

Zitter Podcast Transcript

Karen Wyatt: Hello everyone. And welcome to End of Life University podcast, where we share real talk about life and death. I'm your host, Dr. Karen Wyatt. And this is episode number 340. In just a moment, I'll be sharing with you a conversation I had with Dr. Jessica Zitter about the current caregiver crisis here in the US. It's a current crisis and a future crisis that is only going to get worse.

So we have a very interesting conversation about that topic, but I wanted to take a little bit of time to inspire those of you listening to this conversation, to think about your own community. Who are the unpaid family caregivers around you that might be invisible to most of us that maybe are toiling away without anyone noticing that they need help or offering them support?

There are currently at least 53 million family caregivers in the U.S. These people are all unpaid. They're taking care of a loved one at home, and many of them have had to leave their jobs in order to provide the care at home. They also are untrained. They've had to learn on the job at the best they can for the tasks that they're required to do at home.

And you'll hear Jessica and I talk all about that, but I encourage you as you listen to our interview to start thinking about who is near you that might need some support. Is there someone in your neighborhood or your workplace who's caring for a loved one at home, someone in your church or another organization that you belong to who could use some extra support and help? Then ask yourself what can you do with the skills and the knowledge and the experience that you have. Is there anything you can do to support family caregivers in your community? Maybe you can offer little mini training sessions for caregivers online about how to do certain tasks, how to do a bed bath, how to change the sheets on the bed when a patient is in bed, how to organize and manage medications for a patient. Maybe you could offer some sort of emotional support and give little caregiver wellness breaks online that allow caregivers a chance to think about themselves and their own needs. Maybe you could help organize volunteers who could assist caregivers with day-to-day tasks, like doing laundry, grocery shopping, and meal preparation.

I think this is an issue that is going to require all of us to step up and do what we can, where we live. And we really just have to start paying attention there. There are people providing these caregiving services to loved ones at home, all around us, but chances are, we've never really thought about the kind of burden

that they're carrying and we've never considered how we might possibly be able to help.

So I want to inspire you and challenge you in a way to think about what you might be able to do yourself to help others who are dealing with this. And I will take you back to a few previous episodes. Just recently, I interviewed Jennifer O'Brien about her book, *The Hospice Doctors Widow*. She currently has a series on Instagram called *I think it's the Caregiver as CEO*.

So she's reaching out and offering support and suggestions to caregivers. And another episode from the past episode, number 275, I interviewed Roz Jones who has a professional company that provides training for caregivers. And you might want to listen to that. And episode 293, Dr. Leslie Kernisan a geriatrician has written a book called *When Your Aging Parent Needs Help*. That's really practical and helpful for caregivers as well. And another book recommendation I have is the book *Living with Dying: A Complete Guide for Caregivers* by Jahna Beecham and Katie Ortlip. I'm linking to all of these resources in the show notes for this episode. So you can go to eolupodcast.com.

You now have to click on the navigation bar where it says EOLU podcast. And then look for the show notes for episode 340. You'll find the links for these resources there. If you want to learn more and find more inspiration for what you might do in your own community to reach out to caregivers, it's going to take all of us.

And we really do have to look out for one another. And as Jessica and I talk about in this interview, each one of us will very likely become a caregiver ourselves. Or we'll need care from a caregiver. So this is an issue that affects all of us. So I hope you enjoy listening to the upcoming interview with Jessica and that you get inspired by it.

One quick announcement now and going forward, I am able to offer transcripts for each of these podcast episodes, starting with episode number 338. My conversation with Terri Daniel. So it takes a few days for us to complete the transcript and get it uploaded onto the show notes page. So it may not be available immediately the day the podcast comes out. We're trying to improve that turnaround time, but this is a work in progress right now. Also I am not sure how good the quality of the transcripts may be. It's a little bit challenging to get a really good transcript. We're starting with artificial intelligence transcribing

each episode, and then I have an assistant who's going through and making corrections.

But for some of these interviews, it's a huge task trying to correct what the artificial intelligence creates. So, I'm hoping that the quality of the transcriptions will get better and better as we figure out the best way to do this. So please be patient with us, but just know as a result of all of you who stepped up to offer your support on Patreon, we are now providing these transcripts.

So for everyone out there who has requested, here you go. And I do hope that you'll all continue supporting the podcast through patreon.com/eolu. We still need new supporters also to help keep the podcast on the air to keep those transcriptions coming in the future. So thank you to everyone so far, who has stepped up to make a small contribution to the podcast. I really appreciate it.

So we'll move on to my interview with Jessica Zitter. I'm going to read her bio for you before we start the interview. And just remember to stay tuned afterwards and come back for a few takeaways and I'll say goodbye. So Dr. Jessica Zitter 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 new film that we'll be talking about today, *Caregiver, A Love Story*. She is a nationally recognized speaker on the topic of dying in America. And you can learn more about Jessica's work at these two websites, jessiczitter.com and also caregiveralovestory.com. So here we go with the interview.

Karen Wyatt: Today. I'm so excited to welcome my guest, Dr. Jessica Zitter. And today we're going to be talking about her latest documentary *Caregiver, A Love Story*, along with other topics as well. So, Jessica, thank you so much for joining me today.

Jessica Zitter: So honored to be here with you.

Karen Wyatt: Yeah, I've really been wanting to talk to you about this subject after I saw your documentary *Caregiver, A Love Story* and felt like it's such an

important topic that we don't discuss often enough is the burden that caregivers are under in our country.

But maybe you could start by just telling us our listeners a little more about your film and what inspired you to make it.

Jessica Zitter: Well, um, this film was actually not even really planned. I was just getting the filmmaking bug. Honestly, this was in about 2017, right? When my book came out and *Extremis*, the movie, came out on Netflix that I was involved with. And realizing that, a film that shows going into the house of a person that can be very, very compelling and what I call emotionally priming, so that it makes you want to learn more and possibly change your behavior. So, I had started just shooting footage of various things that were happening around living with serious illness, et cetera.

And one of my friends became very, very ill. And in fact, I ended up helping her get enrolled in home. And watching the transformation between the day before she was in hospice and, you know, two days after she enrolled in hospice and seeing this profound improvement in her quality of life and her happiness and her functional status, I thought let's start filming.

She's this dynamic woman. And let's just show her story. Let's show how great it is when people make active choices about getting off what I call the end of life, conveyor belt, like to go home and to be where you want to be. And so I started filming and it was about nine weeks until she died in hospice.

And I collected all this footage and it was very beautiful and I didn't look at it until about a year or year and a half after she had died. And at that point, I started realizing that so much of the story in this raw footage, the interesting arc, the interesting story arc was not her experience. I mean, of course it was important to show what happened to her, but it was actually her husband. It was the guy that I thought was just going to be there to open the door for hospice. I didn't think he was going to be a main character in this story at all. If she was the one with the dynamic personality, he's a lovely guy, but he wasn't the guy that I was making this about. But I watched in this raw footage, what happened to this guy over the course of nine weeks, this incredible excitement of like, wow, we've made a decision that seems to be resulting in good outcomes.

And then this real crash and burn of this guy's life. I thought this is a story that needs to be told. And more importantly, how the heck did I not know about the story? I'm a palliative care doctor. I send people home on hospice all the time.

How did I not read that? What was going on? So that's how this film was born, kind of by accident.

And I ended up learning about this issue a little bit by accident because honestly, when we focus within the four walls of the hospice or the hospital, we don't necessarily know what's going on outside of the hospital. And I learned by making this film.

Karen Wyatt: You know, it's interesting because I was a hospice physician, retired now, but I made home visits.

I saw patients and their caregivers in the home on every visit. I spent 30 to 60 minutes with them. And even I wasn't fully aware at that time, just how overwhelmed the caregivers were, even though I sat in the home with them and saw them.

Jessica Zitter: Absolutely. And I'm glad you said that, you know, because I feel kind of embarrassed to admit that I didn't really know about this. And it's helpful to have another colleague saying, "Hey, I didn't either." I think it's not as publicized initially. I think these caregivers are secondary invisible patients, so we are not seeing them as we focus. And we spend so much time focusing on delivering patient centered care, which is this kind of new strategy since 1996, 2006 to palliative care focused on patients.

We've left out the caregiver. Now it's time to be even more holistic than that.

Karen Wyatt: Yeah. And one of the things I read on your website about the film is that this is the first time in the last 100 years, when more people are dying at home than are dying in the hospital, which we can call a success on the one hand, because we've made a concerted effort to get more people home.

However, we didn't really consider who is taking care of that person at home. And that a hundred years ago, people had extended families who were available to care for them.

Jessica Zitter: Yeah, absolutely, the whole demographic shift. But there's so many reasons actually, why it is no longer sustainable to care for people at home the way we used to. You know, before the last hundred years where people just started dying in hospitals at a much higher rate, we cannot go back because we have a complete demographic shift.

We do not have the people at home to care for all of the elders and rising numbers of elders with our baby boom generation and people living longer with modern medicine. We don't have the staffing, the home family staffing to care for those people in a way that is sustainable. A geriatrician once told me that you need three full time caregivers to care for every elder who needs care in the home. And let me tell you something with families dispersed and smaller numbers of offspring and people, you know, we don't have three caregivers per person, and that's why we're seeing such tremendous suffering of the people who are left behind.

Karen Wyatt: And that could be three younger, healthy, fit caregivers full-time around the clock. And so most caregivers are spouses who are the same age and have their own health problems to deal with.

Jessica Zitter: That's right. That's right. And then what happens when they're the ones who are dying and then there's nobody left behind?

I mean, this is a really serious public health crisis that is rising right now. As we, as we talk, what one out of five Americans is caring for a person at home who is disabled in some way, an elder, usually with serious chronic illness end of life situation. That is just a huge number of people.

And it's rising. That was the number in 2020, but in 2015, when the National Alliance on Caregiving measured, it was a lower number. It went from 44 million caregivers in 2015 to 53 million caregivers in 2020. And I'm telling you, it's going to continue to rise.

Karen Wyatt: Yeah, it's so true. And Rick makes a good point that he had to give up his job while he was caring for Bambi at home. So there there's not only this physical, emotional, mental burden of caring for someone, but a financial burden as well.

Jessica Zitter: Absolutely people are going into debt. There's a number of people who go broke.

You know, 30% of caregivers use up their savings. They use their savings up. This is a serious financial crisis. When you think about it 60% of caregivers work mostly full time. So here you've got, you know, people working for employers when they absolutely can't do all of the things that they used to do.

They've got appointments and there's just so much going on. So employers are losing 65 billion dollars a year in revenue based on caregiver burden. And so employers have a reason to really start being interested in this topic. And some of the more forward-thinking and larger employers are starting to give benefits to caregivers.

But the problem is you can give all the benefits you want. If you don't have a culture that supports caregivers. And that makes it okay to explain that you are having stress at home and makes it okay to use those benefits. People don't tend to use it. 90% of caregivers surveyed who were workers said that they did not feel safe in their place of employment asking for support as caregivers, they didn't feel comfortable. They felt that they would get penalized, and that is not a culture that supports it.

Karen Wyatt: Oh, not at all. We need to shift in so many different ways if we're going to solve this problem, but we don't have very much time to make changes here before the baby boom generation is in serious need of home caregiving.

Jessica Zitter: I mean, we're at that stage right now. I think we're at the point now where it is going to get worse and it's going to continue to get worse, but we are in catastrophe. That again, if you just look at the data, the incredible medical burden, the emotional, financial. What is happening to caregivers right now is just not a sustainable thing, and it's not just not sustainable for them.

And that's, by the way, all of us, because when you think again of the prevalence, this is huge, but it's not sustainable for the rest of society. Billions and billions of dollars of unpaid work. And if you have that, a breakdown of that community, and if they are not able to function, it's really part of the infrastructure of our society.

If they don't have a social safety net, then the social safety net is going to break for all of them.

Karen Wyatt: It is really obvious in the film as we watch this evolution and the arc, as you called it for Rick, you can visibly see him getting more and more tired and just worn down and exhausted in the process of the film.

Jessica Zitter: And he, by the way, here's a really important point. Rick was one of the lucky ones. You watch this film, you feel this heaviness. Oh my gosh, we've got to do something about family caregiver burden, but don't forget that

Rick was one of the lucky ones. He only did it for nine weeks. The average family caregiver does this for four and a half years.

He was young. He was pretty healthy. The average caregiver, as you say, is an elder and not as healthy as Rick with a newlywed wife. I mean, she loved him. She was swept so out of her way to do everything she could in her power to help him. Many people are caring for people who either have dementia or with whom they did not have a necessarily a great relationship.

You know, Rick had this incredible community around him. Most people are doing this alone in isolation. I could go on and on. I mean, Rick had savings that he, you know, even he, he kind of came to the end of his savings, but he had them. So many people, particularly women and people of color are absolutely devastated by this.

And you can imagine with COVID it was even more exacerbated, but this is a very serious illness, a very serious crisis that Rick represents one of the lucky ones going through this. So that's important to keep in mind.

Karen Wyatt: And I'm just imagining the number of people who get sent home from the hospital with an ill loved one, and they have a list of medications and recommendations of certain things they should do, and absolutely no training for how to provide care for someone at home.

We're doing a dreadful job in hospitals.

Jessica Zitter: And I count myself among them. Preparing caregivers, alerting them to things that they may need to know they may want to do to prepare, uh, really being realistic about what is going to happen, what it's going to look like. We're not training them adequately. I mean, you know, do you know that 60% of family caregivers now are doing medical or nursing tasks that usually were done by nurse technicians?

They're now being done by the spouse, and so people are being sent home with very little training, inadequate training. The Care Act, which, by the last time I looked, I believe 14 or 16 states have implemented, is a state law and is based in California, where I live. It's about caregivers. And it's about stating that hospitals must identify caregivers before they discharge the patient and they must provide training. And I will tell you that I did an informal poll about 20

people who should know about this. Social workers care managers, no one had ever heard about it.

So it, you know, it's a great concept. It's a very important concept of how we should be changing our structures and our infrastructure in the hospitals, which is where caregivers get born. Right? All of a sudden you're going home with someone who's newly infirm. And it's a great idea, but it has not been implemented and it really should be among many, many others.

Karen Wyatt: It occurs to me that in our society, well, we know we've been in denial of death in general, in our society for decades and decades now, but that we're also in denial of the fact that a lot of us are going to end up being caregivers at some point in the future. And I feel like if, if we could make people more aware of that before they reach the point where today's the day you become a caregiver that maybe we can help people prepare themselves a little bit better for what will be required from them.

Jessica Zitter: Absolutely. I mean, you know, we talk about advanced care planning and we talk about, you know, it's about, do you want a ventilator or do you not want to ventilate or do you have an advanced directive sign? Well, you know, the fact is, and I'm sure you've been hearing this whole sort of hailstorm that advanced directive isn't really working. Okay. You know what, but advanced care planning is much more than completing an advanced directive. It includes forethought and foresight about the eventual scenarios that may unfold and for people to just be aware of them and to sort of imagine, well, what would I do and what would I do if I was in an ICU and I was on a ventilator, what would I do if I decided to go home with hospice?

And having some ideas around which to plan and think about what they would do. That preparation I believe is incredibly important in making good healthcare consumers out of all of us and allowing us to, when we get into those situations, it can be exhausting or terrifying or whatever they are to be able to sort of mobilize ourselves and move forward in some way.

So I think this is a very, very important thing that people learn about. I do believe that watching this film and watching our other film Extremis, both of which are short, powerful films, can make people sort of wake up, pay attention and say, oh my. I think I need to start thinking about some basic ideas around this issue, which I otherwise wouldn't have thought of.

Karen Wyatt: And I did want to mention Extremis. I've recommended that film to so many people, because it's just a perfect depiction of what happens when people don't plan ahead. When people have never thought about or discussed death and dying with their loved one.

Jessica Zitter: Yes. And, you know, just for the people who haven't seen it,, it's on Netflix if you want to watch it. And it really does show people in the intensive care unit, and around decision-making around the ventilator and what should we do? And should we take it out or should we leave it in? What's interesting about both Extremis and Caregiver, A Love Story is that, for those families, they actually had made plans in advance.

The problem was they were not fully implemented. For example, the patient in Extremis who ended up getting extubated at the end, um, she had always known she didn't want to get intubated, but the problem was that we, as a healthcare system, hadn't pulled that information out of that family, but she knew what she wanted and it just, it took communicating with her brother to really get that information out. But then it was very, very clear. So she had done some advanced care planning. She had had these conversations with her family, but still she got intubated. So we need to take that as a cautionary tale. You can have all the plans. You still may end up getting into a situation that you didn't want to get into, but if you have had some robust conversations, it's easier to get out of a situation that you don't want to be in than if you haven't had those conversations. And in Caregiver, A Love Story, they had also done planning.

Their plan was we don't want to continue in this. You know, doing these, what were futile treatments. We want to go home. We want to maximize our quality of life. We want to have hospice, but they still came into problems. So in both situations, people had done thinking about what their goals and preferences were.

They just still got into a rut that they needed help out of. And that's, I think the cautionary tale about really, uh, bringing these conversations more into our societies, the people and the healthcare providers taking care of them can really get us out of those ruts instead of just continuing along like a conveyor belt and sending people to facilities.

Karen Wyatt: Since making Caregiver, A Love Story, has it changed how you interact with caregivers when you're discharging patients?

Jessica Zitter: Yes, very much so. It's really funny. Actually the social worker that is on our palliative care team has been saying for a long time, we would see these, these bounce backs to the people who are sent out on hospice and they bounce into the emergency room.

And I would usually say, well, I wonder why this family wasn't ready. Maybe they weren't ready for hospice, or maybe they were just, you know, there was too much dysfunction in the family. And I always ultimately felt like I, I felt like I was sort of assuming it was the family that wasn't able to deal with it. I didn't think about it as a systemic failure for these people.

This palliative care social worker named James who has raised me up and taught me, she used to say, we have to be more clear with patients and families before we send them out. She was saying this to me for years, we've got to be clear about the fact that they're going to be the ones who are doing the housekeeping, and they're going to have to figure out how to do the washing and the breathing.

And the family needs to get people to mobilize their loved ones and their relatives to be around. So that one person isn't getting exhausted. And so what do I do? So now I do what she does. I tell people we all, as a palliative care team, we tell people you're going to need to mobilize your support.

We help them think about bringing what I call homegrown help, figuring out, giving them some sense of all the things that are delegated that they can do to sort of at least decompress the caregiver so that they're not so downtrodden the way Rick was doing loads and loads of laundry, you know laundry is delegatable. You can have someone else come in and do that.

So talking about those kinds of logistical things that you can do to mobilize your support in advance, but also really be more aware of this problem and providing emotional recognition and support and respect to the caregiver. I think that's a very empowering thing for them to feel from their healthcare providers.

And that's not something I ever did. I didn't pay attention to them. I didn't pay attention to their experience. So I think that is just a very, very important sort of psychosocial piece that we can, we can do in the healthcare world. About three weeks ago, I actually, I had this family, a very heartbreaking story, two sisters and their mother who had a new stroke.

She was actually a doctor, retired doctor, very independent and she'd had a pretty severe stroke. And the sisters knew that this is not a woman who could live in any kind of a debilitated state, functionally debilitated state. And so they were struggling back and forth about what they needed to do.

And one of the sisters, who's a doctor, said mom needs to go home and be on hospice. And the other sister, who's the lawyer who was a lawyer with kids said, that's fine, but I'm the one who, cause I live near her, I'm the one who's going to end up having to go to her house every day. And I manage home hospice, which is what the mother would have wanted.

And so these sisters where you could see they're very close, you could sort of see this crisis emerging. And one sister, this is what we have to do. And in fact, her colleagues, her, her medical doctor colleagues were saying "Sandra, you can't send your mother to a SNF. She doesn't want to go to a SNF." And so she felt this pressure to make sure her mother went home.

But this was the sister who was going to end up having to be there every day and couldn't. And so I gave them the film. I sent them a screener. I said, go and watch this and understand number one, what a vulnerable group you are in right now as caregivers. This is a very stressful time, and it's a time where your relationship is going to be under trial.

And so watch this film so that you can start to sort of understand and respect the amount of pressure and stress that you're under. And I sent it to them. They sent me an email and said, you know, this was really helpful for us to watch because it made us understand how sensitive a time this is and how important it is for us to take care of each other.

Even though we want to honor mom's wants and desires and practice, we also need to honor our relationship. And so they really kind of moved on with that new understanding of how vulnerable they were at that moment, to take care of everybody's needs as best as they could.

Karen Wyatt: Well, I love that you've referred them to the film because I think it's so informative for people to watch who've never been a caregiver before to actually see the real thing happening before their eyes. It's not a fictional movie. You can really see what's going on, but I'm wondering if you've had any success informing our colleagues, because I'm also concerned about all the other doctors

out there who are oblivious to caregivers and who are not doing anything to educate people.

Have you had any success talking to them?

Jessica Zitter: Absolutely not just talking to them. We've created several workshops. We've created a workshop, fits into a nice little one hour noon conference where we show the film and then we have a little bit of a didactic and then a little bit of talk back where people can kind of express and think about strategizing ways.

So we've done that for medical residents and medical students. We are currently creating programming for hospice staff, also a workshop. This is going to be a 90 minute workshop. Again, these things all embed the 24 minute film within them. And really the focus for the hospice staff as you know, more than anybody hospice, particularly nurses and CNA's are witnessing this incredible distress.

It's not part of their job description to go in and do laundry. It's not part of their job description to go in and bathe them. So there's a profound, moral distress that comes in the hospice community with witnessing this distress that they don't have the bandwidth or it's not within their purview of what they do.

They're there to provide medical support, but not housekeeping. And a lot of hospices don't have a significant amount of volunteer time for that. And so really the primary goal is to say, we understand we witnessed the caregivers, caring for the caregivers, these hospice staff. We want to acknowledge you.

We want to support you. We want you to know that this isn't, you know, you shouldn't feel shame and guilt about which I'm sure many hospice people do about not being able to fix the caregiver burden. And then let's talk about little strategies that we can use so that you do have resilience and you don't feel beat down.

But this issue in the hospice world of feeling guilty and responsible for caregiver burden is a real problem. And one of the fears I had in making this film was that it was going to be like throwing hospice under the bus, you know, where was hospice and why didn't they fix it for Rick if hospice was involved?

Well, the truth is it's not their job. And I don't want them to feel like it's their job. So I really didn't want anyone to come away from this film. Oh, my gosh, I

don't want to use hospice. They don't do that. They don't support us. That's not true. And that's so, I don't know. You probably resonate.

Karen Wyatt: Yeah, definitely. But I know there's a misconception in our society. Those people who feel really positive about hospice often believe hospice will come in and just take over. They'll provide all the care. We'll have mom at home, but they will have all the support and all these people. And so it is one of the myths we deal with that we have to explain to people. That's not what we're able to provide.

Jessica Zitter: It by no means is. Does the hospice benefit cover that kind of caregiving? No. Oh, and it does everybody a disservice to believe that it does. In fact, I have a keynote talk that goes with the showing of this film that I have delivered in several places.

And it talks about the 3 myths around the end of life at home, about living at home with serious illness or dying at home of a serious illness. And one of them is that hospice will take care of everything. It simply isn't true. And it does a terrible disservice for anybody who thinks it will. The thing is, that hospice that took care of Bambi, they did a fantastic job. They knew Bambi never would have been able to be here, which is where she wanted to be, which is where Rick wanted her to be, without the support of hospice. It never would have happened. So we have to understand what hospice does and what hospice doesn't do in order for us all to move forward in a productive and constructive way.

But we need to provide the support that hospice can provide.

Karen Wyatt: It makes me think that we need an army of professional paid caregivers in every community to just to come in and be able to fill in some of the gaps.

Jessica Zitter: And we need to pay them a decent living wage, and we need to give them the respect that they deserve too, as they do this work, which is profoundly important work.

There's a lot of things we need to do differently. The professional caregiver workforce is really a downtrodden workforce and it's really not serving anybody well. These are very, very important people. They're very important. The experience of serious illness and end of life.

And we need to build up that workforce and make it a sustainable workforce where people feel respected and feel well valued for their work. And we're not doing that.

Karen Wyatt: Yes, absolutely. Well, I had the experience nine years ago when my mother died and wanted it to be at home, I came and stayed with her and it was only five days between the time I got there and the time she died. I was completely exhausted. I was a wreck and I went there thinking, well, I'm a hospice doctor. I know how to take care of someone at home. This will be no big deal. And I couldn't believe all the things I didn't know how to do that I'd never, never done before. How to turn her in bed and how to get her back in bed when she crawled out.

And it just so many things that I was coping with all by myself. Along with not sleeping. And so I have huge empathy now for the caregiver burden. I can't even imagine Rick doing it for nine weeks and the average caregiver doing it for four years.

Jessica Zitter: And, you know, I watched my husband's mother, my mother-in-law die a few years ago and she had, she was also home. She was on hospice probably for a couple of months and we had paid caregivers there. And then for the last six or seven days of her life, my husband flew over and his two sisters, the three of them in addition to two paid caregivers, and they were exhausted too. So you just, you can imagine what is really going on out there.

It's a serious crisis that we have got to solve. And by the way, right now, as we speak, there is a whole infrastructure bill that is being dealt with in Washington, where this whole, you know, idea of supporting caregivers, which started out at \$444 billion, then it went down to \$170 billion. And I'm not even sure where we are now, but it got whittled and whittled away.

And the sad fact is that this is something that is, I don't care if you're a Democrat or Republican. I don't care if you're white or black, I don't care if you're rich or poor. This is coming for all of us. And it really is shortsighted to not provide support in some way from a federal and state approach to support these people because it's all of us.

Karen Wyatt: And I'm sure you read the same article I did in a survey, the United States was ranked far lower than other developed nations in terms of the quality of end of life care that we're providing, which I think is embarrassing.

We have the most expensive healthcare system in the world, and I can't remember what our ranking was, but it was way down there.

Jessica Zitter: 44. I just, I tweeted that. I tweeted it out. We got a grade of C plus, and I said, I don't know about you, but I am not satisfied with this grade. It is unacceptable. It is embarrassing.

Karen Wyatt: It's totally embarrassing and it's unnecessary. There's no reason for it. We should be able to solve this problem with all the resources we have.

Jessica Zitter: You are preaching to the choir.

Karen Wyatt: It's a real problem. Yeah, I think it's going to, it takes a will, a public will, I guess, but a lot of education too. And I know actually you are doing that. Cause you just mentioned you're offering various workshops where people can watch the film and have discussion groups together.

So. Tell us more about what's available and how people could access that.

Jessica Zitter: Absolutely. Well, for me, the whole point of this, of making these films is for impact is to change the structures and the beliefs and the behaviors of all of those of us involved, whether we be caregivers, whether we be healthcare provider, hospice providers. Um, we're actually creating a program right now for clergy to really understand caregiver burden among their congregants and in their communities. The best place to go is to go to caregiverlovestory.com and see the different programs that we have.

We're just getting ready to take our family caregiver program, which goes about an hour and a half, and it's all virtual. And we have a wonderful family caregiver who is training to deliver that. If people want to sign up, the best thing to do is go and sign up for our newsletter at jessiczitter.com.

Sign up for the newsletter and you'll find out when that family caregiver workshop is going to become ready to go. We're working on getting that out there, but we also have programming for, as I said, the healthcare workforce, you know, medical trainees, hospitals, where we can go in and do the programming and the workshop that I mentioned, and people just need to go to caregiverlovestory.com and they'll see the different things that they could do now.

Karen Wyatt: And I also noticed you have a lot of resources on that website, caregiveralovestory.com that I was really surprised to see there. I didn't know, AARP has a site for caregivers that had even instructional videos for caregivers about how to do certain things. I feel like that's really helpful too just for people to know there's a place they can go and learn how to learn a skill that they may not have that they need when they're taking care of someone.

Jessica Zitter: Well, actually we're in conversation right now with AARP because they're very interested in using our film for all of their members. So, um, that's exciting.

They're doing some really robust work around caregiver burden, not only for the family caregivers themselves, but they're also trying to really help to change medical practice and hospital practice structure. So we're really excited to be involved with them as well.

Karen Wyatt: That's good to hear. Cause I feel like this is an all hands on deck situation where we need as many collaborators as we can get to come together to figure out how to solve this problem.

Jessica Zitter: Absolutely. I couldn't agree more. Absolutely.

Karen Wyatt: Well, I'm curious about what other projects you're working on because I know you're enjoying filmmaking, but what else, what else is in the future for you?

Jessica Zitter: Well, we're really excited to be working on our third film, which is called *The Chaplain of Oakland*. And it is through the eyes of my mentor and friend chaplain, Betty Clark, who is the chaplain on the palliative care team that I've worked with for a long, long time at Highland Hospital, it's really going to be looking at racial inequities at the end of life.

And how, you know, people basically die in this country based on their perceived race, the color of their skin. And I think that that's a very important topic. Um, we are really excited to explore that further and tell this important story through her.

Karen Wyatt: Hmm. Wow. I think I'm really interested to see that. And I think you're so right. This kind of media can be so impactful versus just doing talks or

writing articles. I think films are really powerful, a way to get a message across that people won't hear otherwise.

Jessica Zitter: I think so too. And that's been my experience with these two films. I really think it makes people pay attention. It's a little bit of a less threatening, more interesting way for people to get involved in a topic. And then once they're involved, once they're invested and interested, that's when they can go out, learn more and behave differently and in a more impactful way.

Karen Wyatt: Yeah. I have to say I'm just really impressed with everything that you've been doing. And I mean, in spite of working in the ICU and doing palliative care there as well, you somehow find the energy and the time to create these films and the workshops and programs you're doing. And you're just really a blessing to this end of life arena and all the issues that we're dealing with.

Jessica Zitter: Oh, thank you so much for saying that. It's been a haul to learn a whole new, different type of craft. And I'm really excited. I'm actually very excited to be part of a residency program, and really in this sort of cohort of very young, a lot younger than me, and talented filmmakers and really getting a lot of terrific mentoring around this new film that we're doing and learning more about the craft of making films. Not as easy as you would think it is. It's a complicated world out in documentary filmmaking, but really excited and hoping that it will create impact.

And if people want to come and learn more, you can obviously go to caregiveralovestory.com, but also please go to jessiczitter.com, which talks more about the broader scope of what we're trying to do and our program.

Karen Wyatt: And I highly recommend your book, *Extreme Measures* as well. Um, read the book and watch *Extremis*. Those two go together really well in terms of understanding some other issues around end of life care.

Jessica Zitter: Well, I hope people will read the book because the book, again, is a collection of stories, but it's really also a guide to people using stories to enter this world, to help people really figure out what they want to do for themselves. In fact, at the end of the book, I have a very robust appendix a, which is like a six step approach to, "What are you going to do next?"

How do you want to manifest or sort of position yourself to be in the place that you want to be when you come to the end of your life? And everybody, or your

loved one does. I think it's really a crash course for people who want to get a little bit more empowered to care for themselves and to get the care that they do.

Karen Wyatt: Well, I will leave links in the show notes so everyone can find your book and find Extremis, but where can people watch Caregiver, A Love Story?

Jessica Zitter: Well, it's best to go to caregiveralovestory.com for that. We have events that are coming up that are public events. The film is not out on a sort of public platform quite yet, and it will be eventually, but right now there are many opportunities to watch it.

Certainly you can invite me to come and speak or we can do, you know, there's many different ways to do programming with the film of people that are interested. And we're always happy to talk to you in the health sector.

Karen Wyatt: So it would be great for people to do private screenings, maybe even in their home and, rent the film to show to their neighbors and have a discussion group even in and talk about it

Jessica Zitter: There's an educational distributor where people can, if you know, if they want to go and just screened the film, it's usually through libraries and educational institutions, but there's ways for them to access it for private groups.

Karen Wyatt: Yeah. Well, I'd love to see it viewed far and wide because it's such important information. And again, I'll just express my gratitude to you for all your passion and your energy and for everything that you're creating out there.

Jessica Zitter: Thank you. Thank you so much. I mean, Karen, I want to thank you for kind of putting it out there and getting it to more ears. It really is helpful.

Karen Wyatt: Yeah. Yeah. Well, that's what I hope. I wanted to share it with all of our listeners so that they will start thinking for themselves, what will I do if I'm a caregiver someday, or if I need a caregiver and how will I handle that in the future? The time is now when each one of us needs to be thinking about that.

Jessica Zitter: That's absolutely true. Absolutely.

Karen Wyatt: Well, thank you so much for taking time out. I know how busy you are, so I really appreciate you taking time to talk to me.

Jessica Zitter: It's a pleasure, an absolute pleasure. And I hope to talk to you again sometime in the future.

Karen Wyatt: We definitely will. We'll check back in and I can't wait for your next film.

Thank you everyone. I hope you enjoyed my conversation with Jessica Zitter and that you feel inspired to do something in your community to help family caregivers. If you work for a hospital or a hospice or some other organization, you might consider hosting a screening of Caregiver, A Love Story along with a brief educational workshop for your community, because that's a good way to alert people to this issue and get their attention and hopefully to get other people inspired to come together, to see what can be done to help care for the caregivers where you happen to live. So remember, you can go to caregiveralovestory.com. There's information there about how to host a screening. And also what types of workshops are being offered. There's also a resource page where you'll find lots of interesting resources for caregivers and about caregiving that can be helpful. So you could send them to someone you know who is a caregiver. And then remember I mentioned the book by Jahnna Beecham and Katie Ortlip, *Living with Dying: Complete Guide for Caregivers*. That book would be a great gift if you know someone who is right now, a caregiver, or will become one in the future. It has tons of practical information for all of the tasks and the skills that caregivers need to do for their loved ones.

So I highly recommend that book. There was a link to it in the show notes for this episode. So thanks for being here again for another episode. And remember, I'll be back in one week with another interview for you. If you enjoy this content, please tell other people about the podcast and show them how to subscribe and listen.

And hopefully you've already subscribed on whatever platform you happen to use to listen to podcasts. And if you're so inclined, please leave a rating and review because that really helps the podcast move up in the rankings. So that more people who are searching for content like this can find it. We're really trying to grow the group of people here who care about end of life issues and want to come together to try to make a difference.

So, thanks again for all you do, and until we're together next week, remember that we're here for love. That's really kind of the bottom line for all of us. It's all about love. So face your fear, be ready for whatever life brings you next, and just try to love each and every moment of your beautiful life. Bye bye.