Daughterhood the Podcast
Episode #87
Disenfranchised Grief and the Estranged Parent with Helen Bauer

55:42

Helen's website - https://www.theheartofhospice.com/

Barbara Karnes Book - https://bkbooks.com/

SPEAKERS
Guest - Helen Bauer

Host - Rosanne Corcoran

Rosanne Corcoran 00:14
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 the 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.

Disclaimer 01:05
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. I'm so glad you're here.

Rosanne Corcoran 01:29
As a professional, disenfranchised grief is part of your job, not an easy part, but part of it all the same. But what happens when you're not just the professional? When you're the daughter caring for an estranged parent, and the loss is one of those losses. How do you deal with it? And what is disenfranchised grief anyway? My guest today, Helen Bauer, and I get into that. Helen is a certified hospice and palliative nurse with 17 years of experience, an end of life educator, and the host of the Heart of Hospice podcast, through her company Hospice Navigation Services, she helps families make sense of serious illness, death, and grief. Throughout her career, Helen has guided many families through hospice. Then her father became ill. They had been estranged for almost 30 years, and yet Helen was part of his end-of-life care. And then her mother died six months later. Today, she shares how she made the decision to meet with her father, how she dealt with that disenfranchised grief, and what supported her along the way. She also shares how she balanced between hospice professional and daughter, how she carried grief and hope together, why boundaries matter, how her expectations changed, and how she came to understand what it means to be a family caregiver and to live with grief after loss.

Rosanne Corcoran 02:51
Helen, before we get into your story, how do you describe what you do in the hospice world? Well, I'm a certified hospice and palliative care nurse. I currently work as an end of life educator and an advocate. I'm a podcast host, have been for the last 10 years. But my my main focus is the work that I do supporting caregivers to teach them and educate and inform them about hospice and end of life care. And I do that through hospice navigation services. So it's mainly education, but I am a nurse by heart. I have a compliance background, so I know what people are supposed to be getting, and that's the work I'm currently doing. Did you know professionally what disenfranchised grief was before you experienced it yourself?

Helen Bauer 03:38
You know, I did. I had an awareness of that, you know. It's it's grief that's not supported generally, you know, culturally mainstream. And anybody who works in a care profession like end of life care or funeral home care, death care, there's disenfranchised grief there. It's grief that's sort of built in, but there's an expectation that well, you knew this going in, so it shouldn't bother you. So yeah, I I did have an awareness of what it was like, and I had experienced disenfranchised grief as a hospice nurse when I was caring for patients. Well, and that's what I was just going to say, when you're a professional caregiver or your work in the hospice field, you're caring for these people. You become attached to them, sure, and then they die, and then you go to the next patient. How does that affect you? Well, you know, it ends up being what we call compassion fatigue, which is really different from burnout. Burnout is more workload, but compassion fatigue or secondary fatigue is grief that you build up from watching other people suffer and other people grieve, and it's very natural for people who are end of life workers to experience that disenfranchised grief because we are by nature empathic and practicing. Empathy means you take on a little bit of that. So you're right. You experience a death, you support a family, and then you get in the car, you take a drink water, and you take a deep breath, and you move on down the road. You call your next patient, say, "I'm on the way." Yeah, it's a it's an everyday thing.

Rosanne Corcoran 05:20
And that grief, just where does it go? What? How do you deal with that? Do you ever deal with that?

Helen Bauer 05:26
Hopefully, you do, because if you don't, you're not going to have any longevity in doing the work that you love to do. You have to treat it well. You have to treat yourself well. And it sounds so trite, but self care is where it's at. And I'm not talking about the mani pedi massage kind of self care. I'm talking about atomic self care, where you're making sure that you strip off your uniform, your scrubs, or you get out of your work clothes at the end of the day, so that you are taking on your personal persona, getting into your life, and getting into your relationships, um, self awareness, it's hard, and accountability is even worse. But having an accountability partner really helps somebody to say, "Hey, you had a really hard day yesterday. Let's talk about what that looks like."

Rosanne Corcoran 06:17
And disenfranchised grief, as a definition, is a grief that's not openly acknowledged, socially validated, or publicly mourned. So it sounds like with healthcare workers, with hospice workers, that would be a pretty big thing that goes with the job, goes with the territory.

Helen Bauer 06:36
Oh, for sure, first responders, people who work in emergency rooms, people who work in ICU, CCU, things like that. People who are working in what I call care professions. Right. If you're providing care for somebody else, witnessing their suffering, supporting them while they're doing it, helping them manage what's going on. At the end of the day, you don't just walk away like that never happened. Right. Because it did happen to you. It's a secondary relationship, but the way I describe disenfranchised grief is there's no hallmark card for it.

Rosanne Corcoran 07:10
Now you experienced this personally in your own life. Can you tell me how that came into your world?

Helen Bauer 07:17
So my dad got sick in the summer of 2025, and I had been estranged from him for almost 30 years. I hadn't seen him. My dad was a very different type of person. He had a lot of trouble with relationships, and for me and my small sibling group, my brother and my sister, we had been disconnected from him for years. They had stayed in some communication with him, but I had chosen not to. So, as he aged and his health changed, my siblings began to support him more. But I had been on the edges of everything with him and had no contact with him, so it was a very distance relationship.

Rosanne Corcoran 08:06
How old were you when he left?

Helen Bauer 08:09
I was five, and my mother made the choice to take us out of the home and move back at a great distance, several states away. She moved us back in with my grandmother, and so we. That's where I grew up. And my dad, because of his personality, and he may have had some sort of mental illness, but

he was never diagnosed. But he had very, he had very difficult relationships, and he had a lot of trouble maintaining a job, holding a job, okay. So visitation, visiting with us, and and having time with us, or traveling to see us. You know, he lived locally for a while, but he just couldn't maintain it. So we also had a culture in our family, and I guess some of that was you know my mother's generation and her mother's generation, where we didn't really talk about feelings about that, how to cope with it. When my dad got remarried and he had another child, we didn't talk about that. How did that make us feel? And you know, are we going to connect with these folks? And and they were perfectly lovely people, but just a culture of really keeping it private, and that's what I maintained, and and really have maintained all my adult life that this part of my life was private. This is actually the first time I have ever discussed this publicly,

Rosanne Corcoran 09:33
And I thank you for that because I know it's hard. So thank you.

Helen Bauer 09:39
It's my pleasure to have an opportunity to be able to sit with you, someone I know where it's safe and I feel comfortable, and it's my hope that people who are listening that identify with this and relate to this kind of experience will say it's okay that I feel this way and these things are happening.

Rosanne Corcoran 09:58
I have no doubt. So. When he got remarried, how old were you then?

Helen Bauer 10:03
Oh, I don't know, 14 maybe.

Rosanne Corcoran 10:07
During that time, when people asked you about your father, how did you usually answer?

Helen Bauer 10:12
I said he didn't live locally, or I just said my parents are divorced. Because by the time I was 10, he had moved several states away. There was a great deal of distance, and he did not make trips to see us because of the cost. So it was easy just to pretend. I actually connected with a friend of mine, my best friend. I've known her since we were in kindergarten together, and I told her that my my dad had died, and she said that all these years she thought my father had died a long time ago. She didn't know he was alive because I just never talked about him. It was always a private thing, and I guess I kept it private because it was confusing as hell,

Rosanne Corcoran 10:53
And I would think painful.

Helen Bauer 10:54
Yeah, it was. It was embarrassing. You know, everybody else's family seemed normal. Everybody else had two two parents, so you know that kind of disenfranchisement is weird for a kid. What what do you do with that?

Rosanne Corcoran 11:07
Right. Where do you put that? Where does that live inside of you?

Helen Bauer 11:11
My mom did not want to talk about it, for sure. Yeah, their relationship was very very dysfunctional and very angry.

Rosanne Corcoran 11:20
Was it?

Helen Bauer 11:20
Yeah. So it wasn't a big conversation that I was going to have with my mom. We just didn't really talk about that stuff much.

Rosanne Corcoran 11:27
So you hadn't been in touch with him. You didn't want to be in touch with him, and then he got sick.

Helen Bauer 11:32
Yeah.

Rosanne Corcoran 11:33
Did your siblings tell you he was sick? Like, how did you find out he was sick?

Helen Bauer 11:36
Yeah, my siblings were the ones that told me they had been in touch with them. He could use email, you know, when he was younger and in better health, and he kept in touch. He was also financially strapped. He was destitute, so he was relying on my sister, her financial support, and she was very generous in taking care of him. But they would let me know, you know, and sometimes she would forward emails that he sent, so I kind of knew that that he what he had going on. He died in his early 90s, and his health had always been pretty good, which was amazing because he actually he avoided healthcare. He did not trust physicians. You know, he could figure it out on his own. You know, and as he got older, he had some form of dementia, undiagnosed, of course, because he wouldn't go to a physician. But my siblings began to take more of an active role in finding him a place to live. My sister even flew out and found that he was living at a place that was completely unacceptable, horribly unsafe, and they moved him. She and my brother moved him to another place, helped him set up with furniture, you know, things like that. And so they would let me know that they were doing these things. I was really blessed with an amazing sibling group because we had never seen anything like this before. You know, my grandmother that we grew up with died very suddenly in her own home at I think 92. No caregiving needs. She was living on her own. I think she was mowing her lawn. You know, where she was. Yeah, yeah. She was a fierce lady. So we had never seen a caregiving model before. It's it's interesting when you've never seen, if you've never had a multi generational home or seen an example of caregiving, you're flying flying blind. Caregiving caregiving is hard. Yeah, if you're completely in the dark, right?

Rosanne Corcoran 13:35
Yeah, absolutely. Even when you have the light, really sometimes.

Helen Bauer 13:38
Yeah, even well. So, so my healthcare background came in handy. We started talking about assisted living, and fortunately, the timing was so good. My brother and sister found an elder law attorney who would work with him, and at that point, he was completely capable of signing paperwork and his medical power of attorney or medical proxy because my brother ended up making all these decisions for him, and so I was not doing anything hands-on or decision-making for my dad, but I was supporting my siblings while they were doing it. Right. Yeah, and we we had this unspoken respect. You know this is what you know how to do, so we're going to tap you for this expert advice. And this is what you know how to do, so can you help with this part of things? You know, division of labor just very naturally and respectfully, and there has never been any sort of condemnation. You know why you haven't talked to him for 30 years, right? And we've kept in touch. You don't. You don't get to be part of this. That never happened.

Rosanne Corcoran 14:44
Wow. Let me tell you, that's special. That is that is very rare.

Helen Bauer 14:49
Yeah, my siblings are amazing people, and we have a half sister who also lived at a distance from my dad, but she worked and had kids at home. So because she's quite a bit younger than we are, so she wasn't capable of being a caregiver either, and her relationship with my dad wasn't so hot either.

Rosanne Corcoran 15:06
How in the world did that come together to make this work? Because you all just kind of went, "Okay, we're going to take care of dad, even though he wasn't here for us, even though he didn't support us, even though, even though, even though was there a conversation? I mean,

Helen Bauer 15:24
No, we just slow rolled into it. I like a lot of caregivers do. You know, it's just oh, I'm going to help with this one thing, or oh, I'm going to make a call on his behalf, or oh, I'm going to go to a doctor's appointment. Then all of a sudden, you realize six months later, your caregiver, you just didn't identify that way. Yep. So we all acknowledged that he was difficult. I mean, my dad was a gigantic pain in the butt. He was very hard to deal with because he was rude and unkind and sarcastic and very critical, which is one of the reasons he had crappy relationships. Sure, but I think we were all raised with a sense of respect for people, and in the end, there was some discussion about sort of not objectifying him, but removing that he's my dad. I'm responsible for him thinking, and creating some emotional distance, but still respecting him as a human and understanding that we are obligated to him, and he had no one else. He had a sister, but because he disapproved of his sister's lifestyle, her religious beliefs, he had not seen her in 18 years. Wow! Yeah, this is somebody who set himself up to just become a ward of the state, right? Without our our involvement.

Rosanne Corcoran 16:47
So, how do you sync that up in your mind? How do you get from I haven't talked to this man. I don't want anything to do with him. He's pushed everybody away. How do you sync that up? That okay. I'm going to help now.

Helen Bauer 17:01
You know what worked for me was I didn't whitewash anything, I didn't sanitize anything, and my brother and I were in frequent communication. You know, when my dad was really having issues, we would talk two or three times a day, and we both gave each other the space to say degenerate old bastard. You know, we we didn't sanitize anything. We weren't going to romanticize. You know, this was not touched by an angel. We were not going to rally by this guy's bedside. But one of the things that I did, and the timing was so weird, I decided that I wanted to see my dad, and I wrote him a letter, which you have to understand. After 30 years, that's huge. That's huge. So I didn't tell anybody about the letter, and I sent it to him. He immediately got in touch with my brother and said that yes, he wanted to see me. So three months before my dad died, I made a visit up there, and I went in with no expectation that there was going to be some kind of big family reunion reconciliation. And I was giving myself a lot of grace. I traveled with my half sister, who was also dealing with her own, you know, disconnected relationship. Yeah, and we made a visit there together and supported each other. And what I realized was that my dad had declined greatly, and his lack of healthcare was taking over. His mental status had changed. You know, he could not take care of himself anymore, and that he was declining and would continue to do so. And I also realized that his mentation, other than the vascular dementia and the forgetfulness, his personality had not changed, so I was able to look at him and say, "30 years of disconnection, right move." That was the right thing for me. So seeing him there like that, and then he died three months later. But I was able to support my brother. I made one more trip up there. I gave myself all the grace. If I was feeling compassionate towards him, that was great. And if I was remembering things that made me angry, I let that fly. That was okay too. I never tried to make it some sort of cleaned up reconciliation. I think being very real worked for me because authenticity in that seemed very important.

Rosanne Corcoran 19:26
And you said two really, really important things: no expectation and a lot of grace.

Helen Bauer 19:33
Yeah, there was no requirement. I didn't have to like him. I didn't have to like him. I just wanted to see him. And some of that was for me, and then some of that was for him. Probably 90% for me, and 10% for him. But yeah, if I had expected things from that, I would have been sorely disappointed. And I work with a therapist. I had been. Seeing a therapist for a year before my dad got sick and declined, so I had a lot of support there that I felt was very important. And I, you know, I'm definitely an advocate for having a therapist work with you because that was it made a lot of difference for me.

Rosanne Corcoran 20:16
Yeah, it's a lot to it's a lot to get through.

Helen Bauer 20:18

But if I had had expectations walking in, it would have been a disaster. And then, so you get to feel what you feel, and what happens happens. And he was an ass. He was very emotional over seeing me, about seeing me. But then he could not control his the sarcasm and the criticism that was still there. He was still who he was. Sure, yeah.

Rosanne Corcoran 20:43
So you said now it was 90% for you and 10% for him. Yeah. Tell me about that. Why?

Helen Bauer 20:50
I have spent my entire adult life taking care of myself when it comes to the relationship with my dad because he could not do that. So my visit there was about me taking care of myself. It wasn't offering this old man, and if that sounds callous, you have to remember disenfranchised grief and all the baggage that comes with a relationship like that. It affects how you think, and being angry at my dad for not being able to be a dad to me, being angry was just part of the package, so that was for me. It was for my peace of mind, but I also was trying to be respectful of whatever relationship there was.

Rosanne Corcoran 21:35
It's so interesting because I can't imagine getting to the door, and then the minute after the after the initial, you saw him, and then he reverts back to how he always is, because that's who he was, right? Right. What that felt like in your body, in your mind, and how you continued to stay.

Helen Bauer 21:57
We kept the visit short, and you know, going with my half sister, she understood how he communicated and you know what it was like to interact with him. So we had already set our boundaries for how this would go. We would check in with each other to make sure we were okay. You you still want to stay? You still want to do this? Are you okay right now? And we would do that. And because he was hard of hearing, it was kind of easy for us to do that. Sure, but you know, he said, "Are you are you coming back tonight?" And my half sister immediately said, "No, Helen has a flight out tomorrow." You know, she was looking out for me, and then we we had we had set this up to where we were going to be each other's safety net and each other's support because there was nobody else, right? And she was five hours from her own family, and we had we had driven all that way. So we went back to where we were staying, and we decided that we would take showers. This was like 5o'clock in the afternoon. We would pick up dinner, we would put on our pajamas, and we would watch a movie or some silly TV series while we ate dinner in our pajamas. Perfect. Yeah, and it was what we needed. And then, in the middle of things, every once in a while, one or the other of us would pause what we were watching and say, "When you were growing up, did Dad ever this and this, or did you notice today that he was doing this? And it was these little bubbles that would come up and pop, and we would talk about them, and then we would go back to just a couple of sisters hanging out in pajamas. It was really special because it was just what we needed, and we instinctively knew, and so for us to be able to do that, and we didn't know each other very well, but it was it was a recovery time. It's kind of like having a really hard emotional workout, and then you go home and you do these things to recover. You drink water, you take a shower, you have good food. Yeah, you you disconnect mentally and emotionally, and focus on other things for a while, and you have somebody there with you.

Rosanne Corcoran 24:05
And it must have been really supportive for you in talking with your half sister, because it becomes the me too moments of, oh my goodness, you felt like that too.

Helen Bauer 24:16
And we had very similar experiences, but she lived with my dad in her household until she was 10, so she and he lived close by the whole time she was growing up, until she was a young adult. So she had contact and experience with him that I did not. Right, and of course I was always looking for some sort of explanation. I what I really wanted was a diagnosis that I could understand, and I think that's you know that's the healthcare background. Sure, I needed to quantify it somehow. Yeah, yeah. If I could,

Rosanne Corcoran 24:51
You wanted a reason.

Helen Bauer 24:52
Yeah, yeah, exactly. Yeah, was he just a lousy person, or was did he have a personality disorder? Was there something? Really wrong with him,

Rosanne Corcoran 25:01
And if you got that diagnosis, would it have made it better, or was it just something that you were trying to hang your hat on?

Helen Bauer 25:07
I think it was just something that I could hang my hat on, something that would would justify it somehow. I mean, if he was crazy, right? If he had some sort of mental illness, it feels a whole lot better than well, your dad's just a deadbeat, right? Yeah, and of course in healthcare, right? I'm always I even talk to my therapist, and I'm like, here's his behavior. Can you can you give me what you think his diagnosis was? Completely futile, completely futile, and probably useless. But remember, this is stuff from way back when I'm starting when I was five years old. Yeah. So yeah, a lot of work being done there.

Rosanne Corcoran 25:46
Yeah. Well, because little Helen needed an answer.

Helen Bauer 25:49
Yeah, and there isn't one.

Rosanne Corcoran 25:51
Right.

Helen Bauer 25:52
Well, so and and isn't that a component of grief all the time? Everybody wants to know why. Why did this happen to somebody so young, so beautiful, so successful, so nice, so kind, somebody who hasn't had all the experiences. There's no answer to that. Why? Yeah, and there really wasn't for me either.

Rosanne Corcoran 26:13
No. How did your other family members react to your decision to care for him, and how did you navigate that? Like your husband and your kids were they like what What are you doing? What's happening here?

Helen Bauer 26:26
My husband was super supportive. I mean, he's he's lived his adult life with this relationship with my dad. Right? He knew, and he knew my history with my dad. My kids were a little less not understanding that they didn't understand it. You know, here's a guy that you dislike. You you haven't seen him in years. Why are you choosing to go up there now? You're going to fly 1,200 miles, and you're going to get a flight in a few days, and it's costing you, you know, $1,000. Why are you going to go to all this trouble for somebody you don't even care about? Well, the reason was because my brother was shouldering all of it, and I wanted to support my brother. You know, making the visit where I went up and saw my dad for the first time was just a personal choice on my part. My kids didn't question that, nor did I ask anybody for permission. That's not my not my thing. But the relationship was mine. Yeah, that was that was my history. But when I went up there when my dad got sick, they were questioning. They were questioning. Why are you doing this? And I think that's what a lot of people who are disenfranchised caregivers and disenfranchised grievers run into

Rosanne Corcoran 27:42
Absolutely how could how could they not? Because all of a sudden, then it's like, okay, I'm going to do this, but you know, you have this this wound that this person has created in you, and you're going to go put yourself there by choice.

Helen Bauer 27:56
Yeah, why would you why would you do that? Right. Yeah, it's like a dog going back to its own vomit. Why would you do that? It doesn't make any sense. But for me, it made sense. It was the right thing to do. Most of the time, I was supporting my brother more than anything else, because my brother ended up being my dad's decision maker, and he was boots on the ground more often than any of us. And that's what felt right to me, and so here's one of the reasons I was motivated to do any of this. I have always taught families when they asked, "Should I tell this person? Should I call the family in?" You know, I've been disenfranchised, disconnected. There's been bad blood between my parents and my my siblings, whoever, for years. Should I call the family and tell them it's getting close? And if they want to to be present, if they want to be there, this is the time. I always counsel people when you get to the end of this experience. I want you to be able to look at it and look at yourself and what you did, and put your head on the pillow at night and sleep like a baby and have absolutely no regrets. And I looked at my brother after my dad died, and everything was finished with. And I said, I have absolutely no regrets about this. And he said the same. And how many people get to do that? I mean, we we second guess decisions as caregivers, and you know the support that I gave him. I think everybody does that. Yep. You know, even if it's there's not a disenfranchised relationship between the caregiver and the person, but we got to the end of it and like we did what we knew was right, and this was the best fit.

Rosanne Corcoran 29:36

Yeah, that's a gift. It's another gift.

Helen Bauer 29:39
Well, absolutely is.

Rosanne Corcoran 29:40
And I was going to ask you that, like, what was it like when he did die? What did you feel first?

Helen Bauer 29:46
I was shocked, even though I knew it was happening. You know, I knew it was coming because the hospice agency had been seeing him every day, and my brother was not there at the time. There were none of us were there, so having the hospice agency. See him every day. I knew that they were seeing changes in him, and he had gone from care situations, living independently to assisted living, to memory care, to nursing home within a span of, I don't know, five months. Which, by the way, I would never recommend. It was horrific trying to find placement like that. So difficult. My brother managed all of that. The day that I found out my dad died, I was actually speaking at a state conference, so I was out of my state, away from all my people. I had four or five colleagues that I knew who were also speaking at the conference, so I had people there, but I was speaking, so I had to put on my game face. I found out my dad died at seven in the morning, and I was speaking at you know like two in the afternoon. So I had to go down to the conference, and I told one friend who was there, one colleague, and I said I just need to get through the day, and I compartmentalized a lot. Connected with my siblings, and I think we were all sort of. You don't want to dig in deep because this has just happened, and everybody was sort of digesting. So shocked, and then trying to cope until I got done with my workday because that's what it was for me. Sure, and then I made sure that I had a healthy dinner. I had one of my friends with me, and I worked out. You know, tapping into that atomic self care, the simple habits. And I was speaking again the next day.

Rosanne Corcoran 31:33
Oh gosh, of course you were.

Helen Bauer 31:35
Yeah, and I didn't want to stand up in there at you know at my talk and say, "Hey, I just want to let you know that my dad died this morning, so I'm going to fall apart during my, you know. And it wasn't anything like that, and there was not a lot of depth of sadness because disenfranchised grief is seriously messy.

Rosanne Corcoran 31:54
Well, I would think so because even if you said to somebody, "My dad died," oh, when was the last time you saw him, or what kind of relationship did you have, or whatever, and you're like, oh yeah, well, 30 years ago, and they, how was that? How was that conversation?

Helen Bauer 32:09
Oh my God, those were awful. So when you know when I got home, I don't know that I told people that my dad died, but maybe my husband did. But like going to church, and somebody would say, oh, I'm

really, I'm really sorry about your dad. And this is where it gets weird. At least for me, for as a disenfranchised griever, somebody offers this, and you don't know what to do with it because my my impulsive it doesn't pass through my brain, but it's going to come out of my mouth. Action was to say, I don't really care so much. It's okay, and people don't know what to do with that because it comes across as rude, and it is rude. Here's a person trying to offer you comfort, and you're like, don't bother. He was a jerk. As a coping mechanism, my answer to that was I didn't tell anybody, and I didn't bring it up. If I had friends that I was connecting with or I saw I didn't bring it up, and I became isolated. Not the best plan. No, not the best plan. But I had a lot to work through, and people that did not know me did not know my dad. They don't know what to do with that kind of grief, and that's why it becomes it's disenfranchised. People don't know how to support that. No, I was acting like a jerk, but you don't know what to do with it, you know. So, so I learned to say thank you and to tell people if they said, you know, how are you doing? I would say I'm really struggling with letting people support me because I was my relationship with my father was very poor, so I said this it's uncomfortable for me to receive any type of grief support or comfort. I didn't do that with everybody, right? You don't want to share too much, but no, no, yeah, not everybody is gonna know what to do with that, and sometimes that's the easiest thing. And you know, people say stupid stuff.

Rosanne Corcoran 34:04
Of course, they do it's grief.

Helen Bauer 34:05
Right? You know, I had somebody say, "Well, at least you got to see him before he died." I'm like, "Wow! Never, ever, ever!" If you're listening to this podcast, never, ever start a sentence with at least, at least, no. When you're talking to somebody who's had a loss, that that equation does not work.

Rosanne Corcoran 34:28
No, it should be banned.

Helen Bauer 34:29
No, no, and actually, it would piss me off most of the time when people would say that. I, you know, I I didn't know what to do with that. I really didn't. And and for me, because the spectrum of emotions were really messy. As a disenfranchised grouper, anger was a big part of mine. You know, bitterness and sarcasm and and dark humor, which you have to be very careful where you place the dark humor because not everybody gets that. Right. One of the things I really found problematic was working in. You know, end of life care, doing what I do. I even had my nurse practitioner ask me what I was doing to take care of myself. She said, "Do you have any hobbies?" And I said, "Well, I have a podcast. I love podcasting. I talk to all these fantastic people." And she said, "Oh, really? What's the topic?" And I said, "Oh, it's all about death and dying, and grief and bereavement and advanced care planning and hospice and end of life." And she's like, maybe you should find something else to do for a while.

Rosanne Corcoran 35:23
Something, anything, anything but that.

Helen Bauer 35:25

Yeah, yeah, yeah. So I did have some difficulty working, and I did sort of take an additional sabbatical from the podcast and some of the work that I was doing because it was very difficult to talk about some of these topics.

Rosanne Corcoran 35:38
Was that helpful that you were a professional and you knew everything about disenfranchised grief, or did it get in the way?

Helen Bauer 35:45
No, it was absolutely helpful. It was absolutely helpful, and you know, I had had guests who talked about disenfranchised grief, and I went back and connected with their work, and was able to look at that and sort of check the boxes. Oh, yeah, this is how I feel. Oh, this is my experience. Okay, so basically, what I had was a normal, abnormal, you know, whatever you want to call it, a normal disenfranchised grief experience. That's what I have. Yeah,

Rosanne Corcoran 36:14
That's really that's really interesting. And when he did die, did you find yourself mourning the father that he was, or the father that he should have been?

Helen Bauer 36:24
I was mourning the father that he should have been, the dad that I was supposed to have, the dad that was supposed to walk me down the aisle and be at my graduation and things like that, and be there to hold his grandchildren, things like that. I was I was mourning that. Oddly, I also found myself very sad over the finality of ever reconciling. Yeah, because while he was still alive, my eight-year-old girl,

Rosanne Corcoran 36:53
Yeah, little Helen,

Helen Bauer 36:54
Yeah, little Helen, my inner child was still thinking, "Oh, there's a possibility." Well, he and I had already done whatever reconciliation or reconnection we were going to get. That was all he was capable of doing. But when he died, that tiny little hope, that little spark, that somehow we would fix things, and that was never going to happen. I knew that, but that tiny little spark was gone, and I was sad that that potential, that possibility was was forever gone. Yeah,

37:26
yeah.

Rosanne Corcoran 37:27
It's the hope.

Helen Bauer 37:28

Yeah, it is, and it's it's okay to be hopeful. But I can see it from both sides. It was never a realistic hope, and it wasn't one that I was going to try to. That was not was never my goal. I wasn't going to try to make that happen. I knew better, you know, lifelong.

Rosanne Corcoran 37:44
You have been 100% sure of who he was and who he was in your life. It's like everything that came up. It was like you were like smacking it away. Okay, I've got this. I'm going to get rid of that. Do you know? Like, oh, really?

Helen Bauer 38:00
Years of practice, years of practice, good therapy. I think working in end of life care really helped with that. Sure, yeah, because I wasn't going to give myself anything less, and I had a lot of people, a lot. I had a very small tribe of very fierce advocates who said, "Don't talk to yourself like that. You get to do this, and and they were right. And because I have flexibility with my work, which is more than most people do. You know, even funeral home people. I think their policy probably for someone who's had a loss bereavement leave is probably three or four days, right?

Rosanne Corcoran 38:40
Yeah, it's so ridiculous.

Helen Bauer 38:42
It's ridiculous. So owning my own business and making my own schedule, I gave myself the biggest bereavement leave I needed, which was very fortunate because my mom died six months after my dad. Completely different experience, but here's this compounding of grief. So being able to give myself grace like that, it was never perfect, but there was a lot of it. I could look at it and I'm like, oh, that's just the anger coming out. I remember snapping at my husband one day, just biting his head off. Something minor, you know, household stuff. Sure. And I thought, oh, there it is. It's the first time that anger had really shown up, and it wasn't directed at my dad or our relationship, right? Because how do you how can you be angry at a dead person? Well, right, it seems a little irrational. No, no, I wouldn't be surprised anymore. But yeah, maybe at that point. But it was it was coming out in other relationships, and I thought, okay, that was an angry day. I'm having an angry day today, and I I talked to my husband. You know, I said, "I'm sorry. Here's this. Here's where this is coming from."

Rosanne Corcoran 39:47
Right, but don't leave your shoes in the front door.

Helen Bauer 39:49
Yeah, ever. Or I'm going to smother you with a pillow. You know, it was it was it was rough. I'm not sure that he would. I'm not sure that Brian would. Would offer the same the same perspective, but he was very patient, very patient.

Rosanne Corcoran 40:06

Well, but I think it all goes with the whole grieving experience, where everybody thinks you just okay, somebody dies and you get three days bereavement, which is horrific, and then you go back to your life, and you are supposed to be like you always were.

Helen Bauer 40:23
Yeah,

Rosanne Corcoran 40:23
And it's like that. That is not real life. And just because we don't have anything to support us in those times doesn't mean that's not how we're feeling. You can't just go back to your life. Your life is different.

Helen Bauer 40:35
Yeah, you can't schedule this.

Rosanne Corcoran 40:37
There's no way. But because we have such a lack of grief literacy. Everybody thinks, well, she's doing so much better, and then you come out of that, and then your mother dies, and you've got compound grief.

Helen Bauer 40:50
Yeah, and trying to navigate all of that, it was such a weird Bermuda Triangle of stuff. It was this perfect storm because the the week before my dad was admitted to hospice care, my daughter told me that she was divorcing, and then my dad died a few months later. I turned 60, which was a big milestone. My other daughter also began divorcing, and then my mother died. Yeah, and I'm like, holy crap! I'm not going to get out of bed. This is just this is awful. But you know, just supporting my my family, navigating these things that I didn't understand. I I really think my background in end of life care and grief work really helped.

Rosanne Corcoran 41:37
I'm wondering if all of these experiences has changed how you show up for hospice families. I mean, listen, I know you show up for hospice families anyway. That's not, but I'm wondering if this kind of gave you a different lens, especially with those with complicated relationships or estranged relationships.

Helen Bauer 41:59
I think it's like a lot of work that we do, where there's somebody on the other side being able to stand on the other side of the bed as a caregiver changes your perspective. You understand the method behind the madness, which is something that I have always worked on the podcast to provide to listeners, whether they're end of life workers or they're caregivers. If you understand what the other person is going through or what might be motivating their thinking, you know, being able to look through the situation through their lens, you're like, oh, okay, I get this. I know what they need. I understand what they're they're unable to communicate. I understand the grief expression that looks like angerness or resentment towards me is really frustration with the fact that they're trapped doing 24/7 care for someone they don't like. Right. I think it did change. I've always tried to see things from a caregiver's perspective because as a hospice nurse and an end of life worker, you have to be able to look at that,

how can you meet their needs? How can you help them plan for the care that they want, the experience they want? If you don't understand what they're going through, but lived experience is a game changer. I think it will change my work permanently.

Rosanne Corcoran 43:17
Especially on the compliance side, aside from the emotion side, because when you're on a hospice's service and you're waiting for the support for the help to come in, and it's not happening, now you see like, oh, okay, now I know why you're, yeah, you know, angry and unhappy with this service.

Helen Bauer 43:37
Yeah, and we had we had a really bad hospice experience with my dad, he was not on very long. I don't know, maybe a week or two. But the care was really bad at the start, and it wasn't just bad hospice care; it was bad nursing care. And I actually was there when it happened. And I called my brother and I said, "Look, this is horrible care. We need to make a complaint." So we ended up on the phone in a conference call. Me in one town, my brother in another, 1200 miles away, the executive director of the hospice agency and the clinical director. And I'm like, this nurse can never come back here. The care was crappy, and I did something I have never done before. I, I told him who I was. I said, I'm a certified I'm a CHPN certified hospice and palliative nurse. I've been in this business for 17 years. I've been at the bedside. I've been a manager. I've been a compliance specialist. I'm an end of life educator, and I know that this is not okay. And I never do that. I don't like for people to know that. You know, I like to give people the chance to to succeed, right? To build trust that way. Of course. Here I am, this hospice worker, and even I couldn't get good care for my parent. What the heck? Yeah.

Rosanne Corcoran 44:53
And you know the system, and you know how it's supposed to work.

Helen Bauer 44:56
Yes. And I I did tell him that I said. Yeah, the the the regulation is this and this. I got really down to it. I was hoping that they would be motivated, right? And so what it came down to is because we made a complaint, and this is a good thing for caregivers to know, they did change the staff member that was providing the bad care, and things were a lot better after that. The communication flowed the way it was supposed to. Decisions were made according to my brother's guidance, which was what was supposed to happen. And the care in that last five six days was much better. Okay, much better.

Rosanne Corcoran 45:37
And then when your mother was in hospice, was that a good experience in hospice or a not so good experience in hospice?

Helen Bauer 45:45
It was much better than what my dad had. There was some good and bad. Sometimes that I thought, oh man, these people. You know, you ask for a resource for my siblings. I had given them all the Barbara Karnes books that I had here. Absolutely. And I I asked the nurse. I said, "Do you have any resources that you could leave? You know, you know, we don't have anything else. I might I need another copy." And they said, "Oh, we don't have anything like that." So when you are having to tell

your hospice staff, "Hey, there's a great booklet called Gone from My Sight that describes death and dying, et cetera, et cetera," and I'm having to show you this, and you're taking a picture of it with your phone. That's messed up. That was not my job. Yeah, most of my mother's last month, I worked as her end of life doula.

Rosanne Corcoran 46:31
How do you? Oh gosh, Helen. Six months after your father died, after you had to deal with all of those emotions of 30 years of emotions that came bubbling up, and then your mother's in hospice, and then you're her end of life doula. How did that work? And did this grief complicate this grief?

Helen Bauer 46:49
It was it was so different. And and when I say I worked as her end of life doula, I I'm not a doula, right? I'm not a death doula. So I get what you're saying. I just ended up being at the bedside teaching these privately hired caregivers that we had to have 24 hours around the clock. The experience was was very different. We had the assisted living staff. We had my brother and sister living locally. You know my flexible schedule, so I could be in and out and in and out of my mom's place for me, because I was my mom's healthcare decision maker. I was in business mode. It seemed like that I was in work mode a lot of it. But we had this fantastic hospice case manager, the RN, and he would tell me, "Okay, we're going to do this and this." We, my mom, had terrible agitation, terminal agitation. So we would talk about meds, and I would say, "Hey, I've seen this be successful. Could we try this? Or we've already done this, so can we skip over this med and try to get something else?" And he really collaborated with me, made me feel like a peer, like one of the team. And then he would say, "Now tell me what you're doing to take care of yourself. Tell me how you are." And he would remind me, "You need to remember to be her daughter." Right. So we had really good care there. And then the on-call nurse for the weekend that she died was compassionate and skilled. Communication was great. And when the nurse came to to do the the death pronouncement, he let us take all the time. And I knew his phone was going off. There were other people looking for him because he was on call for other people, other patients. But he spent all the time that we needed, and he helped me bathe my mom. You know, provide the the after death care, the post mortem care. So respectful and so kind. And we had an aide that she was Cracker Jack. She was great. She would communicate. She talked to my mom, and I told her up front. I said, "Gotta tell you, my mom's a handful, and she doesn't." One of her things was she didn't like feeling like that her modesty was not respected. She didn't want anybody in the bathroom, even when she could barely walk, you know, and she got UTIs, her skin was messed up because she wasn't showering and she wouldn't let us do it. And so I told the aide, I said, just so you know, she's probably going to be combative combative with you. And she's like, okay. So she went in there and she took care of business and she came out. She said, we're all done. My mother's hair was washed. She was clean. Everybody was fine, and I was overjoyed because being clean is part of being comfortable. And when my mom was healthy mentally and cognitive, you know, had all her faculties about her, she would never have allowed herself to be dirty or her nails to be jagged or any of those things. So that was an incredible, an incredible gift that that part worked out. And even after my mother became unresponsive, the aide would go in there and greet her and talk to her and tell her as she was cleaning her and bathing her. Was that part of the care was was actually pretty amazing.

Rosanne Corcoran 49:55

I wish there were more aides like that. I wish there was more. Education to be like that because it makes all the difference. I I wanted, and I don't know if your mother was aware of it or not, but did she was she aware that you went to see your dad?

Helen Bauer 50:13
No.

Rosanne Corcoran 50:15
Okay.

Helen Bauer 50:15
No, I didn't tell her because she was already declining drastically mentally at that point, I want to say that when he died, my brother did tell her, but there was no love lost between my mom and my dad. So I think maybe my mom was very happy that he went first. You know, you know, it was typical. Yeah, lifelong, lifelong bitterness. So I think she was she knew about it, but I didn't tell her about my trip. It just didn't seem worth it. And that trip was about me. I was dealing with my emotions and kind of figuring out how the puzzle fit together for me, and I could not take on my mother's confusion around that whole topic, and it just seemed hurtful. I think, you know, if I had done it 15 years earlier when she had no dementia, I think she would have been hurt by the fact that I did that. Did your siblings tell her that they were in touch with him? Okay, no, no, they just didn't discuss it. And and my mom, you know, becoming more isolated and less socially active, and you know her world became very small as her dementia advanced. So no, they didn't. Yeah, they didn't have conversations with her.

Rosanne Corcoran 51:32
Okay, your boundaries, Helen. God, you should teach a course in boundaries. I'll tell you what.

Helen Bauer 51:38
Well, you know, I I would say that I'm. This is one of the reasons I don't sanitize my story. I'm pretty typical, even though I have a background in end of life care and I'm familiar with the grief stuff. It didn't change my grief experience. It didn't make me transcend any of this. You know, people who work in care professions still going to grieve. Their families are still jacked up, just like everybody else is, and they're still trying to cope. We we don't necessarily handle it better than anybody else. My grief experience, I don't think, was easier or shorter or any of those things. Just because I have an awareness, you know, knowing about grief and death and dying is not the same as experiencing it for yourself,

Rosanne Corcoran 52:23
And everybody's different, and every experience is different.

Helen Bauer 52:26
Yeah, and you get to do that. Yes, you get to do that. Everybody gets to do it their own way. Yep. Yeah.

Rosanne Corcoran 52:35

Whatever that looks like. What would you say to someone caring for or grieving someone others think they shouldn't.

Helen Bauer 52:43
Here's what I would say: Your grief is real. I would tell you to take time to sit with it, reflect on how you're feeling, and then come out of it and do other things. Dip in, immerse yourself when you need to. Find professionals who can help you talk to them, and then find the experts who are talking about your kind of loss because they're out there. You know, daughterhood and there are other groups. If your person died by suicide, if your person died by medical aid and dying, that's sometimes those types of grief become disenfranchised because again, there's not a homework card for those things, so find your group, even if your tribe is one person that you can talk to. Don't let yourself be isolated, and you don't have to be in a grief support group. That doesn't work for everybody, right? Yeah, there's a grief support group here at my church, but I'm not looking for a religious-based grief support group, and these are my fellow church members. You know, other congregants that I go to church with. I don't want to necessarily display all my personal stuff. So find a place where you can feel comfortable, and don't become isolated. That one person, if that's all you've got, it's somebody you can talk to, somebody you can text with, and take your self-care down to that atomic level. Those tiny little things matter. Those health habits. Put yourself to bed on time. Limit your screen time. Get some sunshine on your face. And the last thing I would tell them is, you get to feel the way you feel until you don't feel that way anymore.

Rosanne Corcoran 54:20
A big thank you to Helen Bauer for being my guest today. For more information about Helen's services and the Heart of Hospice podcast, visit theheartofhospice.com.

Rosanne Corcoran 54:31
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 at 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 caregivers discover the support they need. Follow us on Facebook and Instagram at Daughterhood to stay connected. And if you know someone else who may benefit from Daughterhood, share it with them. Also, a very special thank you to Susan Rowe for our theme music, "Mama's Eyes." This is Rosanne Corcoran. I'm so grateful you spent your time with me, and I look forward to being with you again next time, here in Daughterhood.