

# Daughterhood the Podcast

## Episode #74

### Caregiving, End-of-Life And Pop Culture with Shoshana Ungerleider, MD

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#### **SPEAKERS**

Rosanne Corcoran, Dr Shoshana Ungerleider

#### **Rosanne Corcoran 00:15**

Hello and welcome to Daughterhood the Podcast. I'm your host. Rosanne Corcoran, Daughterhood circle leader and former primary caregiver to my mom, who lived with vascular dementia for 12 years. Through that journey, I experienced every phase of caregiving firsthand, the heartbreak, the joy and the aftermath. That journey showed me how vital support and connection truly are, and that's why this podcast exists. No matter where you are in your caregiving journey, I'm so glad you found us, because caregiving is far too much to do alone. So welcome to Daughterhood the Podcast part of the Daughterhood community, where we empower caregivers to navigate both practical and emotional sides of caregiving together. Here, your efforts aren't just good enough, they're heroic, and here you're never alone. Join me in Daughterhood

**Rosanne Corcoran 01:07**

Before we dive in. I just want to share a quick note. This podcast is part of the Whole Care Network. The conversations you'll hear are here to inform and inspire, but they're not a substitute for professional advice. The views you'll hear are those of the host and guests and may not always reflect those of the Whole Care Network. If you have medical questions, please talk with your doctor and for legal advice, check in with your attorney.

**Rosanne Corcoran 01:29**

Dr Shoshana Ungerleider is a board certified internal medicine physician, science journalist and passionate advocate for compassionate end of life care. She hosts and produces Ted health and the New York radio, award winning podcast Before We Go and founded the End Well Foundation to make end of life a part of life. Shoshana regularly appears as a medical expert on CNN, MSNBC and CBS News, with bylines in time, USA Today, Scientific American and more. She executive produced the Oscar nominated Netflix film Endgame, funded the Emmy winning Extremis and produced Robin's Wish about the final years of Robin Williams's life. In this episode, we explore how popular culture and healthcare meet, how film, media and storytelling shape the way we see end of life, grief, loss and caregiving, and we'll hear Shoshana story of caring for her father through cancer, from documentaries to news headlines, including end Well's part in consulting on HBO s Emmy winning drama The Pitt. These cultural moments guide how we talk about death, support those we love and face our own final chapters. I hope you enjoy our conversation. Pop culture gives us glimpses of caregiving and grief, from celebrity stories to viral clips, but it often misses the real, lived experience. Why do you think there's such a gap between how society portrays end of life realities and what families actually go through?

**Dr Shoshana Ungerleider 02:59**

Yeah, ooh, that's a great question. You know? I think that? Well, I guess I always like to look back at, like, the context right of history and and look at like 100 years ago, for example, things look very different in most ways, I would say. But in the context of of death and dying. People died in their own homes, surrounded by people they knew, granted, they were much younger when they died, because we didn't have modern medicine, right, but children were used to seeing death occur. We, as a society, certainly knew kind of we expected it right, and saw it as a part of life, and had ritual around the dying experience, and knew how to talk about it, and knew what to do with a

dead body, for example. And as time went on and medicine modernized, right? And thank goodness it did. We lost our cultural ability to talk about death and dying, death was hidden away in institutions, right? Kids nowadays very rarely see, you know, their elders in situations where they're sick and at the end of life, unless you know you're visiting someone in the hospital or your parents want you to go and see you know a grandma who's who's at the end, it's the exception, I would say. And so you know how that plays out is that this has become such a taboo topic and on the healthcare side, because as you know, I'm a doctor, how that plays out is that people aren't talking about the end of life throughout their lives. They're not forming a relationship with their own mortality. And certainly, I have seen and the data show that far too many people. People in and around the end of their lives receive care that they don't want, they don't understand, and certainly doesn't, from my perspective, honor the life that they've lived. Because we don't talk about these things again in society, right? But also in health care, we see death as a failure, and we do everything we can to try to avoid failure. And you know, I saw that firsthand early on in my medical training, and said, This is not work for me. We got to do something different here. We owe it to our patients and their families to be talking about this, to providing the best possible care throughout life, certainly. But of course, at the end, right?

**Rosanne Corcoran 05:45**

It's, it's interesting, because I hear from a lot of people when they're talking to the doctors and they say, What about hospice or what about palliative care? And the doctors I've actually had caregivers say to me, they've, they've said to them, why you're giving up. You want to give up on them so soon. Yeah, and for caregivers, that's really hard to take, because you're trying to do the best by the person you're caring for, and you're bringing this question to the doctor, and they're saying, What are you giving up? How do we how do we deal with that?

**Dr Shoshana Ungerleider 06:17**

So tough, right? There's so many even now, misunderstandings, misperceptions about what palliative care is, what hospice is. So much of our work is trying to, you know, accurately, talk about that, make sure that people know that palliative care is a team based specialty of medicine where these folks are fellowship trained in how to care for people facing serious illness, and the data is very clear. You've had study after study show that the earlier that palliative care gets involved, right at the time of a serious illness diagnosis, they can wrap around the patient and their loved ones through nursing support, social work, pharmacy, chaplaincy, medicine to not only help relieve

symptoms, physical symptoms, but also think about the spiritual elements, the psychosocial issues, the financial issues around care that nobody seems to want to talk about and really enhance quality of life for anyone. You know, facing again, you know, a life limiting, typically, illness, and the earlier they get involved, the better the outcome is, right? Patients actually live longer, which is counterintuitive. They certainly have better quality of life. Families and loved ones are more satisfied with the care that they receive. And so we have a long way to go before you know, doctors really understand that there is a huge value. Oh, and not to mention, right? I don't think about cost very often, because it's not, you know, it's not how my brain works, but it also reduces cost. There's savings there when palliative care is involved. And then hospice, of course, is a type of palliative care for people who are foregoing cure, right? They want to just focus on quality of life and comfort however long they have left. But typically it's for people within the last six months of life. And so we try to get really clear about the terminology. But again, like it's from my perspective, it's going to come, the biggest shift is going to come from consumer demand. Those of us that have been caregivers or patients, you know, saying to our doctor, hey, I want a palliative care consult. I actually was on the phone, you know, this last weekend, trying to counsel a friend who was completely non-medical, who was helping her father in law at a hospital, a major academic institution that has a fantastic palliative care department, and it he's like, in his last day or two of life, from my estimation, and hasn't been seen by palliative care. Like, what are we doing? Like, what I it's, it's tricky, right? You know? And I can criticize people all day. The reality is sometimes illness progresses quickly, so we don't always have time, or families aren't ready, right? Or the patient isn't ready to say, hey, yeah, sure, I'll talk to palliative care, but we really need to be doing a better job all the way around.

**Rosanne Corcoran** 09:12

Totally agree. And then when they're not, and it rolls into that, as you said, sometimes things change quickly. So then it rolls into that really bad situation, and then hospice comes in, and then the patient dies, and then it becomes, you killed my father, you killed my mother. And it's that, it's almost like a whisper down the lane at that point where, yeah, it gets that bad rap. And I kind of thought when Jimmy Carter went on hospice, yeah, and he was on hospice for two years. Yeah, I kind of thought maybe it would change that perspective, but I don't think it has. Have you seen a change in that since then?

**Dr Shoshana Ungerleider** 09:53

Or no, I don't know. I don't I'm not sure it's funny, because I Rosanne, often hear the. Positive stories from hospice, and that's just, you know, the world that I'm in the end of life bubble, I very rarely hear, like all fully negative perceptions of hospice. There's most of people fall somewhere in between, where it's like, well, they could have done a better job supporting us. But all in all, it was a good experience. The reality is, I should know the statistic off the top of my head, but I want to say it's the majority of Americans. For majority of Americans, the median length of stay on hospice in this country is 18 days. Wow, right? When we know that people could be benefiting for months and months and months and then even, like Jimmy Carter graduate after six months and then get re enrolled, right and benefit from that support for months and months and potentially years, right? And so we know people aren't getting referred early enough, and my own father was only on hospice for a couple of weeks before he died. Things do progress quickly, and you don't always know when you switch from trying to aggressively treat the illness, like, in his case, pancreatic cancer, to comfort you know how things are going to go. But I do think that the more that we are willing to talk about this, to bring it up to our doctors, especially if you're in a caregiving role, it's, it's, it's definitely worth it to consider early on, you know,

**Rosanne Corcoran 11:29**

yeah, I agree. And it's sometimes, well, most of the time, it's fear based, yeah, like, everything, right? And it's much like, you know, there's lots of caregiving documentaries where you get to see what caregiving is like, like, you know, the last one was Bradley Cooper's right? Caregiving? Yeah, great. Was insightful. It was real. And I know those of us in the caregiving space, we all watched it, and I know from my random sampling of non caregivers, you know, have Did you watch it? Did you see it? No, I don't want to see it. It's kind of, it's, it's upsetting. I don't want to, I don't want to, you know, be bummed out. So it's reaching the people that are involved in it, but it's not reaching those that aren't, but will be at some point, right? So how do you think we go about trying to bridge that gap?

**Dr Shoshana Ungerleider 12:15**

Yeah, I know it's a great question. You know, at end, well, we've always believed that sort of pop culture is one of the most powerful, like levers for change when it comes to thinking about how we talk about and plan around and probably experience right illness and caregiving in the end of life, and certainly the healthcare system only takes us so far. I think the rest of the story lives in how we kind of make meaning, and how we talk about it around the dinner table, and how we again, like see it reflected back to us in

the culture that we consume. And so that's why I got interested in documentary film, really by accident, but and then, certainly now television in in this particular space, so three years ago, and well, started working with the USC School of Journalism a program at the Norman Lear Center called Hollywood Health and Society. And they've been embedded within the television industry for 25 years, something like that, to on any number of topics related to health and science. And we said to them, Hey, let's work together on doing research and then talking with showrunners, the writers, the directors of primetime television, to get them educated and aware of some of these subject, subjects that people tend to shy away from, whether it be hospice, whether it be caregiving, whether it be grief. And so we did for about a year, looked at a script analysis where we, I think, went back 10 years, and looked at almost all of scripted television to see where the keywords like hospice and caregiving and grief came up in what context. And then evaluated, were they accurate in their depictions, you know, was it acute, traumatic death they were looking at versus like death at home, who were involved in goals of care conversations in these television shows? You know, what was the ethnicity of the people portrayed? You know, all that sort of stuff. And, and what we found is that, you know, as you can imagine, it's wildly inaccurate, right? And, and we're not telling the more nuanced, diverse storylines that really people the public wants and could benefit from, certainly. So, you know, I've often felt like people of all ages, right, are primed with information about how life works by watching TV, and I can tell you, I probably 1000s of times at this point, talk to families in the intensive care unit in the emergency room who think that if their loved one's heart stops beating and they get CPR and intubation, they're going to walk out of the hospital the next day, good to go. And the reality is that's that's a rare occurrence. You know. Especially if you're older and more frail and have chronic illness, it's very unlikely that you will even potentially survive that hospitalization if that happens to you and so. But where did they get that? Well, on Grey's Anatomy, not to throw my friends at Grey's Anatomy under the bus, I love them, but you know, they are doing us all a disservice by not being accurate about that portrayal. So all that to say, we spent a good few years kind of educating the folks that make television about some of these issues. And we were lucky enough that shows like The Pit, which is on HBO Max, fantastic show about life in the emergency department, the most accurate healthcare show I've ever seen. And I would tell you anecdotally, you know, everyone I know who works in healthcare loves it because it's real. And got to, you know, almost every single episode of their season they had something about end of life, and we got to help, sort of influence how that was done, and I don't even remember what your initial question was, your thoughts, I'm hopefully answering it

**Rosanne Corcoran 16:09**

absolutely, absolutely, and it's so funny well, because you started end well in 2017 Yeah, and I love how you say Dying isn't a medical issue, it's a human issue, and it really does get lost in the shuffle. And it's interesting that you say it's so real because I tried watching the pit, and I was like, I'm out, because it was so real. I wasn't, I wasn't in the space to watch it yet. Yeah, I'm gonna go back, but it's wonderful to me, because we need that for the exact reasons that you say. And you know hospice pioneer Barbara Carnes, she always says people don't die like they do in the movies, yeah, and the closest thing I've ever seen for real representation was your friend Temby Locke, her from scratch. That's on Netflix. It was it. It went through the whole portrayal of life together, a diagnosis, caregiving, even the palliative care piece, yeah, and the frustration of being a caregiver and trying to get answers, death, grief, all of that. So I think there's ways to do it. But I think in those instances, for those that can't do the hard hitting, we're in the ER, right, people are coming in on gurneys. There has to be some sort of a bridge

**Dr Shoshana Ungerleider 17:37**

if, yeah, yeah, or it's just one more minor story line. You know, in a much bigger narrative, the healthcare shows sometimes can be intense for people that aren't used to that stuff, or just recently gone through something traumatic, the last thing you want to do is put yourself through that again. I get that I had a hard time watching it to tell you the truth. Okay, sounds like I've lived this for my whole career, like I don't need to watch this, but some of the the more kind of, either, you know, romantic comedies, or more narrative, you know, long form shows like, like from scratch, she did such a phenomenal job. And I, and I know, and I know Tempe well, and I know she's a huge advocate for caregiving and for hospice, and so had such a hand in the production and all of it, it was very important to her to get that right, which I think is, is fantastic shows, like a million little things, and this is us also right that were, you know, huge, huge hits have now ended, but they all had fantastic storylines that came in And out right, like at the end of a million little things, the medical aid in dying, storyline, which is beautiful with this is us, you know, the the main character, the protagonist, having Alzheimer's, and then doing some important advanced care planning conversations around the end, like that. I think that was so artfully done. And, you know, kudos to them. I know both of those. I know of what those directors who were involved with our Hollywood Health Society project, and I'm just delighted that they were willing to do that,

**Rosanne Corcoran 19:13**

you know, yeah, and it was so well received, yeah, it was because of the story. And and all of a sudden everybody was talking about it, and you get those flashes of, maybe this is the break, right? Maybe this is maybe this will turn the tide. Do you know it's like when, when they do game shows, and then everybody wants to make a game show? It's like, maybe somebody will want to continue this process of real life storytelling. Is there a way you can share that information that you found when you went through all those shows?

**Dr Shoshana Ungerleider 19:47**

Oh, yeah, we wrote a white paper about it. Did you clearly, we've not done a good job getting it out there, yeah, and it was a couple of years back, and we sort of shared it at our conference. We put it out a couple articles. Came out about it, but, you know, continuing to talk about this, and we didn't, we just finished some more research, looking forward at a million little things, and then the general art of Swedish death cleaning, which was a reality show on Bravo, and looking at how that shifted perceptions. So more to come, you know, in terms of the information there. But I do think, you know, our project has ended with them, but we're wanting to do more of this because, you know, it's our news cycles move very quickly, and there's a lot going on in the world. So the more we can keep kind of beating the drum and talking about this stuff, the better.

**Rosanne Corcoran 20:37**

Yeah, yeah. Well, and that's, you know, we see these clips on social media of, you know, Stephen Colbert saying the worst thing that ever happened to him was a gift, and Andrew Garfield talking about the grief over his mom. I mean, everybody felt that right grief is and grief is the price we pay for love is now like a mainstream phrase, but it seems like people still want grief to be in this little linear package, which we know it's not. Do you think these viral moments create a lasting cultural shift, or do you think they come and go so quickly that they can't?

**Dr Shoshana Ungerleider 21:15**

I don't know. I think we'll only be able to look back in hindsight and know whether or not some of these made a difference. You know, one, one show that I'm obsessed with is Anderson Cooper's podcast. All there is me too. I was just completely blown away by him, his vulnerability, because he's such a different person on the news than He is in this podcast, and he's giving so much of himself and his own story in it, especially

season one, his conversation with BJ Miller, just like totally blew my mind. It was I think that came out in 2022 but, you know, I think the more that we see these cultural icons willing to share their own journeys with the world that normalizes these conversations. And the hope is that the kids that grow up around that with parents who are listening to it, who are talking about it at the dinner table, who are then talking about it at Thanksgiving, you know, with their extended family and their communities, mean that's how I believe that we shift the cultural willingness around this stuff. But I don't, I'm not a researcher myself, day in and day out, so I suspect there's somebody out there looking at this from a from a data perspective or a scientific perspective. I just don't know. I'm not even sure what metrics you would look at to be able to evaluate that. But culture change is really hard. I mean, we know that it end well because we're constantly being asked, well, how do you know if you're making a difference? Like, well, I don't know, like, we reach millions and millions of people every day with our content. You know, the thought is that people are consuming and they keep coming back for more, and we sell out our conferences. But we certainly need more people, you know, involved as part of this movement. So it's been an interesting journey. I will say

#### **Rosanne Corcoran 22:59**

I would think it would be. And you know what inspired you, what made you say, I'm going to start this foundation, I'm going to start this nonprofit, and I'm going to try to change the way we talk about this. What because it's not, it's not like, it's not like, Okay, I'm just going to start this thing. Like, how did you come to that? And what was that? What was that like for you?

#### **Dr Shoshana Ungerleider 23:23**

Well, I started residency, so after medical school, thinking I wanted to be a cardiologist, because I'm fascinated by pathophysiology, the study of disease. I just think, you know, in general, it's, it's really interesting, and cardiology is one area in which it was just really cool. And I think my second month of Internal Medicine is my intern year I was in the ICU taking care of really sick people. I had no idea what I was doing. It was so scary for me, because I, you know, I just, I was, like, a baby doctor, yeah. And then, you know, a few weeks in, I'm like, Okay, so who came in overnight, you know, showing up in the morning around at 5am and it was 10 people in their 80s who had maybe widely metastatic cancer or end stage kidney failure or severe diabetes and coming in essentially in a coma. And I'm like, oh, okay, so these people are intubated here. Why? Why did we do this? Like, what? What were the conversations that took place? What led this person to end up in the ICU last night or this morning? Whatever it was, you

know? And I realized that there weren't conversations that were taking place in the hospital before the person got to the hospital throughout their journey with their doctors who've known them for many, many years, about, you know, how they'd want to be cared for if they were to become, you know, sick. And so that was very obvious to me. And then there was this mismatch of expectations, right? I think patients and families were. Like, Oh, well, so mom's gonna get better and go home again, right? And the answer was often, like, no. Like, we don't even know if she's gonna survive till tomorrow. How is that getting lost in translation here? And it's because we don't take the time really to be talking about that stuff. And then further ask the question of, like, well, so you're here in the ICU getting very aggressive, invasive treatment, which you know, by the way, by default, that's what you will get in this country if you show up to a hospital, unless you opt out of that or have someone speaking on your behalf, that that's not what you want. I think people don't realize that, and especially if you're older, it's really important to be thinking about that and talking about it, right? And so I was seeing that again, like, we just, we weren't talking about this stuff. People were getting care that really they didn't understand or want, right? I said that in the very, very beginning, but it was, it was shocking to me, and I would often bring that up to my attending on rounds, like, well, so you just told me, you know that this person is very, very ill with a poor prognosis. Have we talked to the patient about that? You know, maybe we think about something else here, if, if more, more and more and more treatment, because we can always offer more, that's the issue with, you know, medicine today, again, it's wonderful if, if you can get better, right? But for some people, that may not be what they want. And there's there's trade offs to more and more and more treatment. And if your time is short, it may, you may not want to be spending it in the ICU surrounded by strangers. So finished residency, continue to be really interested in, how do we make sure that all doctors, not just the palliative care doctors, but all of us, are trained in how to have difficult conversations with patients, to break bad news and talk about goals of care? Turns out 70% of physicians are not trained in how to do that, so that's a huge miss, and the incentives are just not aligned for that to happen often enough, and certainly for us to teach it. And then, you know, more broadly, as we've been talking about, you know what? What is the societal shift that needs to happen? Because I, I went to all these conferences when I had more time after residency, and was trying to learn about, well, who are the players in the world of hospice and palliative care and policy around all this? And it was all phenomenal, people who'd been doing this work for 20, 30, 40, years and have made huge strides in sort of making palliative medicine a field. And all of this, we were doing so much preaching to the choir about like, how we needed, well, we need to shift the cultural conversation around end

of life and serious illness care. And I'm like, Okay, well, you don't do that by talking to each other all day long, right? And so being in the Bay Area, San Francisco, you know, there's interesting, you know, tech industry, lots of entrepreneurs, lots of funders, you know, VCs, philanthropists, designers, you know, a lot of health tech going on. And I was seeing these cool conferences pop up that were really interdisciplinary, interprofessional convenings. And so I said, Well, what if we put on a conference about end of life, that is, you know, where we have designers speak and artists and patients and folks from the media and policy experts and, of course, doctors and nurses and social workers, but it's not going to be a physician or health care centric conversation, and so that was the first end Well, I called a bunch of friends who were willing to speak. They all said yes, which I was shocked about. And we sold out, like three months in advance, and had hundreds of people on a wait list to come to this random conference about end of life that no one had ever heard of before. And so we did it again the next year, and doubled in size and sold out again, and had celebrities come and speak. Because getting back to this conversation about culture change, when we see people that we look up to, that we've seen on TV or in film talk about hard stuff, it makes it maybe a little easier for us to be able to do that ourselves, to normalize those conversations. And so from there, you know, we've started putting our content on social media and reached, you know, 10s of millions of people. And that's when I thought, well, there's something here. I'm giving you a very long answer to how end well, started that sort of and in the midst there, I, you know, got involved in a couple of film, documentary film projects, which kind of showed me the power of media and narrative storytelling and further, kind of enriched that conversation about, you know, shining light in some of these dark places that we only experience it at certain times in our lives, but are so, so, so important to be thinking about and talking about throughout our lives.

**Rosanne Corcoran 29:43**

Absolutely. And it's so hard. Like you said, over 70% of the doctors aren't trained in it. They don't want to deal with those emotions and those questions. And actually, Dr Jessica zitter said that to me, they don't want to deal with that. And then. Also don't want to be the doctor that said, you know, he's got a month to live, and then it's six weeks, and they're like, Well, you said he was going to die in a month. Like, there's so much that goes with it. It just leaves us as caregivers and as patients in the lurch, because you can't get that information then, and it just makes it difficult. But you took your experience with your father and his diagnosis of pancreatic cancer, and turned it into this beautiful, honest, heartbreaking just light of a podcast called before we go last year. It was eight episodes. I listened to all eight episodes. It was the most real thing

I've heard. And you went from caregiving through, I'm not, I don't want to give it all away, because I want people to listen to it, from caregiving through twists and turns of things, to end of life. And one of the things, that of the many things that came out, was when you had moved, you had you wanted to move to be closer to your dad, and you said I had to ask my husband to leave his favorite house on his favorite Street, in his favorite neighborhood in his favorite city. Yeah. And as a caregiver, looking at that, it's not we don't provide care in a vacuum. Everything that we do involves our family, yeah. And you know, when you said, I was like, oh gosh, it was so heavy. But what did you feel in those moments? What? How did you wrestle with that, and what did that reveal about caregiving in your family and yourself in those moments?

**Dr Shoshana Ungerleider 31:35**

Oh, my goodness, that's a great question, and thank you for listening to it. I really appreciate that. And I was very kind of you. I sort of felt like I had to tell this story, you know, because I was so shocked by so many elements of it, even though I am an expert in a lot of this stuff and talk about it all the time, and know intellectually, all these things are really, really hard until you really, truly experience it for yourself. It doesn't really hit home, and you don't realize the heights of these, of these obstacles that that you you face. And so, yeah, that we were so lucky because the caregiving journey for for us was really clear. You know, I don't have children, and so I have flexibility in my life and my career. So did Ed at the time, like we really were able to drop everything and be there for my dad. And for most people, I know it is not that straightforward, right? You live maybe 1000s of miles away. You have kid responsibilities, job responsibilities. We had the best of circumstances when it came to that stuff, and it was still like an insane experience, right? It was so hard every single day, and it just, we talked about this before, but like, you just don't realize it. You don't realize until you're in it, that this is the stuff that's important in life, right, to show up for the people that you love and to be there. But our society doesn't value it. We don't create space for it. We don't have enough support for family caregivers, and so I just again, I'm so grateful, you know, to Ed for his willingness to be part of this journey, and I think that throughout the experience, and thank you for not giving away all of the details of my story. But I will just say, you know, I very much faced my own mortality throughout the journey, which was complicated, because this whole conversation about how do caregivers care for themselves throughout it, because the data show the caregivers actually face early mortality, yes, because they forego preventative screenings, going to the doctor, all sleep, all the things they need to be doing to take care of themselves. And so that was a fascinating journey for me in like, creating boundaries around that, because as a

doctor, we give and give and give and give, and then as a woman, right? Yes, not. It's not to say that men don't also give, but like, you know, we tend to be very self sacrificial in our lives, whether you're a doctor or not, right, right? And I bumped up against, really, some of the biggest challenges I've ever faced with, like saying to my own father, like, Dad, I'm your daughter, I am a doctor. I'm not your doctor, right? You need to listen to what your doctors are telling you. I'm not going to step in and make changes or get in the middle of that. You need to respect the fact that I am, just like every other family member here and going through this, and then, in addition, facing my own major health challenges. And so it was, that's part of the reason I, you know, want. Do the podcast, because I just were so many weird, unexpected things that came up that it was and I learned so much through that whole, through the journey, that I just felt like, if, if, if I can share even just a little bit to help others, it's really important.

**Rosanne Corcoran 35:18**

Yeah, and you did, I mean, mission accomplished, you did. It was enlightening. It was informative. It was just, it was beautiful. It was just beautiful. I even though it was, it was rough at times, yeah, it was still like, Oh, my goodness. I mean, you know, when you said you were leaving yourself messages in your phone throughout different times, it was like, Yeah, I I see you, I get you. I understand. Because you don't know what's happening, and you don't know where this is going, as part of it, would you in hindsight looking at it, you know, bring that to the front of the of the discussion before the we can try this, and we can try that. The balance of, what does this look like, and what is this going to give him, versus, if we don't do anything, how long can he live? How well can he live? How do you have those conversations when you're in the beginning like that.

**Dr Shoshana Ungerleider 36:21**

It's so disease specific. So that's what I would say about that. I think if my dad had been diagnosed with, say, prostate cancer or something that tends to be slightly slower growing, lung cancer, even it would have been a different conversation. Pancreatic cancer, you know, his the prognosis at stage four is so poor. It's one of those cancers that you just never want to get. It's the bad one. And so in his case, which was unique because of the genetic mutation that we learned of, we knew that there was a decent possibility that he could be eligible for targeted therapy, meaning an oral medication that could prolong his life with good quality of life if he were to, if he were able to get through chemo. So that's why we pushed him. We decided, as a family that was the right thing to do, because of the hope of that. And so in hindsight, of course, I would have said, Nope, let's go to Hawaii. Let's enjoy the time you have. You just don't know,

right? I think we made the best possible decisions with the information that we had. We, I think made the wrong ones, right? Do you in many, many ways? Oh, absolutely. We all suffered, and my dad certainly the most throughout the whole experience. I didn't, we didn't know that it, you know, he was going to have such a hard time with his appetite and weight loss that his mental health was going to suffer as much as it did, that chemo wasn't going to work, right? We had every hope that it would, because he had the best doctors. And so it's just one of those, one of those things that I, I wish you know, we could, we could have seen the future,

**Rosanne Corcoran 38:10**

yeah, but it's like what you just said, and it's very important you made the best decision with the information you had, yeah, at that moment, yeah, yeah. And you were just trying to, you were trying to go with it. How, how are you dealing with your grief?

**Dr Shoshana Ungerleider 38:27**

You know, like you said earlier, it comes in waves. I sort of see it as like the ocean. Sometimes it's calm and sometimes, you know, little waves and sometimes big sneaker waves come out of nowhere and grab, yeah, I think because I was able to be there with him throughout the entire journey, basically, I sort of, I didn't know, you know what was coming, right? I didn't know when the end would be. But I have seen this illness in my professional life so many times. I did have a sense of where this would go, and so that wasn't surprising to me. And I feel like I got to walk beside him throughout it all and metabolize some of my grief over time. I think I was struck by so much anticipatory grief, you know, yeah, like so leading up to it all, I felt so much, you know, pain and sadness. Because again, like I did have a sense of what was going to go on, that it made the grief after he was gone easier in some ways for me. I don't know that that would be the case for anyone else, but that's just how it happened for me, and honestly, I just felt so much relief, you know, once, once he had died, because it truly was a horrible experience for him, and watching him suffer in that way, because he had been so healthy his whole life, and this just essentially came out of nowhere. For him so and moved quickly. So, yeah, it's, it's been now two and a half years since he died, and I think about him often. And, yeah, Grief is a is a wild journey, for sure,

**Rosanne Corcoran 40:18**

absolutely, definitely, not linear, nope. So before I ask you my final question, season two of before we go, dropped on September 18, what can we expect for this season?

**Dr Shoshana Ungerleider 40:31**

Well, it's different than season one. Season two it's 10 episodes. Each episode is its own narrative. Arc tells its own story, and we bring in wonderful experts. You know, I'm the host, and I am around in the show to guide the conversation, but it's not about my story. This season I really wanted to tell to talk about, you know, other people's experiences with caregiving and grief, and we have subjects around suicide subjects, around living with a terminal illness, how to think about your future self. We have an episode on on psychic mediums of all things. So we kind of span, you know, toxic costs of health care. You know, many, many subjects. And we have some celebrities on and well known experts and then less well known, everyday folks who are sharing their experiences. So I'm a little nervous because it is a very different format from season one. So I hope that you know that the wonderful community we've built around the first season will stick around with us, and I welcome anyone's feedback.

**Rosanne Corcoran 41:40**

There's not a doubt in my mind that it's not going to be great. I mean, I just I'm really looking forward to it. So for my final question, even with all that you knew and all the support that you had and everything that was going on at that time, what advice can you give to a family caregiver approaching this end of life they're squarely in this end of life space?

**Dr Shoshana Ungerleider 42:03**

Yeah, well, you know, I think I was telling you this earlier, I got a call from a friend who I hadn't talked to in a couple of years, who said, hey, you know, I know you're you know about end of life stuff. My father in law is very, very sick right now. What? How do I think about this? Like, I think he may only have a few weeks to live, and he's in the hospital right now, and I said things you got to know are, number one, ask for a palliative care consult if he hasn't had one. It's very, very, very helpful, if nothing else, just to have a thorough family conversation about what the future may hold and what's possible, and certainly getting your head around prognosis is helpful just for planning purposes. I think one thing that surprises most people is that hospice care is typically provided at home or in a nursing facility, and if it is at home, it's provided by family and other loved ones, right? You do have a hospice nurse that's been essentially assigned to your case, and they come out and do an intake for maybe a couple of hours, but you only see them maybe once or twice a week, if you're lucky, in person, and it's for very short periods of time you really are left to be the nurse and caregiver for your loved one, and most people are not trained in how to do that, and it's a huge, huge responsibility.

Administering the medications alone is somewhat challenging if you don't know what signs to look for, and it's you know your your loved one is having a hard time. I had a hard time doing it, and I'm a doctor. I had to call my friend who's a hospice nurse in the middle of the night to be like, here's what his breathing sounds like. What do I do? Like, I was even confused with it all, because it's not what I do day in and day out professionally. So like, if I'm having a hard time, my goodness, like, I can't even imagine what the average family member out there or friend has to do. And so I think having realistic expectations about what's possible there is, is huge. I mean, I guess I could, there's a million other things I could say. I in my experience, was the one who gave my dad his final dose of medicine before he died, and I've only since learned that a lot of people feel very guilty about that. They think that somehow they've killed their loved one. And I even felt like that, so like it's a very human thing, and we got to give ourselves Grace about the fact that by definition, you know, hospice is about comfort and quality of life, so any medication that you're giving your loved one is to make them feel better, be more comfortable, and. And they're dying, their body is shutting down, and you're giving them a gift by making them comfortable with medication or whatever else you're doing, and by no means are you, are you the one that's taking their life? And so I think we don't as a healthcare system talk about that enough. Certainly. I've talked to my friends who are hospice nurses about that particular issue, and they don't always in their kind of orientation process with families. Always talk about the fact that that's actually a really, really common thing to feel guilty about that. And so I just want to tell anybody out there, if you were the one that gave your loved one their final dose of medicine, please don't feel guilty. It really is such a beautiful thing to be able to offer a family member or loved one at the end of their life, even though it's really hard.

### **Rosanne Corcoran** 45:49

A big thank you to Dr Shoshana Ungerleider for being my guest today. For more information about the end well project, visit [endwellproject.org](http://endwellproject.org), and don't miss Season Two of Before We Go Available anywhere you listen to your podcasts. I hope you enjoyed today's episode and found something helpful, whether it was information, inspiration, or even just a little company. You'll find the full transcript and links to resources mentioned today@daughterhood.org in the podcast section. While you're there, explore more of what daughterhood offers. We're more than a podcast. We're a nonprofit community providing free services and support for caregivers, including nationwide virtual support groups. We call circles. On our website, you can register for a circle, sign up for our newsletter and read our founders blog. Don't forget to subscribe and review us on Apple podcasts or wherever you listen your reviews help other

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