start to do this different. How can we change the culture of medicine so that we are all more skilled at really providing this critical information to our patients?

**Rosanne** 19:21

You know, it's hard because we're left as caregivers we're left to trying to find this information. And sometimes when you bring it to the doctor, then you get the Did you Google it?

**Dr Jessica Zitter** 19:31

Yeah.

**Rosanne** 19:32

And it's like, well, yeah, I did,

**Dr Jessica Zitter** 19:33

Of course

**Rosanne** 19:33

Because you're not giving me any.thing No offense. You know, I gotta find it somewhere.

**Dr Jessica Zitter** 19:39

Yes.

**Rosanne** 19:39

And it's it's a roadblock after roadblock. And then I think that's what leaves us with the Oh my God, what did I do? What just happened here?

**Dr Jessica Zitter** 19:49

I know and not only the Oh my god, what happened? What just happened? But the fear, panic anxiety. And then let's not forget the financial exhaustion, the physical exhaustion, the lack of support physically, and it's, you know, but the emotional piece that you just talked about this guilt, what is what just happened? What did I do? Did I not advocate enough? Was I not a good enough daughter was I This was I that? Yes, that's the human for a caring family member who has been put thrust into the role of caregiver who frankly didn't really have a choice. It's not like people go around saying, provide care to my parents or I want to write this is often a volunteer job, or not even necessarily volunteer people get, as Rick says, In the film, you get thrust into this role. And I really think that to, to, you know, to be in that position to love this person. Often, I'm not always some people who don't have great relationships with the person, that's the care recipient. But there is it's an end to feel like there's this perception in society that you're supposed to be a good daughter, you're supposed to be a good wife, you're supposed to love to take care of the the Disney version of caregiving is like that film that came out in 1970 love story, right? Everything the guys sitting at the bedside of, of his of his loved

**Rosanne** 21:14

Ali McGraw

**Dr Jessica Zitter** 21:14

Ali McGraw ,sitting there, you know, at her bedside in love. Well, you know what, they were like, 20 nurses around that woman. He didn't do anything. But he wasn't changing diapers, he wasn't giving her any medications for her pain. He wasn't worrying about whether or not she ate there was a whole staff of people around. So we've got to really figure out how to educate caregivers, so that they educate sounds punitive, I'm saying how to support caregivers, to understand that what they're doing is a gift. It's an act of love and duty, that we all as a society should appreciate and honor and hold sacred, and that everything they do is, is positive. Look, are there situations where caregivers might abuse a care recipient? Of course, I'm sure there are, I'm sure they're not the majority. And

**Rosanne** 22:15

Right

**Dr Jessica Zitter** 22:15

You know, most caregivers sit with tremendous shame and anxiety and fear. And, and frankly, it's a reason why a lot of times people default to saying okay, we'll just do this treatment, and so then the person gets swept onto the end of life conveyor belt, because for caregivers, there is more of a stigma, there can be more of a stigma to pursuing what's perceived as less than doing more, which is always considered more interventions, more hospital, more ventilators, more tubes, and etc. So I think it's really important because that often doesn't go with what the patient wanted. It doesn't often it doesn't go with what most people say they want, which is not to be dying in a hospital.

**Rosanne** 22:57

Right. Right. And but you have to have those conversations, you have to have those conversations. And let's be honest, nobody wants to sit here and think, or call their family around and say okay, so if I get hit by a bus next week, I don't want this, this and this, and how do you come up with those parameters? And how do you have those conversations when people are like, No, no, not not talking about it.

**Dr Jessica Zitter** 23:20

Yeah. So really important point. And by the way, that is both What if I get hit by a bus, what kind of medical care in the hospital do I want, and what kind of care would I want if I actually decided we've got

**Rosanne** 23:32

Survived it

**Dr Jessica Zitter** 23:32

And survived it and or have a chronic illness, and prefer to be at home. Those are all forms of advanced care planning. And they and they're very, very critical to have. And so let me give you an example. Let's talk about the ICU kind of life prolonging treatment advanced care planning piece, right?

**Rosanne** 23:50

Yes.

**Dr Jessica Zitter** 23:50

What happens if you get hit by a bus? Well, again, this is very, very, these conversations have to be specific to the person, right? So if you're a completely healthy, 50 year old, and you are going to get hit by a bus, I can't. It's very, I think it's a very rare person who would say, limit my care in any way. I think most people would absolute, let's just do everything. And I would I would be shocked if someone said that, but let's just go for it. Let's try to get this person back. It's when you start having more and more impediments to living the quality of life that you would find acceptable. And again, that's very, very, very personal.

**Rosanne** 24:28

Right.

**Dr Jessica Zitter** 24:28

There's no objective. There's no objective decision about what's a life worth living and what's not a life worth living. Everyone's going to make their own choice, but everyone needs to be those are the kinds of conversations we've got to be having with our families. What is a life worth living to you? Not like what do you want to do if I get hit by if you get hit by a bus? I think everyone would agree let's try to save your life. Let's try to get you back.

**Rosanne** 24:50

Do your best yes.

**Dr Jessica Zitter** 24:51

Let the bigger and more important questions like how do you want to live what is important to you? What is important for you not to have there are some people who say If someone has to, and I've heard this, this, these or if someone has to wipe my butt,

**Rosanne** 25:05

Right

**Dr Jessica Zitter** 25:05

I do not want you to do heroic measures to keep my life that will not be, if that's the state that I'm going to be in for the rest of my life. I don't want to use heroic measures to keep me alive at all costs. That's important information. Other people would say, I don't care if I'm physically disabled, and someone has to provide total care and hygiene, that is still a life worth living to me. What would make make a life not worth living for me would be if I could not think straight recognize my family, if I was afraid all the time, etc. Those might be conditions. I was in pain all the time, and I wasn't getting good palliative care, which why wouldn't they be getting good palliative care? I don't know. So, for me,

**Rosanne** 25:41

Nobody mentioned it to them that's why. Nobody mentioned it to them.

**Dr Jessica Zitter** 25:44

That's right.

**Rosanne** 25:45

Go ahead. Sorry.

**Dr Jessica Zitter** 25:46

No, I mean, I just I'm just saying that, yeah, these things, it's really about how do you want to live? What are the things that would be acceptable to you? What are the things would be completely unacceptable to those are the conversations that are critically important for people and then people need to understand where they are in terms of functional status and prognosis. Because if you are debilitated with end stage lung disease, and you're unable to get out of your bed, and you're wearing oxygen all the time, that may be an acceptable quality of life for you. But if you're going to get intubated the next time, or if your respiratory status is going to deteriorate, you may say, I'm not willing to take the risk of continuing to use ventilators and life prolonging treatment, because I probably won't get back to this place again.

**Rosanne** 26:30

Right.

**Dr Jessica Zitter** 26:30

I hope that makes sense. I hope I'm making sense.

**Rosanne** 26:32

No yeah, no, that makes perfect sense. And it's all subjective. And then what happens is you can have that conversation. And then you know, you're in the room and something, things aren't going well. And there's a moment of lucidity with your person.

**Dr Jessica Zitter** 26:47

Right?

**Rosanne** 26:48

Where they change their mind.

**Dr Jessica Zitter** 26:49

Oh, yeah, sure.

**Rosanne** 26:50

Or where were you change your mind? Yeah. And then what?

**Dr Jessica Zitter** 26:55

Yeah, so this is where it gets ethically heavy, and complicated. And the bioethicists of yore and yonder have really thought these things through. And the, the, what we're talking about here is, we always want people to speak for themselves, if they can write, and yes, people change their minds. And that's okay. We want people to be able to speak for themselves. But as we all know that people, many, many people, as they get sicker, or whatever their disease processes come to a point where they can't speak for themselves, they don't have capacity, they can't make decisions for themselves, that that where they perceive and understand all the options in front of them, and are making informed decisions. In situations like that, we look for a surrogate decision maker, hopefully, it's been, that person has been identified by the patient. So you really feel that extra level of comfort that this is the person that that patient would want to have speak for them. And then that person, hopefully can channel their loved one and say, This is what she would say, Now, this is what she would want now and not be thinking of their own preferences, but the patient's preferences, because by the hope would be in the ideal world, they would have identified this person early, and then there would have been ensuing conversations around all the things that we talked about before. How do you want to live? What would be acceptable? What wouldn't be acceptable?

**Rosanne** 28:21

Right. And it's, I mean, you know, listen, there's things that come up in the world. And I remember when, when Joan Rivers was, had that the unfortunate incident happened. She had written in her will, if I can't do 35 minutes of stand up, don't save me.

**Dr Jessica Zitter** 28:38

Wow, I didn't know that. Wow.

**Rosanne** 28:40

Yeah. So it's my use part of some useless knowledge I have. But how do you determine that so there's, you do have the conversation, you finally get the conversation, and then you get this abstract setting that you're going to bring to a doctor? And they're gonna be like, I don't know, because and it's just doctors can only work with what they're working with. So you're getting How do you know

**Dr Jessica Zitter** 29:04

Well you're getting into all of the most important, but you should write a book. I'm serious, you should, about the person from the perspective of the surrogate loved one loving daughter, the decision. maker My book has a lot of stories around these ethically complicated situations. There. This is not, you know,

there's not rights and wrongs in science here. This is humans, human decision making. And it's an imperfect science, we do the best we can but we want to do is optimize all of the decisions, for the best to be the best situation for decision making that we can and then we have to hope that they're the right decisions. Ultimately, you're right, without really assertive and planned out decision making and advanced care planning. We're sometimes guessing based on things about this person and how they live their life, about what they would want in this city. And so it's, I'm trying remember your original question

**Rosanne** 30:06

About how do you as doctors, because you don't, you know, you kind of know what's going to happen, but you don't kind of know what's going to happen.

**Dr Jessica Zitter** 30:13

I mean, I think that's the whole point. This is all about uncertainty. You see,

**Rosanne** 30:16

Yes.

**Dr Jessica Zitter** 30:17

Doctors are very, very uncomfortable with uncertainty because one of the things as you're watching your Grey's Anatomy, which I know you're watching, we're supposed to look really smart all the time. We're supposed to know. And people like, Well, what do you mean, you don't know when What do you mean you still, but the fact is, you know, medical science is also an art. And a lot of it isn't scientific. And a lot of it is based on experience. And I think this is what's likely to happen. And these are the four different scenarios, as I've often talked to my patients and families that there are four ways that this can go, it could go this way, which is our best case scenario, it can go this way, which is our worst case scenario. And there are ways in between, let's talk about what we would want to do if we see it moving in this direction, if we see things moving in this direction, and try to have a plan for all the different What if situations that could come up. And that's why, you know, again, we have to acknowledge the uncertainty, we have to acknowledge the fact that we don't have crystal balls in medicine, what we have is the ability, a lot of experience, a lot of patients with similar types of conditions. And so we and what I would call Time Trial information. So we can say, as we're starting to get to know, people, these are the four directions that things could go, let's watch for two days and see if we're going in this direction that and let's keep talking, we should be having conversations with the decision makers, whether it's the patient or the family members, frequently over the course of a week ever watching what's happening to the patient in the hospital or in the outpatient setting, we should be touching base, and helping with decision making all along. And frankly, not only is that important from a medical prognosis perspective, helping people understand prognosis, it's also helpful for building trust for making families not feel abandoned. Because if you can imagine, if people feel distrust of the healthcare system, or abandoned by the healthcare system, a lot of people are going to just say, well, Doc, do everything. Because I don't really trust you're here for my best interest. I feel abandoned already. So if you can really create relationships between the healthcare team and the patient's team, meaning the family members and the patient herself, you foster a relationship where there's trust, and you're much more likely to get into a truly therapeutic decision making situation. Does that make sense?

**Rosanne** 32:34

It makes perfect sense. But, but when you're in this situation, you know, you've got you got 10 minutes here, so let me try to explain everything while they're doing this.

**Dr Jessica Zitter 32:50**

Yeah.

**Rosanne 32:51**

Uh huhm uh huh (looking at computer)

**Dr Jessica Zitter 32:52**

Yes.

**Rosanne 32:53**

So the reality of healthcare does not play in our factor. The reality in health care does not pay play in my asking those questions. Aside from you, which I wish we could clone you and put you in every hospital across the country, trying to have these conversations with a doctor in those moments, because they are moments and then you know, when you're in a hospital, especially now, oh, my God, especially now. Well, good luck. Good luck trying to get anybody. And then when you do get them, you've got six and a half minutes because they got to go. And you're trying to make your case and you're trying to make them understand that this is a person that I care for. But you don't know what they look like, not in this hospital. You don't know who they are. You don't know what they what they are.

**Dr Jessica Zitter 33:39**

Oh, Rosanne beautifully said painfully said. Heartbreakingly said. And there is such a void of humanity in the healthcare system. I don't mean that people are intentionally cruel, but there isn't a lot of real connection. You know, I was just explaining to somebody the other day what a hospitalist is I don't know if people know what a hospitalist is. But it it was in the I guess, mid 80s or early 90s, when people started saying, you know what, primary care physicians shouldn't be going into the hospital to manage their patients as to it doesn't, you know, it's not generating enough money, it's too inefficient. So this whole group of people called hospitalist, take care of patients when they come into the hospital. So those are those people who have their long standing primary care physicians on the outside, those primary care physicians aren't really even generally a part of what's happening in the hospital and in the hospitals where crucial decisions are being made. So that's just one example of the change of our healthcare system towards less communication, less connection, less collaboration, more feelings of abandonment, more fractured care. And all I can say is you're right. It's not it's not adequate. It's not good. Towards the humanity and the humane approach to caring for people in these most vulnerable times. And we've got to change it all up. We've got to change it up.

**Rosanne 35:09**

Yeah, totally. And, you know, I come at it from a dementia standpoint as well. And when, you know, there, there is always that risk of delirium. And then there's that risk of you have surgery for a heart valve replacement or for whatever, and the anesthesia then changes into dementia.

**Dr Jessica Zitter 35:32**

Yup.

**Rosanne 35:33**

And sometimes I feel like the doctors don't. It's almost like they don't know.

**Dr Jessica Zitter** 35:38

Yeah.

**Rosanne** 35:39

And you bring it to them. And they're like, Oh, really?

**Dr Jessica Zitter** 35:40

Yeah.

**Rosanne** 35:41

It's like, wait, I'm not the doctor, you're the doctor.

**Dr Jessica Zitter** 35:43

Yeah.

**Rosanne** 35:44

Why do I know this? And it's not one of it's not on your list of concerns? Yeah, yeah.

**Dr Jessica Zitter** 35:51

We don't set up the healthcare system so that doctors are supported, whether both in terms of time in terms of compensation for those types of activities of communication, in terms of not feeling like, Oh, you know, I'm a bad doctor, because I'm, I'm advising to do less, we completely set doctors up to fail in this in this in this work. And the easiest and most, I don't mean easiest, like, like doctors are lazy. It's just that it's so hard to witness suffering. It's so hard. And we've created this path of least resistance for these overworked doctors. And I'll tell you right now, we're really overworked.

**Rosanne** 36:35

I can only imagine.

**Dr Jessica Zitter** 36:36

The path of least resistance is just First of all, to keep treating, and then to not really not really connect. So we, again, I hate it. I don't want to sound like a naysayer or, but but the current system is not well set up. And what I feel is that we need to do, in a way workarounds around our healthcare system outside. You know, in 2004, I co founded a group called Vital Decisions, which is still going, it does telephone counseling for patients with serious and life limiting illness. And at first we were sort of with my colleague Helen Blank, who was a bioethicist. We were sort of talking about, you know, what, we really want to make sure that the physician of that patient is okay with us kind of coming into the picture and talking to the patient. And so we tried reaching out to all these doctors, is that okay for us, if we talk to your patient, do you mind if we talk to your patient about their prognosis and helping them with decision making, none of the doctors even got back to us. So we made a decision that we were just going to bypass the doctor, we were going to call right to the patient, we're going to say we're a service that is paid for by your insurance company, which you can imagine in 2004 2005 was like, Oh, that's a death panel. You know, what percentage of people wanted to talk to us when we said we were,

**Rosanne** 37:51

I would guess 80

**Dr Jessica Zitter** 37:52

It was higher, it was around 90. Most people were like, We want to thank you. Thank you. Thank you. Thank you. And from there on winning vital decisions, which is now how many years old started in 2004. Many, many years old.

**Rosanne** 38:06

That's wonderful.

**Dr Jessica Zitter** 38:06

It's really, it's it's a workaround. It's, it's saying, We're going outside of the healthcare system. We're going outside of that hospital and that healthcare, that medical practice, and we're just going to come at the patient from this angle, and say, we're here to support you. We're here to help you think through how to think about your mom, and what decisions you need to make next. And that's one work around. There's lots and lots of workarounds, but we got to start doing them because people are suffering.

**Rosanne** 38:33

Well, they are and another workaround that I that I am I thought of was the death doulas.

**Dr Jessica Zitter** 38:39

Ohhhh

**Rosanne** 38:39

So I mean,

**Dr Jessica Zitter** 38:42

Hail to the death, doulas.

**Rosanne** 38:44

Totally, totally, totally. And I think it's a it's a great advent and it's a great safety net. Because, you know, people have great hospice experiences and people have crappy hospice experiences. And there's not a whole lot in between.

**Dr Jessica Zitter** 39:00

Yes.

**Rosanne** 39:01

You know, there's a lot of eh, its fine, but to actually have someone who will come and sit and be in that process, because that process is a process and I I really do feel like it's almost like giving birth

**Dr Jessica Zitter** 39:15

Yes.

**Rosanne** 39:17

On the other end,

**Dr Jessica Zitter** 39:18

It's harder sometimes.

**Rosanne** 39:20

Yeah.

**Dr Jessica Zitter** 39:21

And in some ways more important. I don't know maybe that's not fair to say but yes.

**Rosanne** 39:26

Well, it's it's so much, it's so much that happens and it's so and when you speak when you speak about the uncertainty uncertainty of it all. And it is from top to bottom. But the problem that happens with end of life care is it's it's final. So it's not like you can say we're going to do this oops, it didn't work out the way we thought Oh, sorry. And then here's your here's your sack of guilt and trauma. Now Good luck to you because you're never going to get past that. And that's not fair. It's not fair to anybody.

**Dr Jessica Zitter** 39:56

One of the, I think one of the important services that hospice offers his his bereavement counseling and counseling following the death of a loved one now is every hospice got a great robust counseling? I don't know. But I think one of the things I will say is that it is for many hospices is I think one of the most important things that they offer, which is really supporting the caregiver are the surrogate decision makers in the family, after the loved one dies, and really helping them to process their grief and their guilt. I mean, ideally, the guilt piece should be dealt with before the die so that you're not experiencing that over the course of it.

**Rosanne** 40:31

Right.

**Dr Jessica Zitter** 40:32

I really think it's it's so critically important that we get in there and really, really provide this more robust support, psychological support, physical support, financial support, all the things that caregivers need, do you hear how much money is going into our hospitals and institutions in this country, we have the highest GDP in the world, for healthcare, doing things that frankly, people don't want. Why do we know that? Because a lot, any of the palliative care literature, almost any conversation that you would have about end of life decision making results in people saying I want less life prolonging interventions. So you know, we're just doing, we've really got to sort of re- assert this support and communication and the conversations so that people get what they want. And we should, and it's going to save, frankly, let's talk about the M word. It saves a lot of money, because people always want less than what our default is. And some of that money that saved from that hospital environment. Why the heck isn't it going into the home? Why are we not funding the home?

**Rosanne** 41:36

I will never understand it. I will never understand it. Especially when 70% of people polled want to die at home. Yet one in four die at home. So it's like but and I still I think those numbers are higher.

**Dr Jessica Zitter** 41:50

Well, you know, the good news is there's there is more effort and more work to pull care into the home. I mean, first of all, there's this whole movement hospitals at home. This is like for this is not for hospice patients is for people who want, you know, doing care actually in the home, doing intensive care in the home, there's more sort of attention to the home environment as actually a good place. You know, we don't just need to be in the hospital, just, you know, and so I think there is, and there's a lot more a lot more attention, especially with COVID into the experience of caregivers and sort of a desire to really see caregivers as a group that needs to be supportive. And there's a conversation happening in Washington right now, everybody, your Congress, people are involved in a very important conversation about how to support caregivers, how much to support caregivers, the amount of money that has been proposed has gone from \$440 billion down to \$190 billion. Call your congressmen if you think that this is an important thing that we should be doing more of

**Rosanne** 42:47

Totally agree. The support for family caregivers for in-home caregivers is dismal. It's dismal. And

**Dr Jessica Zitter** 42:55

Very little.

**Rosanne** 42:56

We're trying to we're trying to carry literally carry the person that we're caring for. While we're it's almost like walking into a river and you're trying to hold them up while you're going into the river. I mean, it's it's crazy, and trying to get doctors and interacting with doctors. It's just it's it's so mind numbing to me that this can't be fixed that they can't that it can't be adjusted that this is really where we are it I can't believe that this is really where we

**Dr Jessica Zitter** 43:27

Were we're you know, I mean, we're creating a whole group of secondary patients or invisible patients, these caregivers, we know are suffering physical, I mean, you should just look at the studies on caregivers versus non caregivers that, you know, lipid levels, markers of inflammation. I mean, they're sicker and they're getting sicker because of this work. So that

**Rosanne** 43:48

Would you want my bloodwork?

**Dr Jessica Zitter** 43:49

Yes, seriously, look at your bunch. I mean, we know that people's blood work worsened significantly. We know that people are, you know, missing, we know that employers, frankly, are spending a lot of money on higher health care bills for their for their caregiving employees. I mean, this is really causing a medical crisis for a whole group of people who wouldn't be in this type of crisis. And and so the medical piece in and of itself is something that should really alarm the healthcare community and say, wait a minute, we've got to back it up here. We got to back upstream and say, these caregivers need more support because we're creating a whole group of new patients here.

**Rosanne** 44:26

Totally no absolutely and, and the the long term effects, listen, you know, I'm I will research til my eyes fall out I'm just going to keep researching. And I still felt like I was on an island. We had hospice, there was hospice, and that's great. And you call and they say what, okay, what's going on? And you explain

and they say Okay, well just do this and you're like, well, it doesn't seem right. How is this right? And it feels like you are, you're on an island and you're you're giving these medications. And you're trying to control what you're seeing, but you're not sure what you're seeing, because you're not the doctor.

**Dr Jessica Zitter** 45:06

You know, Rosanne, so yeah, every time I talked to you on the phone while your mother was still alive, I, it was so hard for me to hang up, because I, first of all, because I love you, and I think you in the midst of this profound stress that you were going through, you always had this sense of humor that I wouldn't have had. And, you know, I but I would listen to what you were doing and I thought, How do I get off the phone with this poor woman how the way she needs support, she needs to know what an amazing job she's doing. She needs all sorts of things. And you know, and yes, what hospice would do with you. That's I mean, Hospice is great, but that's the limit of what they do. They're not going to come and sit next to you and give you respite. And they do actually give you some respite if you need it, but they're not you know, they're not they're not that's and I think, and I think it's really important that although there are some bad apple hospices, you know, we should not demonize hospice in this,

**Rosanne** 46:03

No

**Dr Jessica Zitter** 46:03

In this in this in this assessment of what's happening to our caregivers, because Hospice is there for a very important reason. And for the most part, they do a fantastic job. What we need to do is support hospice either to do more themselves, or to provide services that work alongside hospice and coordinate with hospice to support the caregiver, so that there's not this profound distress. I was talking to a hospice nurse recently about Caregiver: A Love Story, because we've actually been, we've been given a grant to create a program for hospice staffs to help them to understand to think about family caregiver burden among their clientele, to help them not feel the shame and blame because that can be very incapacitating for the health, hospice workers are watching people like you, and then they've got to get to their next client, and they can't stay and help you, they get and they feel a lot of moral distress, a lot of moral distress, witnessing the caregiver suffering and where they're not supported to themselves to help with that piece of it. And there's just, there's suffering all around and we just not we need to support hospice people. We need to support the caregivers, we need to support everybody to do this better.

**Rosanne** 47:13

Yes, agreed. And I feel like what happens after all of this is that there's always that second guessing. What did I miss?

**Dr Jessica Zitter** 47:22

Very common.

**Rosanne** 47:23

Why didn't I see this? What all of that? And then what could I have done better?

**Dr Jessica Zitter** 47:30

Yeah.

**Rosanne 47:31**

But we're not. How do you fix? How do you help that? How do you support that? And how do you how do you help caregivers get past that Jessica? How do you get help caregivers get past that?

**Dr Jessica Zitter 47:40**

Two things there, as I said that, as we talked about before, earlier, one of the things is to provide them with the medical backup and support and training that they deserve, and not just dump comfort, you know, dump the comfort thing on that, and assume it's gonna be okay, they need lots of support to do the medical work that they need to do. The second thing that I think that they need is a lot more ongoing psychological support, you our caregivers really, really, really need to be given the emotional and psychological support that professionals should be providing, whether it's psychologists, social workers, they should be connected to at least once a week to really sit down. How are you doing? How are you feeling? What are you worried about, so that they can decompress and process and reflect on what the things are and I do believe that that could be another element. So the physical and financial support of the family caregiver medical training, and then the emotional support of the family caregiver as they're going through this journey would be helpful I'd say.

**Rosanne 48:42**

That would be huge.

**Dr Jessica Zitter 48:43**

Yeah, yeah.

**Rosanne 48:44**

Absolutely huge. And because you are you're experiencing all of this alone,

**Dr Jessica Zitter 48:49**

Yeah,

**Rosanne 48:50**

Basically,

**Dr Jessica Zitter 48:51**

Totally along.

**Rosanne 48:51**

And you're still trying to do the best you can for your loved one with your care partner. Now, there's a lot of talk with palliative care about having the other options, but you can't access these other options. The other options, it's like it's like hospice, it's like when you're in the hospital and you have all these people coming in, and you say can I get a palliative consult? Well, they don't come on till seven. Like you could get a biopsy tonight, but you can't talk to a palliative care person. If you need support in making your decision, we can't help you but we can cut something out.

**Dr Jessica Zitter 49:24**

Well said, Well said.

**Rosanne 49:27**

So

**Dr Jessica Zitter** 49:27

Well said I touche, touche that is exactly right. Yeah, Palliative care is not typically you know, the the strengths that a palliative care team brings the communication, the support, the rubbing someone's back the really knowing how to manage symptoms, that's just not prioritized to the same level of biopsy or some kind of, you know, cardiac procedure or line insertion is and so we don't have the staffing and the availability that other services have and I agree with you 100% that to me, the most important thing I mean, obviously we once you save, stabilize people's vital signs, is get decision support in there, help people understand what is going on so they can make active decisions about what they want to happen.

**Rosanne** 50:13

So that is the number one thing. At the end of the day, the number one plan is to have a plan.

**Dr Jessica Zitter** 50:20

Well, that's number it's number three, because number one, okay, as an ICU Doctor, what I think about first is I want to make sure they're stable, right? And then their vital signs and their pain levels and symptoms. So those are the first two things you got to do, then immediately, what is the picture? Let's make sure this family knows what's going on. Let's make sure we can all do some decision making shared decision making together that is really going to be centered on this patient's preferences and values.

**Rosanne** 50:48

And you have great resources on your website.

**Dr Jessica Zitter** 50:50

Oh, I'm glad

**Rosanne** 50:51

Like and I'm not just saying it because I'm talking to you. You have great resources on your website, between the the wish cards, like I've never seen those I wish cards that's fantastic.

**Dr Jessica Zitter** 51:00

Go wish, go wish

**Dr Jessica Zitter** 51:00

That's fantastic go wish sorry. Which I think did you develop those? How did they come?

**Dr Jessica Zitter** 51:06

No, no no no, they're great. They were developed with someone in the Bay Area. And my friend, a palliative care doctor named Dawn Gross loves to use them. And so she introduced them to me, and I think they're terrific, because they really, it's all about what we talked about at the beginning, which is, yeah, is most important for you about how you want to live.

**Rosanne** 51:22

So how do we help those caregivers that were that felt like they they killed their parents, or they did something that that made a detrimental change in their parents? How do we help them leave that behind?

**Dr Jessica Zitter** 51:40

That is really the that is why hospice has such a focus on post death, bereavement support a family members, because this is a psychological support of a normal, a normal emotion that people are going to have witnessing 24 seven, a person's demise over the course of days, weeks, months, that's very traumatic. And most people are going to need a lot of counseling, I'd say and have it should happen before. As I said, it should be happening before the person dies, it should be happening all along. But they're certainly going to need it after the patient dies. Because Because this is a very, very, very traumatic in a lot of situations go through. It's a trauma, it's a trauma. And you need to support for that if we want a healthy, healthy society.

**Rosanne** 52:27

Well and it's even sometimes there's those you know, you give medication, and then they say, you know, she may not wake up now. It's like, wait, when did that happen? Nobody mentioned this. Nobody mentioned when you give a, b, c or d, this could happen and you might never speak to them again, like

**Dr Jessica Zitter** 52:47

Two two points for that, too. Yeah, it really needs to be reminded to that to the caregiver, which is number one, this person is dying. The reason we're all here is because this person is dying.

**Rosanne** 53:00

Right.

**Dr Jessica Zitter** 53:01

Number two, we're giving medications, to assuage the physical symptoms. That's why we're giving this we're not giving more, we're not giving less, this person is dying. And these medications will help keep them comfortable. These medications will almost definitely not hasten this person's death when they die, they will they will, they will die of their natural causes. And so it's just it's just that constant reminder and that conversation and that reassurance. And that reminder that this person is dying. Let's let this person is dying that's why they may not wake up. It's not because you did anything wrong it's because they're dying.

**Rosanne** 53:42

Right. Right. The elephant in the room is death. Yeah, I got you.

**Dr Jessica Zitter** 53:46

Yes.

**Rosanne** 53:47

But it's just hard because you feel that responsibility because you're responsible for everything.

**Dr Jessica Zitter** 53:52

Very, and that's why I you know, I think it can take years in in Caregiver: A Love Story Rick says, I couldn't go back to work for a year and a half. I was so stressed and anxious. This is a it shouldn't be

this traumatic for a caregiver. I believe that if we had more support along the way for the caregiver, this trauma, this grief and bereavement, that we have to actually provide as part of the hospice service would be mitigated significantly if people had much more support along the way.

**Rosanne 54:24**

I agree. And if they can't get it from the hospice provider that they have, where do they find it? Because the other thing about hospices, there are different groups.

**Dr Jessica Zitter 54:34**

Yes.

**Rosanne 54:35**

And then there's hospice houses, which

**Dr Jessica Zitter 54:38**

Are rare

**Rosanne 54:39**

They're rare they're very rare, some, like the hospice that that we had had actually had a unit. So you could, they would provide a week's worth of how of respite every once every 30 days, which is great. I mean, that's a great feature. But every Hospice is different.

**Dr Jessica Zitter 54:57**

Yes.

**Rosanne 54:57**

So if they're not providing that And where do you find it.

**Dr Jessica Zitter 55:01**

Well first of all, most hospice I believe Medicare requirements are that hospices need to offer three levels of care three or four levels of care, one of which is medical respite. If needed you know, respite for the for the family. So that is something that you should, you know, you need to know what you get, if you sign up with a hospice, there are certain things that you have access to that you want to make sure, you know, they have levels, different levels. If someone for example, another level, it's called GIP general inpatient care, where a person has unmitigated, unrelenting symptoms that can't be managed in the home, they need to be brought to a hospital environment where they can have this managed before they get bring them back home. So there's several levels of care that every hospice you should know to ask if that hospice, do you have respite? Do you have a GIP Do you know most of what's gonna happen is in the home, but um, so your question?

**Rosanne 55:51**

No no there's just different different each hospice has different they're all different tthey all have different support ssystems and how they do it. Tand if you don't like the hopsic e that you're with you can switch hospices, like when you're not locked in, if you don't like the hospice nurse, you can switch hospice nurses, whatever. But yeah, a

**Rosanne 56:10**

Of course you do. Of course you do. Because we are not invisible in your world, which is

**Dr Jessica Zitter 56:10**

Absolutely, no, you're not locked in. You can always fire hospice, you can always de- hospice, you could come off a hospice, if you don't like, there, but there's many other hospices. So don't just give up on hospice, if you don't like that particular hospice. The other thing is, you said, Well, how do you get that psychological support, if you're not going to get from your hospice, and you know what, some people are lucky enough to have the money to pay for extra therapy, which I think is one of the very, very important self care things that that you know, weekly therapy, if you're able to afford it could be a wonderful thing. I think caregiver support groups which are around there, there are a lot of caregiver support groups, people don't necessarily know about them, they can provide profound amounts of support to others speaking to other caregivers, and just having that weekly get together. There, you know, some people will qualify for some resources that are out there. If they are, you have to, frankly, earn little enough to make Medicaid. If you earn more than you can then what then then makes you qualified for Medicaid, you know, like Rick did, and he didn't earn that much money you're more you know, a lot of the services but for people who qualify for Medicaid, they're certain there's certain things that are paid for that that can be helpful. A lot of those are on the resources page at Caregiver: A Love Story.com, by the way. Okay, but yeah, so actually that's another my resources on JessicaZitter.com are sort of an in my book, where I have a whole up thick appendix about like, what steps the six steps for thinking about these kinds of things and making advanced care plans. But in addition, and then just JessicaZitter.com has a lot of advanced care planning resources, but Caregiver A Love story.com has a lot of resources for the caregiver specifically that you should take a look at that.

**Dr Jessica Zitter 57:27**

Not anymore, not anymore

**Rosanne 57:31**

Which is a gift for all of us. It's a gift for all of us. And I always say if you don't have the people that can support you find them. Because we're everybody, we're out there.

**Dr Jessica Zitter 58:04**

Yeah

**Rosanne 58:04**

Daughterhood support groups. There's support groups, hospitals have support groups. Alzheimers Association has support groups. There's Facebook groups that are everything. I know if I didn't, if I didn't have if I wasn't seeing my therapist every week, I don't know how I would have made it through because it's it is a, it is a shock to your system every single day, every single day.

**Dr Jessica Zitter 58:29**

And night and night at night.

**Rosanne 58:31**

Well,

**Dr Jessica Zitter 58:31**

All through the night there

**Rosanne 58:32**

Listen we didn't have any nights. It was just it was just 24.

**Dr Jessica Zitter 58:36**

I don't know how you did it. I don't know.

**Rosanne 58:37**

It was just a constant so, but just to be clear, you're not killing your loved one.

**Dr Jessica Zitter 58:43**

No

**Rosanne 58:43**

You're not killing them by providing them this care or these meds. You're not killing them.

**Dr Jessica Zitter 58:50**

Right. Absolutely not the hospice will teach you how to administer these medications in a way that is safe and that is really focused on managing symptoms. And that in and of itself does not hasten a person's death.

**Rosanne 59:03**

And if something happens because of that, it was not you. It was

**Dr Jessica Zitter 59:09**

It was their illness, the illness that they are on hospice for which is leading towards their death anyways.

**Rosanne 59:15**

Right. Okay. Okay. Is there anything you want to leave anybody with, aside from planning? Is there anything that you, that we have not touched on that you would like to touch on?

**Dr Jessica Zitter 59:27**

Two things?

**Rosanne 59:29**

Go ahead.

**Dr Jessica Zitter 59:29**

Number one, all the caregivers out there, you're doing God's work, you're doing the most incredibly important work I hope that on some level, even though it must be stressful and exhausting at many, many times. I hope you you feel the value of what you're doing and I hope you forgive yourself for not for not it's like being a parent. You know, you can't be there's no perfect parents. There's good enough parents and its the same thing for caregivers. There's no perfect caregivers. There's good Enough caregivers. And so just feel good about being a good enough caregiver and do your best. And in the meantime, the second thing I want to say is, we have to do more to support you. And all of you on this call, I hope you're going to pick up your phones, talk to your Congress, people think about what's going

on in Washington right now, as we're negotiating how much money we're going to apply towards the supportive caregivers and be part of that activism as well.

**Rosanne** 1:00:28

Beautiful, I agree. And Jessica zitter.com

**Dr Jessica Zitter** 1:00:31

Yes.

**Rosanne** 1:00:32

Caregiver a love story.com,

**Dr Jessica Zitter** 1:00:34

Right.

**Rosanne** 1:00:34

And on a personal note, five months ago today, Jessica, this very day, we spoke on the phone in the morning, in my panic state of I didn't know what I was seeing. And we spoke four hours after my mother had died. And you provided such clarity for me, and comfort and the ability to see the clarity in what happened and you saved me years of beating myself up for things that were outside of my control. And I couldn't thank you enough for that. And I have no doubt that you have shared that with the people on this call today. And anyone that will listen to this. So thank you, and thank you for all that you do.

**Dr Jessica Zitter** 1:01:15

Oh Rosanne, thank you for all that you did for your mom and for all that you're doing for other caregivers now and thank you so much for saying that you don't know how much that means.

**Rosanne** 1:01:25

I mean every word of it, every word of it. So thank you. Thank you for being here today.

**Rosanne** 1:01:30

For more information about Jessica Zitter check out her websites, Jessica zitter.com, and caregiver a love story.com I hope you enjoyed our podcast today, head over to Daughterhood.org and click on the podcast section for show notes including the full transcript and links to any resources and information from today's episode. You can 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 Daughterhood 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 Rowe 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 join me next time in Daughterhood.