# Girls Night #225: Practical Ways to Help Your Loved Ones Through Grief and Hard Times — with Jane Butler & Christy Knutson

## 0:00:05 - Stephanie

Hey friends, welcome to Girls Night. I'm Stephanie Mae Wilson and I'm so happy that you're here. Each week, I have a girlfriend over and we talk through one of the biggest questions we have about our lives as women. We're talking about friendships and faith and relationships and self-confidence, about our calling in life and how to live every bit of our lives to the full. Life is so much better and easier and absolutely more fun when we navigate it together as girlfriends, and I cannot wait to get started. Friends, I love the conversation I get to share with you today.

Today, we're talking about how to best care for your loved ones during hard times. To walk us through this, I invited my new friends Christy Knutson and Jane Butler onto the show. Christy is a healthcare strategist and entrepreneur and, after a series of early losses in her life, she is working to improve the end of life experience with a deep belief to be a better way. Jane is a creative professional and entrepreneur, and when Jane's fiance now husband was diagnosed with brain cancer at the young age of 24, they quickly learned the value of grief, support and care in their healing. Today, as business partners, they co-founded an amazing company called Neer to help change the way that we offer care and support during difficult times. In this episode, they're answering hard questions that so many of us face during our lives. Questions like what happens when someone I love receives a diagnosis, or how do I support a friend or family member who's going through something hard, or what do I say or not say to someone who's experiencing grief, and when do I start thinking about end of life planning, whether it's for my parents or for myself, and how do I even approach that conversation and doesn't have to be so depressing Ah, and the list goes on. Friends, these are heavy things to talk about, but I know that we will all be better friends and better caretakers and better equipped as people who go through hard things in our lives because of it.

Friends, I'm excited about this episode because I know that so many women in our community are dealing with grief or loss or really really hard diagnoses, either for yourself or for people you love. I know a lot of the women in our community are responsible for taking care of people in their lives Family members, parents, aunts, uncles, siblings and that's a really hard position to be in, and so, no matter what you're going through today, I pray that this episode helps you feel seen and supported. We're in your corner. All right, friends, I'm so excited for who you get to meet today. I'm sitting here with my new friends, Jane Butler and Christy Knutson, and I am just I'm really excited for the topic that we have today. So before we get into it though, Jane and Christy, thanks for being on the show. Thank you for having us. Can you tell us who you are, what you do and a fun fact about yourself? Maybe, Christy, let's have you go first.

Okay, sure, so I'm Christy Knudson. I'm the co-founder of Neer partners with Jane, and my fun fact is that whenever things are really hard, like in life or in work, they're really stressful. I like to kind of daydream about this dream job that I have, which is to be the person at a cat show who, like shows the cats. So little known fact there are cat shows just like dog shows, except for they're set up a little bit differently, and so there's a person who gets the cats out of the cages, holds them up and just goes on and on about all the details of these cats and to me that just feels like the ultimate and fun and low-key and, like you know, not to say it's not important, but it is a far lighter job than what it is that we do. So sometimes I just daydream about that. And now that TikTok has taken to the cat shows, now I can watch these people do their jobs on TikTok, which is really satisfying.

#### 0:04:02 - Stephanie

That is everything I didn't even know to hope for. That is absolutely amazing. This is like might blow your mind a little bit here. My family growing up took cats to cat shows Shut up.

0:04:22 - Christy I wish.

# 0:04:23 - Stephanie

Honestly, this wasn't my thing, this was my sister and my mom and I kind of wish I was kidding, it is true they somehow. My sister really wanted on I think we wanted a bunny and my parents were like, absolutely not, maybe we can get another cat. We had sort of you know, an adopted cat that we'd had for a million years and they're like, maybe we can get another cat. My mom somehow ended up getting this like fancy cat that they did take to cat shows. So I have some context for what you're talking about and I love that that's your dream.

# 0:04:57 - Christy

That is amazing. Well, you're making my dreams come true, because you're the first person I've ever met outside of an actual cat show like in my personal life who has had a cat in a cat show. So it's kind of a clean thing.

#### 0:05:09 - Stephanie

This is not where I thought this conversation was going to go. Today and I listen, I'm meeting you here. I need to reinforce the fact that this was my mom and my sister's thing. This was not my thing.

## 0:05:22 - Christy

No shame in that game, Stephanie. No shame.

## 0:05:25 - Stephanie

Okay, Jane, let's go with you. I'm excited here. Oh my goodness.

0:05:29 - Jane

I mean, yeah, christy said the bar really really high for what I'm about to say and introduce, but I'm Jane Butler, I'm the co-founder of Nier Business Partners with Christy, I live in New York City with my three kiddos and my husband and I was. I mean, my fun fact was just going to be that I actually went to school for musical theater when I was first considering careers which at this point in my life seems like decades and decades ago, but definitely have a huge musical theater side with some of my favorite characters that I get to nasty on Broadway. So it hits hits close to home.

0:06:05 - Stephanie What is your? What's your favorite musical?

0:06:09 - Jane

Oh tough. I really love Wicked but you have to see it to like fully appreciate, I think, the storyline. And then my it's probably second best one is my Fair Lady.

0:06:21 - Stephanie Big my Fair Lady fan Big my Fair.

0:06:23 - Christy Lady fan over here.

0:06:25 - Stephanie

I love it. I love it, okay. Well, so now the world friends. Perfect. Really glad, you guys let's see. Well, I'll tell you a little bit more in a minute of why I wanted to talk about this today, but I want to hear more about Nier. It's this online platform. Tell us about it, like, why did you guys found it? What is it? Give us kind of the backstory of it.

0:06:52 - Jane

Yeah, I can go first with a lot of why we do now comes from personal story.

And about almost 10 years ago which I feel like I have to kind of update my own story as the years go on my husband was diagnosed with a quickly expanding brain tumor and we were 24 days out from getting married, and so it was quite the reaction, like just it was quite the story, right, like we're about to get married and then this tragedy kind of comes in and we are just in shock of what's happening and I'll condense the story a little bit so that it doesn't it's like a podcast in itself, so like rewind it and do like a 30 second clip.

He went through his first surgery and it was successful and we were able to actually not have to do treatment, which was great, and we did get married on the day that we planned, which again I look back at our pictures and I'm like it's still so much about a celebration of life, even more than love, like the fact that he was there was the gift, the best gift to me.

And then fast forward eight years, you know, moved a bunch of times, established our careers, had three kids and last August he was diagnosed again with the tumor growing back, and I

remember calling Christie we have been business partners with our agency for a while and I remember saying like again, like, is this actually happening? Like I thought we had our brain tumor story. I thought that was it, and I was going through a lot of just kind of the shock and fear and just like overwhelm that comes with a diagnosis like this. And he was able to go through his second surgery successfully again, which I say that very gratefully and humbly. I know that not everyone has that outcome, and so our days are still very fragile, as everyone's are, and I remember calling Christie in his recovery saying there's got to be a better way for us to care and support during these times, and our wheels started turning and that was kind of like one of the pivot points to establishing a platform that does just that.

## 0:09:03 - Christy

Christy, what about you? Yeah, so for me, I've always been interested in healthcare, and just naturally. But then, when I was 10, I became a primary caregiver for my grandmother, who was living with Alzheimer's. From the time I was 10 to 22, I just had a number of serious illnesses and deaths in my close family. I was raised as an only child, but our extended family was incredibly close. So starting at 10, again caregiver for my grandmother, she passed away when I was 16.

I had a first cousin, teresa. We were both only children. She was older than I was, but she was like an older sister to me. We were best friends, she was my person and right as soon as our grandmother passed away, her mom, my aunt, was diagnosed with cancer. I walked through that experience with her and my aunt for a number of years and then she passed away. And within a year of her passing away, teresa was diagnosed with cancer. Teresa's illness was about four years from point of diagnosis and then she passed away when I was 22. So that was for me an incredibly pivotal, tragic, very, very difficult loss. So I always knew that I wanted to go into healthcare before that, but for me that made it even more evident that that was what I was supposed to be working on. Essentially, it's my life's work working within the terminal illness, serious illness and grief and loss space. So she's with me in my work and it's incredible, but it all really stemmed from a really painful experience.

# 0:10:43 - Stephanie

Thank you guys for sharing that. I wish I could give you a hug. That's the worst part about doing this. Actually, tell me about NIR. What is it, Jane? You called Chrissy and we're like there should be something like this. Tell us what it is. Also, I'd love to hear what the process has been like of starting this thing.

### 0:11:10 - Jane

Yeah, I can explain what NIR is. I think also, just prefacing this with telling stories is actually really good for people that experience them. To the people that haven't experienced them, I think there's a lot of beautiful healing and retelling and opportunity to just invite you in, Because in today's world we don't talk about hard things and yet there's an opportunity to be like it's okay, if you're having a hard time, you can talk about it, and so I preface all of from what our story has come from is that we're very the. We're jumping to the deep end because that's where people

need it most. So NIR is like a Similar to a wedding and a baby registry, where there's always all of these logistics and gifts and comfort items and things you can do to be proactive.

We're applying that towards terminal illness and loss.

So if somebody's diagnosed, typically that involves on the healthcare side of things, a lot of appointments, logistics, care items, comfort items, things that you need that you don't want to have to either purchase on your own, or people want to help and they want to do it for you.

You can create a list, say I need all of these things or I need you to do all these things, and so we facilitate that, we organize it and make it easier for your community to say I can do that, I'll take care of that, I got that, and then that is able to kind of elevate some of the needs in front of your community. And then we also have the loss side of things, where at the end of life there are just so many logistics that we don't either know about or we don't talk about, and again it can step in and be the support that you need during that time too. Instead of just having meals and money, which are extremely helpful, it actually puts those to a little more action and actually gets you moving to accomplish some of the things that you need to do that are necessary during those times.

#### 0:13:07 - Stephanie

I have so many follow up questions. Well, yeah, so let's pause for a second. Tell me I feel like I can picture. Well, give me a couple of examples of someone's diagnosed, some of the things that you can have people sign up for, or some of those care items, because, yeah, I know what goes on a wedding registry. I know it goes on a baby registry. Although that was hard, I remember being like what is this stuff Like?

I don't know what any of this stuff is do I need all of it? So both of those things were hard, but I can picture what those registries look like. Yeah, what are some of the things that are needed?

### 0:13:49 - Jane

That are needed. Yeah, no, that's a great question. So if I can apply it to my story, which I feel like I'm going to be able to connect with the most, since I lived it when Andrew was diagnosed that second time, I wasn't just planning a wedding, which I had my own wedding schedule and everything on that being diagnosed the second time, I'm a mom of three. Right, I live in New York City, he has his work and there's all these people that want to help and it's amazing, but it's like I don't know how to facilitate that. And so one of my dearest friends basically said sent everyone to me and she got her spreadsheets out and she was organizing like this person's going to go there and pick up the kids from soccer.

Because I think one of the best things about during a hard time not best, but one of the most effective things during a hard time is that you try to keep some things normal, especially for kiddos, who everything else has already been. They can feel the change in the air. In many ways there's something wrong. Things are different now to try to still apply what their normal schedule would look like. So my son had soccer a few times a week Like somebody would need

to do that while I was taking Andrew to the hospital, or I would need transportation, or I would need someone to help clean my house, because there's been people in and out Like there's a variety of really practical ways that if you just like saw it in a list people would say I can do that, I can come and empty the dishwasher, or I can come provide breakfast that morning or I can watch the girls while you're at the appointment, and there's a variety of things that we can do and actually use other people's giftings if we were just able to clearly say have somebody say, ok, this is what they need and when.

And then, as for gifts, on a lot of the terminal illness set of things and Christie can talk into this too there's some really practical things that people need, whether it's certain pillows or healing products or self-care items that, as friends who are creating the registry can add because they would know you best. And so there's a lot of opportunity to just come around the family or the person in need and have somebody lead that in a way that knows them and that can care for them really intentionally, versus just saying, well, here's \$100 and I'll pray for you, and I think the prayer is not important. It is important, it's necessary and we can do a better job in caring intentionally and knowing people well.

# 0:16:08 - Stephanie

I love this because I think that we, when someone's going through something, anything you go what can I do? Right, because you don't want to insert yourself into the moment, you don't want to be a burden, but even asking that question is like a little bit of a burden because it puts the ownership on the person who's going through the thing to then organize the team and the last thing you have any energy for is organizing adults. I became a mom almost exactly three years ago to twins and it was right in the height of COVID and it was just absolutely the most overwhelming year of my life, basically, and we had so much help and it was so great. We had our family who all quarantined like crazy and basically lived with us and I mean it was awesome. But trying to figure out, is my sister-in-law going to do the dishes? Is my brother-in-law on washing bottle duty, organizing all these adults when I was trying to keep myself and these tiny babies alive was just a lot, and so any time my mother-in-law kind of ran point, which was really great, except when she wasn't there, then it was like who was in charge here Me?

So I love that and I love the real, really personal. I don't know, having those care items where you're like. I know that this is the pillow this person likes, you know, and having a good pillow doesn't fix everything, but it helps a little and that's good. Christy, tell me more about on the end of life, terminal illness, kind of thing. Jane, I know you said that there are things that we don't even know that we need or need to do. What does near help us do for that?

## 0:18:07 - Christy

So I can just give like a concrete example, almost like a case study, and we can kind of walk through that so you can see what it looks like in a very specific example. So let's say we have a couple and they have children and the husband was diagnosed with, received a diagnosis and knew that he was toward the end of life. Let's say maybe he had a few months to live with his prognosis, and so in that case the family, like Jane said, would identify a care coordinator. So in Jane's situation it was one of her really good friends. It could be an adult sibling, it could be a

friend. You know someone in a faith community as you identify a care coordinator and they are typically the ones who set up the care registry.

The care registry can be set up by the patient or the family themselves, but usually that's too overwhelming, there's too much going out. So the care coordinator sets up the registry and there's two main areas of the registry One is tasks and the other is products. So on the tasks, and that's where they would work with the family and figure out, to Jane's point, you know who needs to be picked up. When do the the flowers needed to be watered right Is there transportation issues back and forth to doctors appointments. You know we need somebody to set up a hospital bed in the downstairs, for example, so that's where you add all those tasks and that way you can share the registry and people can sign up for very specific things. And then on the product side, it can be anything from comfort items to very helpful medical supplies. So oftentimes and a lot of things are covered by insurance. But, as we all know, a lot of things are not covered by insurance, especially when it comes to the comfort end of things.

And right now, you know, the problem with with not having a solution like this is that families right now are left to just kind of receive what they receive and of course they're grateful. But in some ways that can become an added burden, because if you're receiving 10 of the same thing from very well-meaning people, then you've got to figure out what to do with it and you've got kind of the emotional, mental guilt of well, do I need to make sure I'm using it? You know all of that, all the logistics, and so this really streamlines the process, so that you're not getting duplicates of everything, but also that you can ask for what you need. Because when somebody texts you let's say, a friend from church texts and says, hey, you know, I really want to send something that will be helpful, what would that be? We don't know oftentimes what budget they have in mind, and so of course, we err on the side of asking for something really small, maybe financially, because we don't want to be a burden. But maybe this person has the resources where they really would like to to buy you, you know, a \$300 Vitamix blender so that you can make the exact kind of smoothie that your stomach can tolerate right now. Right, and so we just.

Again, it's empowering people to give in the best way possible, primarily for the family and for the patient, but also for the person who's giving. So, yeah, so you can set up a care registry at that, and then go from there and to your point about what things people may need that they don't know. That's what. That's where it's really helpful to have a registry to choose from, so that the care coordinator isn't just having to think of all these things. They're able to kind of shop and then add things from our recommended in recommendation list onto the registry. So, for example, if someone's having a mastectomy, they may not know that there are pillows to help with lymph node removal, that there's seatbelt protectors, that there are specially made pillows to hold ice packs that are shaped so you're not having to finagle and make all these things work that were created for that purpose.

0:21:43 - Stephanie

Do people cry a lot when you guys talk about your work? I like, I feel like they must.

0:21:49 - Jane

I just yeah, and so do we, Like we can, we can talk about it because we know or like it is. It is so from our hearts to build this, and we've also been able to. We've cried a lot on our own Zoom calls. So I feel like we it is a safe place to just connect with a lot of the pain that goes on and to say like we cannot remove the pain, but we can certainly care for it. And so how can we do that? And I feel like that's kind of where we're like we've got to do something to connect the pieces.

# 0:22:19 - Stephanie

I love it. I feel like I'm like not even crying because I'm sad. I'm crying because I'm so grateful that this exists, like one of the. There is that deep need when something is happening for people at all distances from the the incident or the illness, where people are all grieving and there's like the waves of grief or the ripples of grief can be so wide and you, you really don't like as a third cousin or something, you don't want to insert yourself into this Like, you just don't want to be a burden, you don't want to make anything worse, but you really genuinely want to help. And so, having a way that is helpful, having one link like to be able to send out to anyone who wants to help, I just this is such a service, not only for the people who receive the diagnosis and their immediate caregivers, but like for everyone who's even tangentially affected by this, by this we I live in Nashville and we had a school shooting earlier this year which don't even I can't.

I'm just going to leave that there. I have so many feelings about the fact that that's something that so many of us have experienced. But watching our community come together was so beautiful and I was so thankful for just a handful of individuals who either, you know, were parents at the school or were best friends of parents at the school, who gave some really practical ways to help, and so the whole community, the whole world, anyone who wanted to, was able to donate to. You know, providing therapy for the parents of every kid that goes to the school and you know, like just all these different some of me, the Easter baskets for every single family there.

You know, I think people are still doing their laundry and you know it's been six months or so, like I just, but I know that people had to coordinate that in all kinds of different ways to have some really centralized ways of saying, hey, this is what we need in the midst of this, because so many people want to help and that's amazing but also can be really overwhelming. So I just I'm just over, just overwhelmed by how much I love this. Tell me what it's been like to make it, because that's making a building, a company is hard and there's so much that goes into it. So what is that process looks like for you guys?

## 0:25:11 - Christy

So it's been a wild ride, of course, as it is with any kind of a startup or a company. And to give a little bit of background, Jane and I have been working together for a number of years. We had a marketing agency, marketing and creative agency for many years before this, and we're partners, so it really helped in that our relationship, our partnership, was already really solid going into this, and I'm especially grateful because we knew that it would be difficult, but it's really hard to prepare yourself for how difficult it can be sometimes, especially when you're building something that is so closely tied to personal experience. This is not something that is

separate from us or from our lives or from our hearts in any way. It's something that's deeply personal, and so it raises the bar kind of on what that means to carry it out every day, and so really it's been an interesting experience.

We've experimented with different models over a few years in terms of thinking about okay, we know that we have a set of problems, we have a set of gaps, from the point of diagnosis to after death care. We know that in our culture, in the healthcare, in society, there are all these gaps in care, and how do we figure out how to build solutions to fill in some of those gaps, and so that's really what birthed the care registry, and we also have a care directory which, to your point earlier about not really even knowing what is out there, this is one of those things that we only each of us will only ever experience a certain number of deaths in our life. Sometimes they happen later in life, not always, but oftentimes later in life, and so when you're especially if you're in your 20s, 30s, 40s, and you're dealing with an ill-loved one, you don't know what to even ask, and so you can't really learn how to do this. Well, until you've done it, and at that point maybe you've missed a lot of opportunities for connection and for care along the way. So that's part of the reason why we added the care directory as well, because, just being in this field, when we had the marketing agency, we worked with a number of other startups in the end of life space, mental health space, healthcare space, and through those we were exposed to all these companies, all these founders who have built really beautiful solutions to incredibly niche problems.

That, again, it's not widespread. People don't talk about it. You don't want to talk about it unless you have to talk about it oftentimes. And so you get yourself in a position, you find yourself in a position and then you don't know what's out there. So the care directory is to help match people with services that they otherwise wouldn't know about, because and it's not just really uber serious services yes, you need to have a will, yes, you need someone to help you with your end of life planning, and also there's an invitation to work on legacy projects, and that's something that you don't have to wait for a diagnosis to get started with. And again, beautiful companies, beautiful founders who have built incredible ways for you to share your life story through video, through writing, writing letters now to leave behind for the people you love, and we just appreciate any chance to expose people to what's out there.

## 0:28:45 - Stephanie

I love that. That's so awesome because you're exactly right, I feel that way about weddings. You plan a wedding and you learn everything the hard way, even though there are so many resources out there to kind of walk you through it. And it's like you just get good at it and you have your wedding and then all of those skills are just like sitting in the back of your head and you hope that, like your sister will, will, you know, actually want your help when it comes to time to plan her wedding. But it's yeah, it's one of those skills that you have to really learn the hard way, and then you don't really get to use it that much, and so it really makes sense. I'm just really grateful for that.

I want to ask you guys just some. I know that women in our community are in all kinds of different places. I know that for a lot of women, you know they're receiving diagnoses. I know

that so many women in our community have people in their lives who are sick. I also know that so many people are grieving losses right now and again.

This is stuff we just don't really talk about, and so you end up having to go through it alone and I hate that. So I want to just ask some of the like questions. I know that all of us are asking about really hard moments in life like this. I want to first ask and just hear you know, because you guys have been doing this for so long and you guys have been through this personally I'm just excited to hear what you have to say If someone we love receives some sort of health diagnosis. What are some of the things that you found it helpful to say? Because I feel like so many people are afraid of saying the wrong thing and then also a lot of people do say the wrong thing. So what are some things that are, like, actually helpful to hear when you're on, when you're going through something like this?

#### 0:30:40 - Jane

Yeah, no, those are. That's always such a great question and I want us as a society to get better at it. I want us to to just recognize that we're not. No one has like a hand of aces that gets just cruise through life without any pain or loss, like it's for humans. We're going to face it and I think one of the biggest things that I typically just like say to people right away is, if you're not going to say anything, then just be there or just say I'm here and just recognize that your presence is a present in itself, because if you don't say anything, some people like type something and then they, like you know, erase it really quickly because they're like oh, I don't know how it's going to come across and just to say like I'm here, I'm so sorry, I'm here, I'm thinking about you, like just recognizing like you are there and with them.

Whether it's physically, you can be there with them, or through a text Like just call that out, because so quickly when you're in painful moments and grief you, even if you are the only one feeling like it, it's just another reality that you feel like everyone else is just off with their busy life, and hospitals are the are the craziest place for that. I remember going in like near exciting people are walking the streets, there's a world of you know people and then going into hospital and feeling like time just stops, like it's a separation from like all the exciting things that they're. And then what I'm facing in the hospital and I just had friends say like I'm here, I'm thinking about you. I know it's like a lonely to be inside of a hospital. I just recognizing where I'm at was like, okay, I'm not doing it alone, I'm not going to do this. It's painful and it's heartbreaking and, yes, I am his wife and I'm the only person who is impacted as his wife and I'm being supported by my friends and family by just saying I'm here, for white people should not say I cautious people all the time, and I think it's tricky in faith communities.

We always want to reason it or slap scripture onto it, to just be like well, you know, it got to work this all out for good, or or everything happens for a reason and it's those those are, so those can become weapons to someone who's truly hurting. A lot of scripture. If you really read the Psalms and really read through, joke it's. It's just lament, like just just to sit and just to say like I'm so sorry this is happening to you, I'm so sorry you're facing this, I, I'm with you in the pain, I'm sitting with you, you can pray, but don't try to just remove the pain like accept that it's a reality for them and that's okay, like the Lord is still with them, as he is with you in your good

moments. And so I would cautious people to be, to not be quick to respond, to try to make it better, because that's not helpful. We think that we should just be exempt from pain and everything is better, but that's not helpful in the moment.

I think empathizing and sitting with them is going to be the the biggest thing that builds connection and care to their hearts, and to recognize that. You know, if we're, if we're going to talk about in faith community, christ did that Like he. He grieved, he cried, he. He did not like eliminate the pain from his life. He was, he walked out and he lamented. And you don't hear the disciples saying it's going to be okay, like you know, remember what the whole story was. Like everyone like they, just they sat with him.

And I think there's something there that we don't allow. I want us to get better at, either in faith, faith communities or just in your social circles, like just someone's going through her hard time. Sit, sit there with them, empathize with them, just do what you can to let them know you're not, they're not doing it alone and they won't do it alone because you'll be there and you can admit. I had friends say I have nothing to say, I'm just here, and I appreciated that. They were like nothing is going to fix this, right, I'm not going to say anything that's going to make it better, and I'm here and I'm like okay, that I feel like is puts a little bit of water on the fire, versus adds to it. That's probably what I would say to someone who's asking like what do I do? What do I say? I would have them really think through those, those things, yeah.

#### 0:35:01 - Christy

Christy, what about you? I agree with everything Jane said, that Jane said that beautifully. And then I would also think about the timing of whatever it is. However you're reaching out, I would think about the timing of that. So, yes, for sure, if someone receives bad news, if an accident happens, reach out absolutely and let them know that you're thinking of them. But then really do whatever you need to do in your own kind of organizational methods to make sure that you do not let these people who you love be forgotten.

Because it's very easy, for you know, it's the onslaught of support at the very beginning and then the longevity of care afterwards trails off right. The longer an illness goes on, the longer your grief goes on, the less people reach out to you and the less people provide support, because they either assume that you've moved on or, let's say, in the case of a serious illness, they just kind of assume at some point that you've got it figured out and there's really nothing else to do or to say. And yet you're still left living in that personal hell. And that's where the isolation can really take hold and the loneliness can be just excruciating. And so I would say, you know, practically speaking, think about how can I make sure that I'm checking back in with this person, not just in the next week but in the next months, if it's a loss or if it's a death. Make sure you know you mark anniversaries on your calendar Because, again, those are the days where there's a lot of support at the beginning and then it trails off very guickly.

#### 0:36:39 - Stephanie

I love that. I love that. Put it on your calendar. We put birthdays on our calendars, absolutely.

# 0:36:44 - Christy

Absolutely Try and remind yourself. Put death anniversaries on your calendar. Those are incredibly profound days oftentimes for those who are left. And also you know, of course, if someone loses a mother or father, put mother's day, father's day, their birthdays. The more personal you can be, the better. And you know, oftentimes you hear well, I don't want, I don't want to reach out on Mother's Day and say something because I don't want to remind them of their loss. You are not reminding them of their loss. They have not forgotten. You know, if you have lost someone who you love, you know that you are thinking about it. It is, it is, even if you're not thinking about it every moment, it is just below the surface, every single moment. You are not reminding someone of their loss. You are entering into their pain, with them and helping alleviate, at least hopefully, some fragment of loneliness and isolation.

# 0:37:35 - Stephanie

That? Yep, that's amazing. Talk to us about the rest. Like Jane, like you said, outside the hospital the rest of life is still kind of going on, and I know you said it's helpful to have some things be the same. When everything is upside down, how do we like what are some practical ways we can I don't know like manage the fact that like a part of our life is totally falling apart but the rest of life is still going? How do we kind of balance those things or, I don't know, live in that tension?

#### 0:38:18 - Jane

Yeah, yeah, I would say it's a tension, right. It's like you're walking a tightrope when you have kind of pain on one side and yet normal, like your previous commitments are just responsibilities on the other side. That you know, my kids were seven, four and two during his second surgery, and so there was an element of like I can't just put them aside. Children will not be put on the back burner. They will not let that happen ever and that's okay, like that's how they're, that's children and they're beautiful. And I think that I remember having my friend who was also my care coordinator. She basically gave me like open permission to call her texture 24-7. And there were just many times where she would say did you give yourself space today? And whether that was like a five-minute space in the bathroom just to cry and be alone and let my children watch some cartoons, because that's okay and you know, when you're in a time it's okay in many ways in motherhood but it's okay to just say I need five minutes, I need the bluey episode of eight minutes to help me recenter and get in a good place, because you're balancing so much. Like your brain is like fight or flight when it comes to stuff like this. And so I would say you've got to give yourself your space to be able to walk that tightrope and to be able to recognize the needs on both sides and to say, okay, I'm going to serve and help in this situation. And I'm also going to say I'm going to delegate someone else to be there at the hospital with him so I can sit with my kids or so I can go and do something that just brings life to me because it is so draining. There's some really beautiful products. Right now there's a company called Help Texts. It's H-E-L-P Texts and they have a whole like grief and mental support for caregivers, and so you can like set it up for a friend who's caregiving for someone who has terminal illness and they can receive these like really beneficial check-ins to say, okay, am I doing this? Okay, like to for them to just have somebody else say have you taken time for yourself today? Do you need to go on a walk today? Have you cared for yourself physically today, whether it's, you know,

exercise or a healthy drink, or is there other ways that we can remind ourselves that you need to be cared for too? So creating space is a really huge thing. And then I would say, during times of terminal illness and loss, there's things that we can recognize in our own lives, that kind of tag, along with space, of what gives you life.

So I know that some people, when they lose, when they lose a spouse, a lot of people think, well, I'll just take their kids so they can just like grieve alone. And I think for some people, their kids is actually the best thing for them to be with. They're just like actually no, I want to sit with my kids and they bring life to me because I just that might be the most life-giving situation for them is like I just want to be with my kids. I don't want to be alone or I don't want to be with this person. I actually want to be with that person.

So I think right now, if you're in a time where you're not facing pain or loss, to really get to know yourself, like what does bring you joy, what are things that really do make your eyes sparkle again, whether it's I love flowers, I love literally walking through floral shops and just staring at flowers. I think, and I feel like we've missed out on that in this digital age of like what around us gives us life or who around us really does give us life, and take note of that, because those are going to become really beautiful things to help you when you're in a time of chaos and confusion, of navigating through, giving yourself space and then finding what brings you life and then being able to kind of bring those back in during that season. I think it's like a really helpful way to walk it out.

# 0:42:17 - Stephanie

This is sort of a like next door neighbor question, but, christy, I'm thinking about you going through being a primary caregiver at 10 and like really spending these 12 formative years of your life caring for people. How do you, I guess, like what advice do you have for someone who is in a caretaking role like that to not like lose themselves in it? And I mean, maybe it's, maybe it's not possible, maybe it's like these are the things in life that that swallow us, and when we're able to come out, we come out, but I just I feel like that's so, that's so consuming. Is there a way to not be totally consumed by it?

## 0:43:07 - Christy

Yeah, that's a really tough question. That's a really tough question because every experience is so incredibly different and you have not only do you have the differences of experience in terms of what the diagnosis is or what the prognosis is, but also you know different levels of care and support and privilege, right. So we were incredibly privileged in our experience and that we had incredible healthcare professionals around us. We had a really strong network of family and friends to lean on. So in many cases we were just surrounded with an, you know, an embarrassment of riches, right In terms of like, support and care for us. So I I preface it by saying that because we were incredibly fortunate and so many people are not and oftentimes you meet caregivers, especially either adult children caring for an aging parent or spouses who are in much more isolation, and so it's it's different. So I would say, in many ways the answers are different. So if someone is not surrounded by community, if someone feels like they're more isolated and they have less resources, then really leaning on nonprofit and government support

is really helpful because there are some governmental health organizations that will provide respite care. So, on the more on the really practical, tangible side of things, doing everything you can in your spare time to research what those options are. They vary state by state so it is a little bit tricky, but oftentimes if someone's listening now and they have a loved one who is maybe in the hospital, you will be. Even if you don't know it, you are always assigned. You have access to a social worker. So trying to find a social worker within that hospital network or the physician network, that's a great first step in terms of trying to get yourself some respite care if you're the full time caregiver. So that's one side of it. The other side of it, if you do find yourself in a situation where you have a lot of support, then I would echo a lot of what Jane says in terms of, you know, giving yourself permission to ask yourself what would help me right now? Like, right now, it doesn't have to be what's going to help me next week.

Oftentimes we cannot think, we can't even think in day chunks, we can only think in hour chunks. And, like last summer, I spent the greater part of the hospital, or the greater part of the summer in the hospital with my mom, who was struggling with an acute health issue that thankfully, she recovered from, but it was. She was hospitalized for most of the summer and in that time, even as someone who is, you know, I have, I have been in the healthcare setting. I know what resources are out there, so I wasn't starting from scratch. Even so, I remember telling my husband at one point I said I can really only think about in two, in two hour chunks. I can really only see the day in two hour chunks.

Because, again to Jane's point, when you're in a hospital setting, you are in time is a different beast and you are operating in a completely different paradigm. And so just giving, giving yourself grace and knowing that of course I'm not going to function mentally, physically, spiritually, the same as in this situation, as in my normal life, and giving yourself permission to take things just to a few hours at a time and then try to find as many resources as are available. And if you keep keep hitting brick walls, just you know again, as much as your energy allows, keep trying because there is support out there. It can just be be really difficult to find sometimes. So that's that's really part of why we exist is because it's it should not be hard. You should not have to use all of your energy to find the resources and to find the help. You should just be able to focus on the time with your loved one, and we envision a world where that is closer to being the case. But but right now, you know it's a, it's a limitation.

## 0:47:04 - Stephanie

Is that one of the things that you guys have in the resource part of NIR, like the resource directory, like respite care or government assistance or how to find a social worker, like things like that?

#### 0:47:20 - Christy

We're working on building that out. So, because those things are so specific state by state, that's in a later phase, but it's definitely on what we call our product roadmap. Right now, we focused on resources that are more nationwide, and a lot of those resources are digital, simply because they're easier to access, and so that's kind of the first phase, and then we'll be growing into more specific care from there. But and I don't know if this will be helpful to share now but we

do have a caregiver bundle, which is a resource that we put together. It's not it's not exhaustive, it's not everything that's out there because, again, we don't want to overwhelm, but we just picked a few select services that we have found to be incredibly helpful.

Who you know, we know the founders oftentimes in these and really trust what they're offering, and so we pulled those all together in a caregiver bundle and you know that's available. If your community wants to download that, we do have just like an easy landing page for them to kind of go to. It's stay near dot co slash girls night and they can find the caregiver bundle there. And, again, there's many more resources beyond that. But if someone just needs one single place to sink their teeth. That's a good starting point.

#### 0:48:33 - Stephanie

That's awesome. Thank you for putting that together. Yeah, as part of the caregiver bundle. I'm wondering, you know I'm watching people in my life start to live in kind of more like sandwich roles, which is something I didn't really well. Can you guys describe that or define that for us? Like what is it's I guess people cut, like the sandwich generation, or is it more talk to us about that? Sure?

# 0:48:59 - Christy

So sandwich generation is just an idea that you have an individual who is simultaneously caring for their children while they're caring for aging parents. So they're sandwiched right in the middle and they're being pulled in both directions, you know, at the same time.

## 0:49:14 - Stephanie

Okay, okay. So I have more people in my life who are who are stepping into that role and really who are, who are starting to care for aging parents. Are, you know, starting to take over? You know, financial responsibilities or passwords, or you know just starting to kind of step into those roles, and I know that that's like just how life is, that you know me and my friends were walking in that direction and we're going to get there, you know, at some point, I hope very, very long from now, but what are?

From what I'm seeing, it's like how, like, for people who don't have a diagnosis, or maybe who have one, but like kind of a long prognosis, how like are any of the resources that either you guys have or companies that you're connected with? Do they give like here's how to do the logistics of this, meaning like wills or trusts, or, yeah, how to get your parents passwords? Or I know that both, both my parents and my in-laws if anyone's like going on a big trip or something, they go. Here's where the folder is it's in mom's desk and it has all the instructions and it has the lawyer's name and stuff, and I mean we get that talk like frequently. Do you guys have any resources or know of anybody who has like, here are the things you should start doing. Start by contacting your parents bank and getting your name on there, or something like that.

#### 0:50:51 - Jane

Absolutely yeah, there's some really incredible like pre-planning is kind of what they preface it with getting the parents for older generations in order that we have on our website as to who we

would recommend and who we would suggest. We also are actually making a checklist of like what we can do to say, like is this ready, is this done on behalf of our parents? That's helpful to like navigate through and you can also just apply that to your own life. I know that there's like a huge percentage of people our age under 40 who don't have their wills done and I'm like or don't have life insurance, and these are like I know that these are like old mentality items and also they're really practical and really helpful and will save your loved ones so much time and money and chaos. If you would just like read through these and get your life in like a little bit of order.

I feel like these two things are just so crucial to have, and I know that Andrew and I did that and once we signed it, I remember saying that's a huge thing. That was like our kids are going to be better off. I now know that we've prepared and planned for our kids well, whether you have a ton of money or no money, it doesn't matter. It's the logistics of where do your kids go, what happens to this property or what happens to this item, like it's just clarity, and if you can take that first step forward, that is. That's a huge step for us to take, like if we can all just move in that direction, we're doing our children and younger generations a favor, and so we can be the wave to better prepare. Well, so our website does have those things to just bring about awareness, like what can we do? How do we walk this out? Well, and it's really helpful, okay, okay.

### 0:52:38 - Christy

Yeah, I would add to that too. If you go to our website and to find the find services area, there's an end of life planning section there and I would encourage everyone to not be put off by the term end of life planning. You do not need to have a medical diagnosis in order to begin planning for your end of life. So my husband and I are in our thirties and we've already completed our end of life plan. Now, of course, those things will change over time. You know, and it's a living these are living, breathing documents that you can edit as life circumstances change.

But it especially if you're a parent, it is crucial that you set your kids up well, and so on the in the care directory we have there's, you know, a range of two.

You know, to Jane's point about wills, if you just want to have the kind of bare minimum done and you want a more DIY solution and you have a pretty easy estate situation you know you're younger, you don't have a lot of complexity then you can use an easier DIY solution like a trust and will.

Or if you're ready to do you still want to go the DIY route and do it yourself, but you want to involve not just will, but also password protection.

You know you want to make sure you have all the password organization that you're on accounts that you've had conversations about.

You know if you were in an accident, living will, type conversation conversations you know what kind of care do you want to receive and not receive? There's another resource there called Lantern that provides a DIY solution, and then if you want more of a more in depth approach,

where you're assigned, there's a another service called elder, and they will match you with an end of life designer and you work one on one with essentially it's like a, it's kind of like a personal coach or just a personal mentor to go through a very holistic process to help you think about your life from you know, from start to finish, and get all those things in line, while also thinking, okay, knowing that eventually we are going to die, facing your mortality and small burst at least. It gives you an opportunity, it's truly an invitation to live differently, and so we've found that, whether you engage at a DIY level or a higher level of support in these, it can really transform the way that you live now, because you're living with essentially with the end in mind.

## 0:55:00 - Stephanie

Love that. I love that. Thank you guys for for doing this research and for for, like, breaking it down. It's so, it's just overwhelming. It's overwhelming as a like a grownup who has, you know, my house and my business and are, you know like what are all the things that we need to have in place, and it's overwhelming as a parent, and it's also overwhelming as a daughter, and it's it's a weird thing to have, you know, that conversation with your parents where they're like this is where the document is. You're like I don't even want to be thinking about this.

Also, like, is there a backup somewhere? You know, I don't know, these are all the questions that were, like, started. I know, I know that my friends and I are starting to ask and or are about to have to start to ask at some point in the next, you know, decade or so, and so I'm just really you guys are just doing awesome work. Tell me again, christy, and we'll link to it in the show notes. Tell me again the page, the landing page that you guys have for us.

## 0:56:02 - Christy

Sure, stay near in EAR dot co slash girls night, and on that page we'll have the caregiver bundle that I referenced, and we also, depending on when this podcast is coming out, we also have a holiday gift guide that helps give ideas for gift giving during difficult holidays. So we're obviously coming up on the holiday season. So, whether or not, whether you know someone who's going to be spending that time in a hospital or someone who's grieving a loss, maybe this is their first holiday season without someone they love you know someone just received difficult news. It's a different experience, and so we put together a guide to help you connect with them, you know, in a really meaningful, thoughtful way this holiday season.

## 0:56:48 - Stephanie

I like you guys. I just like I feel like I need to throw something. I'm so happy that you made this. Thank you, it's awesome, seriously, thank you. I feel like you're going to get so many messages from women in our community and I hope you do guys reach out and encourage them, because I know that creating something like this is difficult, but I just I really feel like you guys have taken one for the team Like a gift guide Are you kidding? For people who are have just lost someone. I mean, like this is just everything we need. So, really thank you. Thanks you guys. That is it. Thank you so much for coming on the show. We're going to link, like I said, to all of your everything in our show notes, but again, thank you just so much for the work that you guys do.

Thank you so much, stephanie. It's a real honor to connect with your community. Yeah, thanks for having us.

# 0:57:42 - Stephanie

You guys aren't Janie and Christy amazing, my goodness. This conversation was so helpful for me and I hope that it is for you too. Now, don't forget that if you ever want to find links for any of the things we talk about in our Girls Night episodes, you can always find those over in our show notes. Just head over to girlsnightpodcastcom and you'll find links for everything, including links for Jane and Christy's. You can check out their website near and so you can follow along with all the great stuff they're doing.

All right, friends, that's it for today's episode, but we have so much good stuff ahead this season and, with that in mind, now is the perfect time to make sure you're subscribed. Subscribing to the show is the best way to make sure you never miss an episode. It won't send you an email or anything. It just makes sure your phone downloads the latest episode when anyone's released. And I did want to take a quick second to ask you a favor If you enjoyed this episode or if you've been a Girls Night fan for a while now, would you take just two quick seconds to leave us a review and a rating on iTunes? Those reviews help out our podcast so much and it really would mean so much to me. So if you would take two quick seconds to do that, I'd be so grateful. Friends, thanks so much for joining me for Girls Night, and I'll see you next week.