

## Podcast 353 Johnson-Young Transcript

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Karen Wyatt: Today, I'm very excited to welcome my guest Jill Johnson-Young. Jill is a Licensed Clinical Social Worker and an internationally renowned speaker, author and co-owner of Central Counseling Services, a large, multi-therapist mental health center. Jill is passionate about helping people navigate the loss of loved ones and in debunking the myth that there is one right way to grieve. She is the author of numerous books about grief for adults and children, including her most recent book, *The Rebellious Widow: A Practical Guide to Love and Life After Loss*, which we will be talking about today. And you can learn more about Jill and her work at [therebelliouswidow.com](http://therebelliouswidow.com) and [JillJohnsonYoung.com](http://JillJohnsonYoung.com). So Jill, thank you so much for joining me today.

Jill Johnson-Young: Thank you for having me. I'm so excited to be here.

Karen Wyatt: Me too. Ever since we met on a zoom call and I got to know a little bit about you, I was just excited to have you as a guest and to hear more about your story and talk about grief because you have so much wisdom to share in your book.

Jill Johnson-Young: Thank you. I kind of live in the world of grief and have my entire career.

Karen Wyatt: Yeah, I understand that. I mean from reading the book - you're trained as a therapist, of course - so you have professional expertise. But you have also dealt with your share of grief and loss as a two-time widow - I guess I can call it that - in your life. So I thought maybe we could start by having you just tell us a little bit about your own story.

Jill Johnson-Young: Sure. So, in my career, I was the first social worker for our local AIDS project before we had the name AIDS, and when Ryan White was still very much part of the living world. I was part of the losses that we had there, which were numerous and nonstop. And then I was able to... In my career as a social worker, you get to sort of meld and move. And it's a delightful career to have for people who don't like to be locked in, which I don't. So, I was able to do hospice in two states, as well as now in my private practice to be able to specialize in grief, and loss, and dementia, and end-of-life, and chronic illness - all the fun stuff. And in all of that, what I discovered, in addition to my own life with the loss of both of my wives, is that most therapists are not really great at grief. In fact, some of them really suck at it. And I'm sorry guys, it's really true. And they don't know what to say. And so they say all the things that nobody should say. So I was married for 23 years to Linda, and together we adopted our two children. And we were in the process of adopting a third when she died. We lived for a time in Florida where she discovered she had breast cancer. And you know, I will say thank God we were in Florida at the time because we worked for a company and I worked for the hospice. And we got

all the right care because she was found with 14 positive notes and she was already stage three. And that was a routine mammogram. So ladies, get your mammograms. I'm going in for mine next week. With that, we were told she was going to be dead by December, and that was in July. I remember like this sort of tunnel opening up and the floor feeling like it wasn't really firm. And then I took a look at Linda's face, and I just knew that it needed to be about her. So she looked at the doctor and said, I'm going to focus on beating this. Jill's gonna manage the illness and be the social worker, and we're gonna beat this thing. And she did, she died cancer free. But we were in a car accident once we returned to California and adopted our kids. And she shredded her ACL, and she ended up in surgery and after surgery. She got what they called pneumonia over and over again. And we were in the hospital one day waiting for a pulmonologist appointment that never seemed to happen. And the hospitalist pulled me aside and said, here, take a look at this. That's when we had light boxes - for those of you who remember those when we actually did real X-rays, and they went on up there - and he said that's not pneumonia, that's pulmonary fibrosis. She's gonna die. Take her home. And that's how we discovered she was terminally ill. So with pulmonary fibrosis you get, at most, five years. And she made it to 3.5. And the pulmonary fibrosis came from her chemotherapy. So ultimately the treatment for the cancer that saved her life and gave us that time is what took her life while she was ill. She was very much the nurse that she always was. We gotta plan, we gotta get ready. She fought like crazy; she worked until six months before she died. And she started telling me, after hospice started, "You have to marry Casper the hospice nurse." And I said no we're taking care of you right now. And Casper said, you know hospice comes back and does grief work; we don't come back and marry people.

But she told everybody. She told the minister, the kids, my mom, everybody - this was the Linda plan. She had a three page bucket list, and Jill marrying Casper was on that list. And after she died, it turned out she was right, and I did marry Casper. And it was a very good match, and we were very much in love. I broke all the freaking widow rules. I pissed off a whole bunch of people. And then about six months into our marriage, Casper started with symptoms that made no sense whatsoever. They were global symptoms. And that turned out to be Lewy-Body Dementia. And Lewy-Body Dementia is a no-win. All the dementias are - all 12 of them - you can't survive them. But early onset Lewy-Body Dementia means you have five years or less. And she got three. And she died in 2013. And part of my crew that took care of me while I was taking care of Casper included Stacey, who was the mortician who took care of and met with Linda to plan her funeral and then came and took Linda at the time of her death. So she couldn't say she wasn't warned because she saw all the crazies in our house, including us and all the pets and all that, everybody. She came back because she started seeing blogs I was writing about trying to get Casper diagnosed and trying to take care of her. And I had a smaller group of people because I've lost people who disagreed with how I grieved and disagreed with me being married again because, apparently, someone thinks it's a democracy and they get to vote on whether or not you get married. So, after Casper's death, Stacy and I started seeing each other and now I'm married to Stacy, the funeral director. And we've been together eight years as of this month. How's that for a story?

Karen Wyatt: What an incredible journey. It's mind-boggling, and I can't imagine - these dual caregiving journeys must have been so intense for you back to back.

Jill Johnson-Young: Exhausting - they were absolutely exhausting.

Karen Wyatt: Yeah. And you saw different types of caregiving, I would think also, because Linda with pulmonary fibrosis and Casper with dementia - different issues you were dealing with.

Jill Johnson-Young: Very different issues. Although Lewy Body Dementia - bless its heart - ugliest dementia on the planet. My apologies to all the other dementias because they're ugly too. But Lewy Body has Parkinsonism, and so you have falls and you have trouble swallowing and you have all the other things that go along with Parkinsonism. In addition to dementia, in addition to psychosis, which is the number one feature of Lewy Body. So she'd have moments where she was completely out of it. She had moments where we were in different periods of time. I woke up one morning, and I was told her parents had been there because we had a flood downstairs. And I said, well that's inconvenient because I've been sleeping without any clothes on. I hope they didn't come up here because, you know - you have to have a sense of humor when you're dealing with this stuff. But then they snap back. So people with Lewy Body remember the loss of memory. They remember the crazy, they remember what your face looked like when that was going on. They remember all of it. So between the two of them it was a lot of energy. And that's why people who are widowed after having long illnesses wrapped around them do tend to remarry and remarry sooner because they did all their grief while they were caregiving.

Karen Wyatt: Yeah. And you already alluded to the "widow rules." And then the title of your book being *The Rebellious Widow* - I assume that's where it comes from. But I'm just curious to have you explain what the widow rules are that you encountered.

Jill Johnson-Young: The widow rules. They just suck. They really do. And what they are is basically how everyone else wants to manage the widow managing her grief for their comfort. So, don't smile too soon. Don't smile too often. Don't look too sad though, because that makes us sad. Don't look too gloomy because that makes us feel bad for you. Don't say their name. Oh wait, do say their name because then we'll think you've forgotten about them. And for God's sake, don't remarry. Widowers, please remarry. Widows, not so much. There's a huge dichotomy. And it's crazy-making because, unless you've actually walked the walk, only you get to decide that. It's like a scale for me. There's the Betty White, and then there's the Jill. And then there's everyone else in between, right? Betty said she had Alan; she didn't need anyone else ever. She had her dogs. And I obviously needed someone else, and it was well-matched. But I also need my dogs. You can land anywhere, but nobody should be able to tell you how to grieve. No one should try to say there are five stages because there aren't. No one should tell you that you have to finish five stages and get to acceptance because that's not reality. That's anticipatory grief before someone dies. And the widow rules are designed to make you grieve the way it makes other people comfortable and it's not fair to widows.

Karen Wyatt: Yeah, that's such a good point. It's other people observing your grief process and wanting to control it or direct it a certain way instead of allowing you to have your own experience.

Jill Johnson-Young: I left one job after Linda's death because I literally couldn't get any peace at work. Once I returned to work, I had people coming by, telling me that I didn't look sad enough or I look too sad or I shouldn't have returned so soon or I should be doing more to keep myself busy. I'm thinking, I've got two-and-a-half kids. I'm in the middle of an adoption of a 16 year old from group home care. I think I've got enough on my plate, folks. And I emailed my boss one day and said, I'm gonna put black crepe paper over my cubby and I'm leaving for the day. I can't tolerate this anymore. These people need to stop.

Karen Wyatt: Yeah. It's very interesting judgment, and I sometimes wonder if it comes from people who themselves haven't experienced grief. They just have ideas from maybe a movie they saw or something they read that makes them think they understand what this is about.

Jill Johnson-Young: Yes 100%. Dementia is The Notebook - that's everything you need to know about dementia, which is utter BS. I hate that movie. Love James Garner, hate that movie, right? Because it makes expectations that are just so wrong. And then, you know, with grief, what you should imagine if you want to know how people who are grieving or feeling is that scene in the cemetery with Sally Field in Steel Magnolias, right? Just hit her, right? Because there's tears and there's sadness and there's anger and there's laughter and there's memories and it's all just wrapped up - that's real grief. But if you are in a lot of the widow groups, you'll see people say, if I hear one more person refer to my spouse's death akin to their divorce - when they got to choose that - or their dog or their cat. Grief shouldn't be compared. My loss of my wives is not the same as someone losing a child or a parent. I have lost a parent as well. And in-laws. That's a different kind of loss. But the way I look at grief, is it's something that you deal with and you march through and you finish and you move into whatever new life you want to create, but you get to create it.

Karen Wyatt: And you explained in the book that you and Linda actually spent time together while she was alive going through anticipatory grief together, talking through it, working through it. So it's not like grief begins right at the moment of death and carries on from there. You'd been grieving for quite a long time, probably already grieved when she first got cancer to a certain extent and then - so you had already done a lot of the work of grieving and you got to do it with Linda and process with her, which had to be amazing in a way.

Jill Johnson-Young: It was such a release, and it was an incredible sense of connection because when your intimate partner is dying, much of the intimacy dies before they do, right? And that's one of the topics I like to do speaking gigs on is, let's talk about the loss of intimacy so that people who are working with couples who are dying...Because when

one person dies, the couple dies of course. When a couple is dying, we need to be able to talk about that and foster whatever kind of physical and emotional intimacy they can still connect to - we were able to do that. But that's because Linda was an ER nurse and she thought that way. And I was able to do that with Casper because she was a hospice nurse for God's sakes, right? Every hospice should have a nurse named after a friendly ghost.

So we talked about it and in the times where she was more together than not, which was most of the time, she would talk about her death. She would talk about what she wanted for me. We would talk about my future. We would talk about the fact that this wasn't fair because it wasn't. Three years is not long enough. And both of them were dead by the age of 58, which is how old I'm gonna be next week, which is a little bit weird. So yeah, it gives you a sense of, I get to take them with me because they've told me how they want to be remembered and what they want me to take from them into my new life. I treasure that.

Karen Wyatt: Your book and your story have caused me to think so much back to my hospice days when I really feel like - to a large extent - we were not very aware of the grieving, the anticipatory grief of the spouse. I think we were tuned into, oh, the patient is going through all this loss as they're approaching the end of life, but I'm not sure that we paid enough attention to the spouse and I feel bad about that now. But I think that's very common. I think oftentimes the spouse is overlooked.

Jill Johnson-Young: It's 100 percent. The intimacy and the physical needs of the couple as a couple... I actually did some research on it now. It wasn't university research, it was, I have people around the world on my list. And so I sent them all the same survey and I sent it to people who work in the profession as well as grief people as well as people who had lost spouses or were losing spouses. And 100% of the spouses said, I wish someone would talk about this. And 100% of the providers said, there's no way I'm bringing this up. It's gonna feel weird to me, and there's that divide. And at our house, it did come up because we had Casper as our nurse. And so Casper fostered it the week Linda was dying. She was downstairs in our living room at her choice. She said, she's going to be gone by the end of the week. You need to crawl into bed with her and you guys need to make some body memories. Nobody says that. And then when Casper was dying, I went to work and I came home one day and our bed was literally tied to the hospital bed. Both beds had been pulled out from the sides of the room. So there was walkways on both sides and that happened because Casper told the nurse there's gonna come a time soon where I won't be able to hold Jill and I need to be able to do that until the last possible minute. But because of Lewy Body, she had a sleep disorder that could be really dangerous. So we had to have the hospital beds. So some nights I could protect myself. It's classified as lethal now in the ICD, as a matter of fact. But on the good nights and then the good afternoons, we could drop that barrier down and we could snuggle either across beds or she could crawl into the big bed with me. That only happened because she as the patient spoke up.

Karen Wyatt: Wow I love that term body memory. I think that's a great term to use.

That makes it simple for people to understand why that's important that you have many different types of memories with your loved one. But those memories of physical touch and closeness are precious and, as we've said, they're neglected so much during this end of life process.

Jill Johnson-Young: And they're so important during the grief process, right? That's why when I know couples who are dying or even people who are losing other family members, first thing I say is get the camera and take the pictures of hand holding; hold hands and take the picture. Not so much the gel goo to make the hand thing because that's gonna eventually break. Take the pictures. Take a video of you guys holding each other and telling each other some stories. Those will make a difference in the hard moments, especially between 2:00 and 4:00 AM when everyone else is asleep. Alright, so you've got that.

Karen Wyatt: I'm so touched by this because right now in my life, I have a friend who's dealing with a brain tumor and so I'm observing her and her spouse as they're going through this process together and wondering - and sometimes it's hard as a friend on the outside to know - what do I say? What could I tell them to make this journey easier? Because I feel like I have a pretty good understanding of how it could unfold and things that might happen. And I know it's all completely unknown territory for them. So what should I tell them? How should I talk to them about these things?

Jill Johnson-Young: Ask them if their needs as a couple are being honored by their hospice, and if they don't have hospice yet, make sure they do sooner than later. And make sure it's a really good hospice because you and I both know there are a lot of hospices that are not the way they should be. So that's important. That's part of why in the book I wrote about how to fire your hospice if you've got a bad one because you should take charge of that. But as a couple, they need to take the time that they can to record messages so that he's got messages to - I'm assuming it's a he - he's got messages to listen to afterwards that say I love you. That's hugely important, to make sure that there are instructions for whoever is going to be there not to take the sheets after she dies. Let him have those and the bedclothes because people want to be helpful and they want to get busy and they destroy some of the most precious of stuff that nobody thinks about.

Make sure that they're talking about what do they want and what does he want? What does she want for him? There's a new book that just came out right now by Rabbi Steve Leder. I don't know if you know him but I absolutely adore him. And his new book is basically the ethical will but it's written in non-Jewish terms. What do I want for you? How do I want to be remembered? What do I want for your future? And it's literally a workbook. I don't work for the man, but I love his work and I recommend that now frequently because it creates those conversations. I found that it was important for me to be able to just sit with Linda late at night. She couldn't sleep anyway because she worked nights and she couldn't breathe, you might as well just sit up and talk all night and we talked about everything. You know, what childhood memories, what did she want for our kids to have memories? What did she want me to do for our grandchildren? All of that. I've got.

Karen Wyatt: That's beautiful.

Jill Johnson-Young: Yeah.

Karen Wyatt: I love that. These are great suggestions. These will be really helpful to me. And I know you emphasized in the book also the importance of the caregiver caring for themselves to make sure they maintained their health. And you had a lot of really good suggestions there of things I hadn't thought of. But making sure the caregiver doesn't feel guilty asking for certain things or asking to talk about things or even wanting to plan out their own future and talk about the fact that they will have a life after the death of the spouse because that's the reality.

Jill Johnson-Young: And you can't; you really can't ignore the reality because it's sitting right there. You know if there's a hospital bed in your house and you've got hospice, somebody's going to die. And as a former hospice social worker and a double widow, you know "die" is the term. And so you do have to talk about it, and you have to be prepared for it. Linda wrote her own obituary and she did it with one of my best friends. She didn't want to do it with me. So Wendy came in and sat and did it with her. She planned her own funeral. She set the dress code because she did not want black at her funeral. We wore Angels' shirts; mine said "first coach," right? And Hawaiian shirts. We had Hawaiian shave ice at Casper's funeral because she loved Hawaii. We did those things to make that a celebration of them and they could plan their own celebration.

Linda wanted a luau to say goodbye to everyone and she died much too quickly to allow us to do that. Had she lived, we would have had a wake for her while she was still alive.

Karen Wyatt: That's so powerful. And also hearing you say that Linda on her bucket list included her thoughts for you and, in a way, giving you permission and encouragement to move on, find another relationship, don't be alone the rest of your life, be with someone else and that she wanted that. She loved you, she wanted you to have that. Because you were a young woman and, well regardless of what age, where she just wanted you to be with someone.

Jill Johnson-Young: She knew that I had the kids and our kids had some like, they were all older and getting out of foster care. So you know, there's some stuff that goes with that. But she knew the kids had bonded to Casper and trusted her, and she wanted me to have joy in my life again because she knew just how exhausting her illness had been and she completely acknowledged it. The problem with all of that is the people in the household know that all of these conversations are happening and the people even just right next door across the street or across town, although they consider themselves, you know, best friends or whatever. They're not hearing the conversations and they're not in that space. They're not grieving yet, right? My girlfriends grieved with me ahead of time because they were there. But most people were just sort of still doing that, "But we can still hope. We can, you know, maybe this will go longer." No, it's not, it's not going to go longer. She can't breathe folks. She had 3% of her lung tissue left when she died and her

heart was functioning at about 10%. There was not much Linda left, although her sense of humor was there and her great big warm heart was there. And so for her to be able to pack into that, I want Jill and the kids to go have a life, I want Jill to have support. I want Jill to be able to lean on someone. That was important to her and she knew that. And you know, we've had seven years of illness - between the two illnesses - out of 23 years. That's a significant portion of a life together, right? And so she wanted me to have that, and I'm very grateful to her for that. And I'm grateful that we had those conversations. We just happened to be a good match, and having a nurse around means things are practical.

Karen Wyatt: That's true. Very true. Well, you made a really good point that people in your outer circle - who are not in the middle of everything that's happening - their grief doesn't begin until the death occurs. And so they're completely oblivious to the fact that you've been doing all this anticipatory grief work in advance. And they assume that your grief is beginning at the moment of death as well. So they overlook the years and months and days and nights of grieving that you've already done in this process.

Jill Johnson-Young: They're not privy to it. They're not privy to the back injuries and the shoulder injuries. My left shoulder is thrashed from lifting and carrying and - God help you - wheelchairs? A tip for anyone who's got someone who's sick, get the transfer chair that has the four small wheels because the ones with the big wheels will thrash your shoulder and you will have that for the rest of your life with you, right? So I was able to do that grief. I was able to be relieved when she took that last breath. It was stunning. It was mind numbing. I remember sitting in the window still thinking, I'm never going to get to four months. But by four months, I was really, really okay because we've done all that grieving. And the cool thing about marrying someone who knew your late wife is they knew your late wife and you could talk about her.

Karen Wyatt: Yeah, that's true. They are actually part of your grieving process as well, not a total stranger to it.

Jill Johnson-Young: Casper made sure that, you know, on Veterans day that I took the kids to the cemetery and put up the flag for the navy for Linda because she was retired navy. And she made sure the kids brought Linda's memory into every single event because she wanted to honor Linda. And not many folks understand that who are outside that system. They see it as replacement, like when the dog dies and you get a new dog - which dog people all know, you're not replacing your adding to. You don't replace. But other people outside the system don't get it. And so for them, it's a challenge because they don't see that you are in fact continuing the love you had for your late spouse in the context of the relationship with the new spouse who you also love in a different way. I don't know if that makes sense. But it makes sense to my brain.

Karen Wyatt: Yeah. Yeah. That makes sense to me. And I wanted to talk a little bit about first, as I said before, your book is so helpful. It's full of tips that come directly from your experience, I can tell.

Jill Johnson-Young: Boots on the ground!

Karen Wyatt: Tips for caregivers, a couple of you talk a lot about: setting boundaries, which I think many caregivers have a problem with. And one thing you did was make lists of things you need people to do. So a list. So you could just hand it to people. Here, do these things to help. And then a list of things not to talk about. I love both of those.

Jill Johnson-Young: Don't talk to kids whose parent is dying about the parent dying. Talk about school, you know, take them to the mall. As long as they're wearing a mask these days, right? Do the things that kids need to do. Don't tell them that they should be grateful that they're going to have an angel in heaven. Please don't ever say that, right? And it's important if you're losing a spouse to have help. And one thing that caregivers don't do universally is ask for help. Oh no, I got this, I can take that. Nope, I can do that, too. I was traveling for work seeing foster kids in northern California by a plane with Linda at home with one of the kids. And I'm thinking back at, it was like sheer insanity, and I finally had to say, no, I need help. I need someone to come in and do these things and these things, and I don't have the energy to get them to youth group. Can someone pick him up and take them to youth group tonight, right? I need someone to mow my lawn. I need people, and that gives people who want to help an opportunity to help within the context that they are able to.

Karen Wyatt: That's so true. And I like the idea of having a written list because you can hand it to them, and they get to choose from the menu what they would like to offer when they step up. Because so many people do come forward: let me know what I could do, what can I do? And that it seems like that's a nice easy way to say, here's what I need. And you don't have to constantly talk about it or talk through the list. You have it written down and you can show it to them.

Jill Johnson-Young: Can you be in charge of setting up a mail train? We didn't have those when mine were sick. But can you do that? Can you take over my phone? Can you answer my emails that are, you know, people wanting updates? Because I don't have the energy. It's mind boggling to me that, when someone is losing their spouse, that other people are expecting individual responses about how things are going. You don't have the energy for that.

Karen Wyatt: Yeah, you're right about that. That sometimes the caregiver is expected to also take care of other people who are upset and grieving and wishing for more information. The caregiver ends up being the point person that other people come to expecting some kind of support and help from the already exhausted caregiver.

Jill Johnson-Young: Or the griever. I have those conversations every single day with my clients, whether they're in the process of losing or they've already lost and, you know, they're mind blown that someone would say, I'm so sorry about your loss. You know, it's really hard for me. Can you help me? And so we practice, you know, I really can't. I'm sure you've got people outside your circle that you can reach out to, but I need the support right now. And if you can't support me, then, you know, we can catch up in a few months.

Karen Wyatt: Mhm.

Jill Johnson-Young: Boundaries.

Karen Wyatt: Yes. Perfect.

Jill Johnson-Young: Put that hula hoop around you and keep it tight.

Karen Wyatt: It's so important. And it's not rude, it's not thoughtless. It's essential.

Jill Johnson-Young: Self-care.

Karen Wyatt: Exactly.

Jill Johnson-Young: Self-care is not a spa.

Karen Wyatt: And part of this problem is other people just don't know; they don't know better. They don't know that they're burdening the caregiver or the griever. They don't know they're asking for too much. They can't see that. So we have to show them. We have to point it out to them.

Jill Johnson-Young: Right. And they think they're being helpful by saying, tell me what you need, but the caregiver knows they're saying that because it makes them feel good to say it. But there's a large chance that they don't actually have the energy or the inclination to do that, and they've got a busy life too, right? And then after the funeral, the grieving widow looks around and everyone's gone back to real life and they're trying to rebuild their life. But if they do it in a way that upsets everybody else's widow rules, then those people have time and energy to come back and tell you about it. And it's not fair; if someone is going to lose their spouse, they get to decide what they want to do with the rest of their life because they're the ones that have been left behind.

Karen Wyatt: Another really novel suggestion that I read in your book - you mentioned that you found adults to connect with your children as they were going through Linda's dying process, and after her death, other adults outside the family who could kind of help look after them. So talk about that a little bit.

Jill Johnson-Young: You know, I'm a social worker, so I tend to micromanage a little bit; I will admit that. And so I knew we were gonna have a crowd. And I had three kids. And I knew I needed to focus on Linda, and I knew these would be my last hours at some point with her, as well. And so I spoke individually to people I trusted and assigned one of those people to each of my children. The children didn't know it, but the adults did. And they all committed to being there regardless of the day or time when she was dying. And those folks kept an eye on the kids and sidled up to the kids. And then when that child looked like they were in distress, that adult simply plucked that child out of the room and took him off to the side and got him something cold to drink or hung out with them in the

front. They spent time with them. These same people had eyes on them at the funeral; so that if it got to be too much, that adult could take that child and exit. And each of the kids at some point needed their adult. And it was hugely helpful to me because then I could focus where I needed to be, which was on my dying wife.

Karen Wyatt: Exactly. Because as a wife and a mother, you couldn't possibly have the time or energy to care for all of those people who needed you. And definitely the kids needed attention as well. It just couldn't come from you in that moment. And I think that was really brilliant to have people who knew them well, who would recognize when they might need something else that you were not able to provide. Because think of all the stories we hear of people who talk about, in their childhood, when they had a parent die and no one tended to them. No one was with them. No one talked to them.

Jill Johnson-Young: And they were afraid to go to their other parent because they were distressed. They need someone.

Karen Wyatt: Yes, and that's so brilliant to actually plan it and ask adults who know the child, please be there for this child. This child only. You just have one child to look after.

Jill Johnson-Young: Everybody gets a kid.

Karen Wyatt: It's part of your job, and that's how you're going to help this whole situation. And I mean, I don't know but I would imagine that really helped the grief process for your children as well.

Jill Johnson-Young: It helped their grief process and it helped the helper too, because the ones that I asked to do that helping were people who were not necessarily comfortable with grief and loss. But they were steadfast with my kiddos and part of their lives. And those folks really helped them get through those really hard moments. And it meant that while Linda was dying - she died on Good Friday of all days. And I had all three of my kids and my niece and nephew and my twin nieces and the cats and the dog - like everybody was on this hospital bed. I don't know how everybody fit. And I was kind of perched on a windowsill leaning over Linda, but I knew that all I had to do was look up and I could catch the eye of those adults, and they could come and grab the kid. And that when Linda did die, that those adults could take those kids when they were ready to leave the room- underlined when they were ready - and hang out with them a little bit, and steady them up a little bit. And likewise at the funeral, I walked in - of course they always have the front row assigned to the family, right? Well we have a big family. So there were like four rows. I took the front row, and I ended up there by myself with all three of my children and my niece and nephew and a giant stuffed frog that we had bought my niece and nephew for Christmas years ago. And I didn't have enough arms. And I was speaking and they were all speaking. And it felt like a business management system more than a funeral for a little bit there until I remembered I had the helpers. And then I could say, you know Sherry, will you take Carrie? I could whisper, and zing - she was gone. Right? And that helped. Our youth minister came down from the front of the church to sit with

one of our kids because she was one of the helpers. It helped. I can't recommend that enough to anybody who's facing a loss.

Karen Wyatt: Yeah, that's very nice, and it's the first time I've ever heard that suggestion before. So that's something about your book. It's full of things that I haven't thought of before or heard about, but it's so valuable to anyone going through this. And I want to back up a little bit because one of the early chapters is on receiving the diagnosis. And having just experienced this with my friend, this is really the first time in my life when someone I love has witnessed receiving a terminal diagnosis. So in spite of all this hospice work dealing with all kinds of different people, it's so different when you witness the moment. And it was challenging and devastating in so many ways. So I wanted to have you just talk a little bit about that and share some of your wisdom.

Jill Johnson-Young: The date of diagnosis is... it's funny, it's got the same initials as date of death, D.O.D. And it feels very much like the beginning of the other D.O.D. And sometimes folks are expecting it. Sometimes they're not. I had no idea that pulmonary fibrosis even existed, although it kills a tremendous number of people and it's 100% fatal, and 60% don't survive the first six weeks. So we were ahead of the game already with that. But I remember standing in that hallway - and then a second time when Linda went into heart failure because PF also tans your lungs, which tans your heart so your heart can't beat normally. So you end up in heart failure as well. So we were at the cardiologist. And he said yes, she has right sided heart failure. She's just gonna die sooner. Take her home. And again, you already know she's dying. But there's that, what did you just say? It's a stunning, jarring moment for your brain. And for the spouse, it's a little bit about, oh crap, now what about me? Which reverts immediately to, I need to caretake right now. I need to be the supportive spouse. I need to make sure that I respond in a way that meets your needs, not my needs because I'm a social worker. I'm gonna hug you, but not everyone is a hugger. My current wife is definitely not from a huggy family, right? So their first response is not the hug, it's to stand by and sit for a moment and breathe. But what do you do with that? And how do you incorporate that? And after Linda and I met with her pulmonologist who was a friend of hers and he told us you are now on hospice, you're going to be pushing up daisies soon. There's nothing you can do. And those were the words he used. We went to a place here in Riverside called The Mission Inn which is just beautiful and has a really old bar from the turn of the last century. And we had a glass of the most expensive cabernet they had and sat for a moment and just sort of went through where our life had been and what this meant for us and how she wanted to manage it. And we texted the kids and said, we're gonna be back late, and immediately they knew she was dying. It wasn't even a question; it was a statement.

And when we got that moment with Casper - it took forever to get her diagnosed because neurologists are not great with dementia. Point of order for any neurologist listening, you need to be better at dementia and much better at Lewy Body. It takes an average of five neurologists to get that diagnosis right. And it took us three years out of three and a half. And I was the one who had to suggest the diagnosis. And when he finally said the words - and I love that neurologist, he was the best one we ever had - we went out and Casper was with it enough to say, that was the bad one, right? That's the one we didn't want.

Yeah. So how much time do I have and how much time do we have? And then we had lunch and she choked. And I started to get up, you know, here comes Heimlich Jilly, right? And she said, sit down. And she said, and no feeding tubes, don't even think about it. Like how many people would go from choking to no feeding tube?

Karen Wyatt: A nurse.

Jill Johnson-Young: A nurse is exactly right. And so we got her POLST form done right away and got the doctor to co-sign it that day so nobody would do a feeding tube. And at the end of her life, she went 37 days without food or fluid. And I had to look at that POLST over and over and over again to know that I was doing what she wanted. And I stood by it, which is no mean feat for a caregiver because other people are making all kinds of suggestions about how you're killing your loved one.

Karen Wyatt: I was going to say that's also an area where there are plenty of rules that other people want to impose on you.

Jill Johnson-Young: Right? You're killing her. You're keeping her from having fluid. And that's not true. But you have to know end-of-life. And that's where we need to have conversations more. And that's why I wrote the book because I had tons of blogs I wrote. And I talked to an editor and she said, Jill you don't want an autobiography. No one wants to read that, nobody. They want to know what to do. And so the book was written for folks who are managing an illness that's going to be terminal: managing hospice, managing the dying process. Because nobody talks about that. And then managing your own grief and doing it your way so that other people don't try to manage you because there are books like that. No, not at all.

Karen Wyatt: And another aspect that you write about is facing all these challenges as a same sex couple, which I know there are obstacles there as well that you have to overcome.

Jill Johnson-Young: And they're growing obstacles because of the current political situation. It's going to only get worse from here. We were on the cusp of Prop 8. Linda and I fought Prop 8. Linda and I celebrated the end of Prop 8 for that brief moment. That's how we managed to be legally married. And then when she died, Prop 8 died for us. And then Casper and I couldn't get legally married until Prop 8 died with the Supreme Court. And so when Linda had her first surgeries in Florida, we had powers of attorney, durable power of attorney, all the documents you could ever have. And all the nurses there had to say was, yeah well we don't believe you're a couple so we're going to disregard all of it. And that's exactly what happened. I was locked out of her hospital room. The nurse blocked the door with the bed - and hear me correctly. I love nurses. I've been married to two of them. But some of them just need to not be in the profession, and she was one of them. It's easy to be discriminated against in so many ways, and it's easy for people to discriminate without telling you they're discriminating.

We were delayed in getting Linda's legal disability paperwork because the nurse practitioner and her pulmonologist office disagreed with our marriage. Like she had some power to disagree. So I had to finally get the raw paperwork from the office and she had crossed out the words "wife" and "spouse" on every page, and wrote "significant other" in quotes. Like they say they're significant others because she wasn't going to give the documents to me. She was going to let us go without income. She was going to let me not be able to feed my children because she had a need to discriminate, which is mind boggling to me.

Karen Wyatt: It's alarming to me that even having documentation and legal power of attorney and healthcare proxy forms - all of those - that that could be just disregarded.

Jill Johnson-Young: When Kaspar had to have a heart procedure, they did a heart cath and they were still trying to figure out what's going on with her. And we were legally married at that point. We checked in and the person in registration at our local hospital said, do you have your marriage license? And I looked at her - it was the same hospital where Linda had worked and had worked for many, many years. So they still knew me, and I'm a rabble rouser. I've been in every newspaper. I've been on every news channel. And you google me, you'll find me. So the other person in registration knew who I was and that saved us because she pulled that registration clerk aside and said, you are messing with the wrong couple. They're going to sue us and you. And all I had to say was, did you ask them for their marriage license? Because I heard you just say they're married. And she tried to say, I have a right to ask. And I said, we're going to go. You're gonna be sorry. They switched out clerks. They took our marital status, and we were married again. But they can erase you just like that.

Karen Wyatt: Oh that hurts. It hurts to hear that story and to see that, even within the medical system, there's that much discrimination. And how much awful burden does that add to your caregiver journey and the grief that you're experiencing already?

Jill Johnson-Young: And how much does it scare the patient who's afraid that, if you've upset the caregiving staff, that they're going to then in turn retaliate, right? So Casper was afraid to have me step out even for a second because she was afraid they were gonna retaliate against her. And that's a real fear. I slept at the hospital in Florida because Linda was afraid to be alone. Once we had pushed the envelope on "Jill gets to know what's going on," her surgeon refused to give me her pathology report. He said, I told her what I found. She was asleep, dude. She's been in surgery for four hours. I told her. You can wait. And he could, he could do that. And he did. Because that's the way that he believed his beliefs overrode our relationship as a married couple. And my need to be able to take care of my spouse.

Karen Wyatt: Wow, I'm curious as you, having worked in hospice, did you experience any of that kind of discrimination within hospice from hospice staff? Because my hope is that hospice is a little more inclusive. But I don't know, I don't know for sure.

Jill Johnson-Young: You know, our hospice that we had for Linda turned into the hospice that I went back to work for in hospice. I didn't see any discrimination. I saw nothing but profound respect for her. Our doctor was and is an exceptional hospice doc. He's the one who goes out and sees his patients, right? He knows every one of his patients. And he recently took care of my late father-in-law.

But when Casper was dying, the staff came and said goodbye to her - and she was a beloved nurse there. And one of the nurses who had cared for Linda too, I walked her down the stairs after she'd come to say goodbye. And she said, she was looking at our wedding picture, which was in our hall stairwell. And she said, you know, I never believed in marriage for you guys and I still don't. I totally disagree with it. I'm glad you had each other, but I disagree with your relationship. Now, why she had a need to tell me that while my spouse was dying upstairs, someone that she had worked with and called on hundreds of times... Casper had saved her butt a couple of times. But she still had a need because of her beliefs to tell me what her beliefs were and to vomit them all over me. And I was like, bye wow. So it's you know, it's there, you just don't always see it. And you're right, hospice staff are completely different.

When I worked for hospice in Florida, we had a huge number of AIDS patients. And I saw our staff, who belonged to some of the most fundamentalist churches, step right up and show the greatest of care and dignity and love for our patients and no questions asked. I saw one young man who was dying, who literally made himself die 12 hours earlier so his dad couldn't get his ashes because he knew his dad was on the way from Ohio and he needed to be cremated right away. So his mom and his partner could get his ashes and go scatter him before his dad could get there because his dad was hateful. And our staff just stepped right up and cared for these folks. But it's there, like in every community, it's there. And you know, in the mortuary community, my wife Stacy saw lots of discrimination and heard lots of stuff in the back room. The trans community faces that all the time right now with being misgendered after death.

Karen Wyatt: Yes.

Jill Johnson-Young: In California, we have a law now that says that the way that a person presents is how they have to be presented after death, but in other states, not so much. Right? Stan can become Susan again and be wearing a dress in a casket.

Karen Wyatt: Yeah. It's shocking that we're still dealing with this amount of discrimination.

Jill Johnson-Young: It's only gonna get worse again. You know, our current Supreme Court seems to be bound and determined. So I'm fearful, and I don't use that word lightly. I am very much fearful about what's coming. We've had more than one discussion in our backyard coffee time about when retirement comes - is there another country? And I didn't want to have to have those conversations. And I'm caring for my mom with dementia next door right now, we can't go anywhere. I have grandchildren here. And we

have six poodles right now who are seniors who need care, and you can't take them just about anywhere. But it's a scary time, and the discrimination is going to come back.

Karen Wyatt: Yeah. Unfortunately. So we all need to be aware of it and we need to be aware of the impact that it has on individuals and their lives.

Jill Johnson-Young: And we need to make sure that, when we're in hospice teams and we're in IDT meetings, that we are referring to couples as couples. And not only caring for them as a couple, but also making sure we're reinforcing for everyone around the table that this is a couple. And regardless of who the couple is, they deserve all the same support, care, and dignity for their relationship, all of it.

Karen Wyatt: Exactly. I mean that's basic human goodness and dignity.

Jill Johnson-Young: You would think, right? And we need to make sure that when someone is in the grief work with that hospice, that we're acknowledging who it was they lost and then supporting them and whatever they want to do in their grief, not what we think they should do in their grief.

Karen Wyatt: Exactly, right, allow them to be the rebellious widow!

Jill Johnson-Young: To be the rebellious widow and to adopt all the senior poodles on the planet or whatever they're going to do.

Karen Wyatt: Well, one thing I really appreciate from our conversation and from your book is your use of humor. And you emphasize that - how important humor is. And even during these really challenging dark times of life, humor can make all the difference.

Jill Johnson-Young: It does, and it's the only way. That's the way hospice staff keep themselves emotionally healthy. I have found - with great love and reverence - the sick and twisted humor the hospital people have behind closed doors and on cell phones and text messages because it's self-preservation, and it helped us a lot. And I use humor with my griever because griever don't have people laugh at them very often, right? They get that look, people say, oh, I'm so sorry for your loss and they screw up their face. And they, even when you're wearing a mask, you can see the look and imagine what they're looking like. Griever want to have some laughter in their lives and they need to. We know it changes our endorphins. We know it changes our cardiac system. We know it clears our heads. We need to really work towards that. You don't want fake humor, but you definitely want to have some humor introduced. And it's a great way to talk about intimacy with a dying partner because you can ask, all right, which one of you made the first move, right? Humor and yet also looking at the intimate part, and it works really well.

Karen Wyatt: Yeah, that's great. A great way to tie those together. And I think just giving ourselves permission to laugh, whether we're a caregiver or we're a care provider coming

into the situation to know that there's permission to see the humorous in any event and to bring that up.

Jill Johnson-Young: Right. And you know, we had one of my favorite hospice nurses, Jenny. I said, you know, I really don't want to be doing this anymore. This is really awful. I hate this. She said, I get it. You are doing what you have to do with the situation you've been handed. You didn't get to vote on it. We don't either, but we'll get through it, Jill, we'll get through it. And then she said, what's the hardest part? And I said actually cooking the dog food because we've always kept our dogs' food at home. And the next day, a nurse showed up with packages of home cooked dog food. And they were labeled so, one of them said naughty reindeer. And one of them said chickens who talked back, right? So we even, just in that, the humor was injected. And so every time we opened a bag, we had a little moment of a smile. It doesn't take much to inject humor into the situation in a most appropriate way. And to lighten it up a little bit.

Karen Wyatt: Such a good point. A good, a good thing for all of us to remember. And I mean, looking back on this entire interview and all the things we've covered, your information that you share and your wisdom is just so valuable, Jill, and I'm really grateful to you for that.

Jill Johnson-Young: I'm grateful that you have this podcast. It helps a lot of people. And you know, we both know how very little the conversations happen about grief and loss and death and dying. And you know, I remember saying 40 years ago, we need to talk about this more. And I'm still saying it. I'm like, seriously? It's been 40 years, what happened? I know we're still trying, still trying to make a difference. Still trying to make it part of everyday conversation, which is where it belongs.

Karen Wyatt: Yeah. Well tell us a little more about your other books. Well, first of all with *The Rebellious Widow*, where can people get that?

Jill Johnson-Young: Everything is available on amazon. *The Rebellious Widow* is also available at [therebelliouswidow.com](http://therebelliouswidow.com). I'm available at [Jilljohnsonyoung.com](http://Jilljohnsonyoung.com), which sounds really weird to me because social workers are not generally "dot com," but now I'm a "dot com." And you can also find me at [centralcounselingservices.com](http://centralcounselingservices.com). And I see people only in California because of state laws, but you can find the books on amazon. I've got books for children about *My Pet is Sick*, *It's Time to Say Goodbye*, *Someone I Love is Sick*, and then *Someone I Love Just Died*. They are written for children, but in words that children understand and appreciate. They have hand drawn artwork with an artist that I found in South America who is amazing. And so they show things like someone in a hospital bed, and they talk about, it's okay to ask the person there to help you get into the bed so that you don't hurt your loved one. But you can crawl into bed and hug them. People around you are grouchy right now. It's not because of you. You're going to go to something called the visitation probably. Make sure you don't have to wear scratchy clothes and that you get to go out for ice cream afterwards. I totally set up parents for ice cream and donuts in these books, flat out ice cream and donuts, right? Don't fall in the hole at the cemetery. It'll scare your mom.

You can walk up to the casket, but don't let anyone make you kiss the dead person. It talks about cremation, it talks about a year after and remembering someone. The one about pet loss talks about going to the vet and the vet saying there's nothing more we can do, and putting the pet to sleep and then the grief afterward. Going home with empty arms, holding onto the collar, getting the cremains back. They have help in the back for big people. What words you need to know and how to talk to your kids so that you are not traumatized and they are not traumatized because kids like to know stuff, and they need to know if someone is sick and dying that they might still go to the doctor but they're still not going to get better.

Karen Wyatt: Yeah, that's excellent. And then I know you also have some courses, right? Some online courses?

Jill Johnson-Young: I do. The courses are designed to help people learn the things that I think are important about grief and loss and death and dying and dementia. There's an intimate partner loss one, and there's going to be a few more coming up in the next little while so people can just go to [Jilljohnsonyoung.com](http://Jilljohnsonyoung.com) and learn all about those. And they can put in the code `podcast50` and they will get 50% off.

Karen Wyatt: Oh wow. That's great, `podcast50`.

Jill Johnson-Young: `Podcast50`.

Karen Wyatt: Alright, see podcast listeners, you get rewards for listening.

Jill Johnson-Young: Golden tickets! And they're not expensive, right? So they're there so that we can all do better with grief and loss because I know that, when I was first a grieving widow, the therapists I ran into were truly awful and didn't know what to say or how to say it. And I want that to not happen to anybody else, definitely.

Karen Wyatt: Well, Jill, I'm just grateful for your time. Thank you for joining me. It's just, it's been a pleasure to read your book and then talk with you for this hour. I've really thoroughly enjoyed it.

Jill Johnson-Young: Thank you for having me.