The Big Ordeal Cynthia Hayes

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https://www.cancersupportcommunity.org/

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SPEAKERS
Rosanne, Cynthia Hayes, Disclaimer

Disclaimer 00:02
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Rosanne 00:42
Hello, and welcome to Daughter hood the podcast. I am your host Rosanne Corcoran, Daughterhood Circle Leader and primary caregiver. Daughterhood is the creation of Anne Tumlinson who has worked on the front lines in the healthcare field for many years and has seen the multitude of challenges caregivers face. Our mission is to support and build confidence in women who are managing their parents care. Daughterhood is what happens when we put our lives on hold to take care of our parents. We recognize this care is too much for one person to handle alone. We want to help you see your efforts are not only good enough, they are actually heroic. Our podcast goal is to bring you some insight into navigating the healthcare system provide resources for you as a caregiver as well as for you as a person and help you know that you don't have to endure this on your own. Join me in daughter hood. Cynthia Hayes is a former freelance journalist, management consultant, marketing executive, executive trainer, and cancer survivor. Cynthia used her 30 years of experience in interviewing synthesizing information and telling a story to write The Big Ordeal, Understanding and Managing the Psychological

Turmoil of Cancer. Her research for the book included interviews with patients, caregivers, oncologists, psychologists, neuroscientists, and recovery experts of all kinds. Cynthia and I speak about the emotional response to cancer, the need for open dialogue between caregivers and their care partners, the importance of support, and the many facets of cancer caregiving, I hope you enjoy our conversation.

Rosanne 02:19
Caregivers, no matter the illness or condition are tasked with many of the same issues, the search for information, the stress, trying to manage your own needs and feelings really trying to balance at all. But with a cancer diagnosis, there is an urgency and a level of panic and fear that accompany it from the actual diagnosis, to waiting for results to everything in between what are some strategies that caregivers can use to get through those times?

Cynthia Hayes 02:47
You know, I think the experiences is so challenging both as a patient and as a caregiver, because the stress changes the hormones in the in the brain and makes it so hard to think it makes it hard to prioritize and compartmentalize. But that's in many ways, the most important thing. And of course, you know, we're overwhelmed by the enormity of the diagnosis and all that needs to be figured out and all that needs to be done. And all that needs to be set in motion in order for treatment and recovery to happen. But by compartmentalizing and, and prioritizing and biting off just one little thing at a time, we can get through that enormity. And you know, what's important to remember is to impact take that deep breath that allows you to sort of signal to the brain. It's okay, I'm not dying this infection, there is no lion chasing me across the prairie, I can take a deep breath. And that helps to lower the stress hormones enough so that you can in fact, make that masterlist begin to prioritize and say, Okay, these are the three things we have to deal with in the next hour. Let's focus on number one first, that's hard. But that comes easier with practice. And of course, you know, the first day you hear of a diagnosis, you are at the most overwhelmed, but there are other times during the patient and caregiver experience when that sense of being overwhelmed. And that sense of oh my god, we have so many decisions to make. And so much pressure we have to deal with that keeps coming back. And so the sooner you can remember, deep breath, we'll list it all out, prioritize and focus the better things your going to get in the long run.

Rosanne 04:38
I mean, it's very helpful because you're already 15 steps down the down the lane, but you still have to do this first step.

Cynthia Hayes 04:46
That's right.

Rosanne 04:46
So being able to compartmentalize that and then Okay, let's go from here, but it's hard to do that to stay in this present moment when you have to plan.

Cynthia Hayes 04:55

It is and you know when I was diagnosed, I got the diagnosis three days before a trip I had planned with my kids meeting our favorite cousins out on the West Coast. And what was nagging me in the back of the mind is can surgery wait until I get back? I just, I couldn't wait to get back question. Like, I think I stopped listening, which, of course is another part of the stress response, you know, when we are overwhelmed, we tend to have tunnel vision and not take in a lot of extra information. So the moment you hear that diagnosis, whatever, then the scary diagnosis is your brain just sort of shuts down and you stop hearing the rest of the information. Of course, I was so focused on Yeah, but can I go to Napa Valley and drink some wine? I didn't hear what the rest of the doctor has already said yes. Thankfully, yes.

Rosanne 05:51
Thank goodness. Well, and you do you have your own cancer diagnosis. I mean, you can certainly share your diagnosis your story, and then why did you want to write this book?

Cynthia Hayes 06:00
Yeah, that's a great question. And my diagnosis was endometrial cancer. They discovered it on a pap smear. I had zero symptoms. I was behind schedule for a gynecologic exam, my doctor was chasing me and I'm like, nonchalant about it because the media says, oh, every two years, it's fine. And the doctor called me and said, no, no, no you get your butt in here, now it's been over a year time for a checkup. And thank goodness, she chased me because the week after the visit, she called to say there are some, you know, blabbity, blah cells and your Pap smear and I don't like it, and you need to come right back in for a biopsy. And I just sort of shrugged and said, you know, no big deal, no big deal until I Googled what those blankety blank cells were, and then it was instant panic that I was going to die of a highly aggressive form of cancer that had you know, 40% survival rates. So thankfully, you know, biopsy confirmed it, but then I had surgery and six rounds of chemo, and I was on the lucky end of that. That set of numbers, but it was while I was going through chemo and was weak and bold, and pathetic, and weepy and just overwhelmed by everything that was happening. And I was at the gym, trying desperately to make the wheels of a of an exercise bike go around, when a total stranger sat down on the bike beside me and started telling me his cancer story. Now, obviously, with a cancer patient, there was no question in anybody's mind about that. But what was surprising was how much of the experience we shared from an emotional perspective, even though physically our situations were entirely different. He had melanoma, his was a quote unquote, incurable disease, mine had slightly better odds. And that is 15 years earlier. I was going through it, but he talks about the sense of isolation, his tremendous fear, his difficulty in communicating with his spouse about what was going on with him psychologically, is overwhelming depression is fear and anxiety. And I was like, Oh, you had that? I had that. Oh, what did that you had? At that? I think, well, if this happens, if this is common, Why does nobody talk about it? And that got me wanting to know? Well, just how common is it? And, you know, why does it happen? If it is so common of what's what's behind the emotional turmoil? And then, you know, what does that mean, for those of us going through it either, as patients who are caregivers, and of course, you know, like Fred Astaire and Ginger Rogers, caregivers go through everything in high heels and backwards because they are not the center of attention. But they have to keep everything else going. While dealing with the emotional and physical support of the patient, and meanwhile, trying to somehow deal with their own emotional and physical needs. All of a sudden, as a caregiver, you have, you know, twice the burden, because you're used to share household responsibilities. Now,

they're all on you. You used to share financial responsibilities. Now, they're all on you, you are as afraid for the patient as the patient is for him or herself. And that compounds into a really dramatic emotional ordeal for for all of us. I felt that with time we started talking about some of this stuff. That's why I wrote the book.

Rosanne 09:28
I totally agree with you. And it is it is, it's not just one person, one person receives the diagnosis. But there's two people or maybe more, if you're if God willing if you're lucky that you have that type of support network, you're all experiencing that from your own point of view. And it's a it's a dance, it is a dance.

Cynthia Hayes 09:51
It is a dance and of course, you know, even if the emotion are somewhat predictable, in terms of you know what They will be the intensity and the way we express them vary enormously I, you know, we're, we're different people with different lived experiences and different DNA and different, you know, hormonal brain pathways and all sorts of stuff. That just means that, you know, my anxiety may look different than your anxiety, my depression may look different than your depression. And so, even in familiar situations where people have lived together for a long time and think they know each other, it can be really surprising that, you know, oh, I didn't know you were depressed? Well, maybe you didn't know because I didn't want you to know it. Maybe you didn't know it, because you were afraid to acknowledge it. And maybe there's a lot of both of that happening at the same time. So it's, it gets complicated.

Rosanne 10:52
Absolutely. And you you write about the protection that each person wants to provide, the patient wants to protect their caregiver, the caregiver wants to protect their person. How do you how do you balance that? How does How do you flesh that out?

Cynthia Hayes 11:08
Yeah, it's really tricky. You know, I think that sometimes, people are unwilling to express their emotions, we're unable to express their emotions, because they are not ready to deal with that emotion themselves. And if you state it, then first of all, it makes it real. But second of all, then you have to be willing, and able to deal with it in conversation, because now we're going to come back at you. And, and sometimes, you don't want to communicate that emotion because you know that your family member, your loved one, your care partner is not going to be able to deal with that emotion. And so yes, you are being protected. But if I am protective of you, by not sharing my full emotions with you, and then you are being protective of me by not sharing your full emotions with me, we have this knowledge gap in here that over time becomes a huge gap in the relationship. And we either pussyfoot around, or we, you know, stomp all over each other's emotions, because we don't know what we're what we're really dealing with. And it's, it's hard, because, you know, again, sometimes you're just not ready to deal with it. And sometimes you don't have the kind of trusting relationships, even with those that you deeply love, where you can feel comfortable sharing your deepest emotions. And so it really does become a difficult cycle for a lot of a lot of families where, you know, like, I might feel, okay, telling this to one family member, and telling something different to another family member, based on my

relationships with those two different people. And based on how I know, they're going to respond back to me, but then they might have a conversation. It's like, No, you're wrong. No, you're wrong, because I haven't, I haven't told them the same thing. So it gets complicated.

Rosanne 13:03
Well and it's hard to because you know, when do you have those conversations? Sometimes, it's like, I need a minute. I need a minute. I have to, I have to get here myself. And then there's denial, where I don't want to talk about it doesn't exist. I'm not going down that road. As a caregiver, you have to know how to navigate both of those terrains with your care partner. What's the best way to try to do that both with denial and with the I need a minute?

Cynthia Hayes 13:33
Yeah, yeah, I think it's a really tricky question. And I think ultimately, the answer is what's going to feel best for the patient within the bounds of what you as a care partner can tolerate. And, and that's tricky, because, you know, sometimes we need to talk and sometimes the patient doesn't want to talk about it. I know my husband and I have very different tolerances for talking about body parts, pain, discomfort, medical issues, whatever. And I can get into the space in a way that is really irritating to him, because he just doesn't talk about. And to me, it's like, well, if you don't talk about it, and how how are we dealing with, you know, but I've learned Nope, it's his body. I just got to shut up. And sometimes that's what you have to do until it gets to the point where it's interfering with your ability to take care of, of him or her. So, you know, that's yet another stress that is borne by the caregiver at a time when, again, the patient is the is the star of the show. We're just a supporting cast. But we have to support in a way that's the appropriate

Rosanne 14:45
And it's all that balance. And you're trying to find that balance.

Cynthia Hayes 14:50
Yes, exactly. And what works today may not be what works tomorrow. What is appropriate today may not be appropriate tomorrow. You know, I owe is presented sort of a badass attitude. It my oncologist used to refer to me as one badass patients. And that fit with who I was that I could handle anything and my family that I could handle anything. And my husband walked me to my first chemo and then said, Oh, this is scary. I don't want to look at those needles, I'll think I'm out of here. So I have to be at the maintain that that badassness. But I didn't always feel badass. And so, you know, where could I let down? Where could I express that? That true emotion, I had to sort that out. Because if I overwhelmed him, I wasn't going to get any support. But if I didn't express my emotions, I also wasn't going to get any support. So finding the right way, as a patient can be hard. And then finding the right balance as a caregiver can be hard. Tricky, tricky navigate,

Rosanne 15:59
It's a maze with what you feel is a time pressure. Because it's like you have to get this you have to get that I have to find a Doctor Who. And that's the other stress is in that decision making. Because you're making these decisions together. And, you know, when you try to find a doctor, you know, you ask around you check the reviews online, if you can find that. It's it's painstaking. With a cancer diagnosis.

It's basically Hey, you have cancer, and you need to see somebody like tomorrow. And that alone, you know, you may not agree with who you're seeing, or you may have well, what if we do here? Well, what if we go there? And again, it's just more stress.

Cynthia Hayes 16:35
It is it's a very challenging time. And I think that what, what I learned and in the course of writing the book, I interviewed over 100 cancer patients, a whole mess of experts of all types, a bunch of caregivers, oncologists, psychologists, exercise physiologist, you know, even neuroscientist, and it's a fascinating process. And what I uncovered was that, you know, the first reaction is fear and anxiety. And those are really, really high for most patients and caregivers right at the beginning. But when it comes time to make a decision, it's like somehow, we managed to actually make that list and clarify and prioritize and get through that process. And the stress is very high. But then once we make a decision, it's like the stress comes way down. Because it's like, okay, it's Besides, we're moving forward, we're getting through this. And it's like, there needs to be a switch in the brain that goes from that anxiety and sense of being overwhelmed to that clarity that comes with having made a decision. And of course, some people just, you know, whatever their doctor tells them, that's what they do. And other people are much more like, No, I have to gather all of the information and all of the recommendations. So not everybody struggles as much as as you were I might have. But it's, it's clearly a very stressful time. Because you do feel like you have to hurry. This is cancer, this is bad news, but also that you have to get it right, and that there is only one right answer. And of course, that's not the truth. There are lots of different ways to get there. And we make the best decision that we can with the information we have on hand, and then we move forward. But we often feel like there is only one right answer, and how do we know that we have found that one right answer? And of course, the one right answer, for me may be a very different answer than for my care partner or another patient in the same circumstances. And so it becomes a question of how do you weigh information with your comfort and your trust in your medical provider? Because ultimately, you're putting your body in the hands of somebody that that you trust? And you know, what makes you feel good about that relationship? Is it that this person had the most information? Or is it that this person had the warmest smile and the greatest confidence that he or she was gonna take interview. And you know, we all approach these decisions differently. I am definitely an information gatherer and got multiple opinions. But ultimately, I think I made my decision based on a gut reaction to the document, I ended up trusting my life. It's unclear that there's a, you know, one prescribing method there. I think we're all again, very different than how we're going to make those decisions and whatnot. But we definitely have a much lower level of stress when we've made that decision. As scary as the next steps may be. There's a sense that when somebody is going to take care of it now, I've made the hard decisions now I just need to listen and follow instructions and do what's expected.

Rosanne 19:46
No, that's, that's wonderful. And you even have a graph in the book that's entitled The emotional turmoil of cancer and it ranges and it ranges from shock and disbelief to accepting the new normal. Can you tell me how you figured all of that out and I I'm sure from your experience, but..

Cynthia Hayes 20:01

Sure you know, I'm not the only one to have tried to document this. And so there's sure, terrific work that's gone on long before me. And that served as as sort of the foundation for my work. But but, you know, after interviewing hundreds of patients and loving caregivers, the patterns were just clear. And the fear and anxiety that really stay with us throughout the entire process are our, you know, they, they ebb and flow the most, and some of the other emotions emerge at specific times during the treatment process or recovery process or whatever. But that that fear and anxiety were almost universal. And, you know, as I said, come and go a bit, but they, they're pretty pervasive in cancer.

Rosanne 20:47
Being aware of that is so important. And it's so helpful as I would think it would be helpful as a caregiver to know that.

Cynthia Hayes 20:54
I think that's right. And I think that, you know, first of all, you know, because we don't talk about emotions, we think when we start having these emotions, that there must be something wrong with us, you know, why is it that I am so weak and pathetic, that I can't, you know, smile everyday through cancer and maintain a positive attitude? Well, you can't because your hormones are all messed up your brain chemistry is all messed up, any your body is all messed up. So no, don't expect that of yourself. But the the media, the way we talk about cancer, the you know, rah, rah raise money effort, and the you know, the fight terminology all leads to the sense that we need to be positive. But in fact, there are a lot of things working against that, that positivity. I think one of the most interesting conversations I had was with that neuroscientist who was explaining to me that there, there's a class of proteins in the bone called cytokines. And cytokines allow the immune system to communicate with itself. And they're pro inflammatory cytokines and anti inflammatory cytokines. And for the most part, they're kept pretty much imbalance in our body. But if you get a paper cut, the pro inflammatory cytokines are released, and going to that site and say, oh, we need some platelets over here, let's clear up this site, we're losing red blood cells, let's get some more red blood. Ooooh let's make sure there's no infection. So all of a sudden, you've got pro inflammatory cytokines. That's why you get a little redness where that where that paper cut is, and after a couple of days, as that papercut heals, the anti inflammatory cytokines come along and say, oh, yeah, looks good. Let's get rid of all of the excess platelets, white blood cells, etc, etc. And everything goes back to normal. Well, that's a papercut throws off your cytokines just imagine what a massive surgery where it turns out, the presence of cancer, the dying of cancer cells, when treatment happens, chemotherapy in and of itself is an inflammatory process. Radiation is an inflammatory process. Immunotherapies are pro inflammatory cytokines. And so we are just awash with pro inflammatory cytokines. And it turns out that the brain reads that excess pro inflammatory cytokine as a massive sickness, and just sends us back to bed. And that's why all we want to do is climb into bed, pull the covers over our head and pretend like, you know, the world doesn't exist, because I'm just going to die right here in my, in my little bed. And of course, you know, we have the ability to fight that. But we have to really work hard against it, we have to, there are things we can do to change that brain chemistry, everything from a little bit of exercise, like, okay, get up and walk to the kitchen, a little bit of exercise, I'm not talking about running marathons, or you know, laughter or hugs or, you know, other brain, stimulating the release of other brain chemicals that can help counteract that. But it's ridiculous to think that you're gonna go through cancer and never want to cry. It's, you know, absurd to think that any major, you know, surgery or disease isn't going to cause an emotional response. You know, not to

mention the fact that men and up to cancer treatments, whether it's surgery or chemotherapy, end up screwing around with our hormones. If you're a woman and you have a hysterectomy, those ovaries that might not have been producing eggs might still have been producing hormones gone, you are dying, you've got prostate cancer, and you know, they remove your prostate. Oh, there goes another hormone producer, we're gonna give you more steroids that's gonna give you you know, more hormones and the different types that are going to exacerbate your energy, but they'd be your anger, you know, so there's all sorts of things going on in your body that drive that emotional response. But again, we don't talk about emotions, and we don't talk about cancer. So we're certainly gonna own up to the fact that there are any emotions associated with cancer. And of course, that expectation that we stay positive, throughout the cancer experience is just one more burden. And one more way that we as cancer patients feel like we're not living up to expectation. That's a really, that's a really hard thing. You know, it's hard as a, as a patient. I mean, I think one of the low points in the emotional cycle is when you're sort of midway through treatment, and you've got a little bit of chemo fog, which, by the way, it's not really related to the chemo, it's related to those pro inflammatory cytokines. So it doesn't matter whether you're having chemo or not, you're gonna get it. But you've got your brain functioning quite right, you know, you may have lost some of your hair due to treatment. So you're not looking like yourself, your energy is low, you're not feeling like yourself. So you have this major identity crisis. And your role in the household may have changed, you know, so you've got this emotional crisis that comes from I don't know who I am anymore, I'm no longer the boss of my household, I can no longer do my job, I can't think I don't look like who I'm supposed to look like, I don't feel like who I'm supposed to feel like, who am I, and that, in and of itself, it's just such a destabilizing experience for for so many cancer patients, of course, the household is trying to accommodate this new way of being in the patient. And then often, the patient eventually recovers and wants their old roll back in the household. And that doesn't happen either. So the challenges don't end when the treatment ends.

Rosanne 26:34
No, and I totally agree with you words matter. And that battle terminology. That gives you the impression that well, I guess, they just weren't trying hard enough. That's why that's why the cancer is winning. Or she never complained, well, maybe she didn't complain, because she didn't feel comfortable that there was anybody willing to listen to what she wanted to say. It's, it's very hard, because you're exactly right. All of this is happening, it doesn't happen. It's not like you go and you know, you're getting your teeth cleaned. You're having this. I don't want to say poison, but the chemotherapy

Cynthia Hayes 27:11
It's poison.

Rosanne 27:11
Is poison. And you can, you can expect that not to affect you as a person. And I think it's important to change that, that type of terminology to help both the patient and their caregiver, because then the care, you know, if if it's not working, and then the caregivers, people look at the caregiver like, well, what are they doing? What are you doing? You're not helping them enough? You're not, you know, did you try this treatment? And what about that? And I think it's just, it's that it's that cycle that just beat you down.

Cynthia Hayes 27:44
Yeah, I think that's right. And I think that the the language is hard, and some people are really motivated by the language, I hate the battle language. But some people are really motivated by it. They feel like they need to, you know, that rallies them to fight to push harder to push themselves a little bit harder, when we really get in trouble with when we say somebody, so until lost her battle with cancer, she didn't lose her battle. Treatment failed her was failed by the medical, you know, treatments available. But, but it's hard because you want as a patient, you want to feel like you can help the process along. But meanwhile, is unclear that there's anything that you can do or not do that is going to make the treatment any more effective. And then obviously, you know, you should give up smoking. You shouldn't smoke through cancer treatment, regardless of what type of cancer, you know, there, there are some obvious things, but a lot of it is beyond our control, just like it is beyond our control, who actually gets cancer, you know, there are people that have smoked three packs a day for, you know, 90 years and lived a perfectly fine life. And then there are people like me who like eat healthy exercise all the time, don't generally play with asbestos, but somehow managed to get cancer. So it's, there's a lot that is just beyond our control and recognizing that, while it is beyond our control, we can do things to strengthen the immune system. And that may help us but also letting go of that sense of responsibility that comes with control. And I think that that's that's the problem that's embedded in that battle metaphor is that we are responsible for how hard we fight and you know that that how hard we fight is going to determine whether or not we win the battle is a bad metaphor, really bad metaphor. That said I do encourage people to get plenty of sleep, eat well exercise to the ability that they can give in their cancer and as care partners to do the same because all of those things help to reduce stress and stress depletes the immune system and you want to do whatever you can to support a healthy immune system. And so therefore, you know, don't drink to excess, even though diagnosis may make you want to do that, Take a walk every day, that's going to help, there are days when you're undergoing treatment, you just can't. But maybe the next day you can and so take a walk. And so those, those little things can make a difference. And they not only help to strengthen the immune system, they also helped to improve your mood. And so those little things can make a difference. But they can't, they're not going to change whether or not the treatment is working for your cancer, you know, that was that ship sailed a long time ago. And, you know, the good news is that there are so many new treatments these days, that I know a number of cancer patients who, you know, the first treatment didn't work, they started the second treatment. And then they started the second treatment, they were hopeful that one didn't work, they started a third treatment. And the doctor said, Well, I don't know what's going to happen after, you know, after this one if it fails, but I'm sure that another one will come along. And lo and behold, another ones come along, you know, so, you know, there, there are new developments happening all the time. And so even when it's a late stage grim diagnosis, there's still hope that you know, something else is going to work even if this one doesn't. And that's a very different circumstance than it was even you know, five or 10 years ago, the they've made huge advances with immunotherapies. And PARP inhibitors and cancer vaccines and all sorts of new treatments that just didn't exist before. That are, you know, it takes some degree of digging to find the clinical trial that might work or a doctor who's willing to experiment, but there's a there's tremendous hope, at this point.

Rosanne 31:58
Thank goodness. How do you balance that hope and the reality?

Cynthia Hayes 32:02
Oh, well, you know, I think that that's a challenge for all of us. And something that is definitely an individual process. I think that what is helpful for most people is a you know, one day at a time, sort of approach, and to not allow ourselves to get overwhelmed by the what if's. And it's hard not to go down the road of the what if this treatment fails? And what if that happens? And what if I can't do this? Like, you know, you wake up, and it's like, okay, I feel pretty good. Today, I'm gonna go enjoy my day. Or I wake up, and I'm not feeling so good. And it's like, Alright, I'm just gonna, you know, rest up today, and maybe tomorrow, will be better and really focusing on what is good today, what works today. And having a goal of, you know, I'm going to recover, I'm going to get better, I'm going to get strong enough to do X, Y, and Z. That's great. But what do I have today? What can I look forward to tomorrow? But what do I have today. A dear friend of mine is on her fourth cancer, and I don't know what's going to happen. I don't know if they're going to come up with yet another treatment that will keep her going. But every single day, she embraces it with energy and a smile. And it's not to say that, you know, she's not crying in the shower every day or cursing at her husband for some, you know, minor infraction. But she also finds a way to find the joy every day. And I just look at her I think that's, that's amazing. That's, that's what I would want, no matter where I am in life is to be able to find the joy in that in that particular moment of that particular day.

Rosanne 33:48
That's amazing. And it's beautiful, because it's really, it's all we all have.

Cynthia Hayes 33:54
It is.

Rosanne 33:54
Whether we have an issue or not. It's all we have. Because we don't know, we don't know what our lives hold. We don't know what's in front of us.

Cynthia Hayes 34:02
That's exactly right. You know that that proverbial bus could come barreling down the street any moment. But, you know, we have this sense that we have control over our lives and that we have agency and and and I think I think sometimes these diagnoses and and hurdles in life are harder for those of us who are used to being able to control our environment. And, you know, I work as a mentor now at a couple of different cancer centers helping newly diagnosed patients get through their treatment and maintaining some degree of support thereafter. And what I have come to see is that some people don't expect to be able to control their lives don't expect to be able to influence their environment, and actually just take cancer more in stride than certainly I did. Because I was so used to, you know, being the boss of my life. And if you're not the boss of your life, And this is just one more you know

Rosanne 35:03
Bump,

Cynthia Hayes 35:03
Stupid thing. Yeah, one more bump in the road. And I guess, finding the resilience that comes with recognizing that, no, I'm not the boss of my life, but I can be the boss of getting over this bump, I can be the boss of finding a way to smile through the day. And that resilience is something that comes with practice, you know, none of us is really born resilient, but we are made resilient. By learning that, you know, whether it's as a as a baby, eventually the diaper will get changed, and I will be more comfortable to as a child, but no, I can't always have my own way. But it's okay. Because sometimes I do, too, you know, as a as an adult learning that life doesn't always go the way I want it to. But I have the ability to cope. And and of course, cancer or any major diagnosis is a large bump for most of us. So it takes a little bit more effort to find the resilience to get over that bump. But I think that resilience is something that we we all can get better at. And the more we work at, the more likely we are to get better.

Rosanne 36:14
It's almost like resilience is a muscle, like how do you build that muscle? What is your what's your favorite way of trying to develop that?

Cynthia Hayes 36:22
Yeah, I think it helps to have a bunch of different tools at your disposal for for coping. And I do think that I like to talk about there being sort of three different categories of coping mechanisms. There's coping by doing coping by thinking and coping by remind body combination things. But a coping by thinking is what I come by naturally, it's the compartmentalizing, it's the problem solving. It's the research and information gathering. And it is using all of our cognitive skills to try and solve what seems like an insurmountable problem. But you can't rely on just those skills, because there's a lot of times when it just seems like it is insurmountable. And so that's where the coping by doing comes in. And that is the exercise and the diet and the sleep. But it's also the laughter is the hugs, it's the playing with the dog. It's the all of these things that have been proven time and again, to cause a release of positive chemicals in our brains. So exercise releases endorphins that makes us feel good. A hug gives us oxytocin, although it has to be at least a seven second hug in order to actually stimulate that release of oxytocin. Oxytocin is the hormone that is stimulated when a mother's nursing and bonding with her baby it's, it's a feel good and connected, sort of hormones, and we can fool our brain into being better and therefore actually convinced the brain that it is better by stimulating the release of these, these positive chemicals in our brain. And we'll do that by sitting in the sunshine for 20 minutes. Okay, don't get a sunburn but go and soak up a little bit of sunshine walking in the woods. It turns out that walking on a city street is good. walking in the woods is even better because of all of the chemicals one inhales from trees apparently is very good for us. In Japan, they refer to it as forest bathing, where you actually take a walk in the woods for 30 minutes and just, you know, soak up all of those chemicals. So all of those things, that's the coping by doing. And then the third category is Mind Body coping. And that's everything from you know, Yoga and Tai Chi to massage and meditation and prayer. And turns out that knitting falls into this category, because you're reciting that knit one, purl one Knit One purl one, and your hands are busy. And lo and behold, your brain has to relax. Because you can't also be focused on your worries, because you're so focused on what your hands and your so all of these things that involve your body doing one thing and your mind doing something different at the same time, are actually really, really good for you.

Rosanne 39:08
That's really great.

Cynthia Hayes 39:09
So by having all of those skills that are just disposal and sort of sequence, when we apply them and how we apply them allows us to be more resilient. And the more we practice those things, the more we build that that resiliency, and you know, and what works one day won't necessarily work the next day. And so that's why you need to have, you know, a quiver full of arrows to start flinging at it.

Rosanne 39:35
Yeah, it's collaborative. It can be collaborative. So your care, your the caregiver and their care partner, they can do it together, or they could do it in their own, you know, support because that's that's the other question the importance of support throughout this process for both the person living with their cancer and their caregiver. They both need support because even at the end of the day they're still dealing with things separately.

Cynthia Hayes 40:03
They are, they are. And that's the important thing to keep in mind. And, you know, if I'm the patient, and you're the caregiver, and I need to talk about it, and you need to go take a walk in the woods, we're at a bit of an impasse, because I want and want to hear to listen and which is why takes a take the village. One of the things that I learned about long after my diagnosis was that, you know, there are tremendous resources available out there, for patients and for caregivers. But again, we have to know to ask, right, and so that means that we have to know that it's okay, if he feels this way that we need them. And therefore, no, I definitely the things that just frustrates me no end about our health care system, you know, if you, if you break your leg, and you're in pain, you know, ask the doctor for some careful, appropriate pain. But if you're going through cancer, and you are an emotional wreck, we don't know that it's okay to ask your doctor is going to support available. And of course, there's so many types of support everything from you know, antidepressants, and, you know, things to help with mood to exercise classes to, I don't know, there's all sorts of support groups and, and there are support groups for people who are newly diagnosed people who are dealing with a long term diagnosis, support groups or patient support groups for caregivers. And there's one on one support, you know, so many people say they are hesitant to join a support group, because they don't want to be weighed down by somebody else's angst when they're trying to deal with their own. There are so many great one on one mentorship programs, Imerman Angels Cancer Support Network, Sharsaret, and in all of these organizations, they offer one on one peer mentoring. And so you can be matched with somebody who as your exact same cancer, and you know, has gotten to the other side, and you can not hear their story if you don't want to. But you can hear what they learned from their story. And you can hear how they got to the other side. So you can you can tailor your support needs with a peer mentor in a way that you can't win support groups. And then there are of course, tremendous resources online for learning about what you can expect the emotionally or physically from your DM to know. But again, you have to know to ask and that's the that's the hard thing I think right now is like, nobody tells you that it's okay to need these things. And so therefore, you don't assume that there are these things out there,

Rosanne 42:45
Again, with anything, the caregiver is the last part of the equation when you're dealing with the medical establishment. They just are they can't bill for you. There's no code for you.

Cynthia Hayes 42:55
That's exactly right.

Rosanne 42:56
And it's hard because we are the backbone. We are the backbone of the system. And yet we're a complete and utter afterthought.

Cynthia Hayes 43:04
Yeah

Rosanne 43:05
And so is the emotional support of getting through anything. And it's it's mind numbing, that this actually happens. The flip side with with support is that you don't realize, as you said earlier, oh, you feel that way. So why this isn't strange. I'm not losing my mind, because I feel this way you feel this way. And it gives you that

Cynthia Hayes 43:28
I'm not being a selfish, horrible person to feel the way I feel as a caregiver resenting the fact that my life now revolves around a patient.

Rosanne 43:37
Yes. In the Yes, yes. Absolutely. Oh, my goodness. Really? Okay. Well, for sure. Oh, there's my exhale. Yes. Yeah, absolutely. And, and I think that's really that grief that runs through grief runs through from the moment you receive any diagnosis, but especially with a cancer diagnosis. It just runs, your life has changed, their life has changed. Everything that you had planned for has changed. Even if everything works out. It's still changed. It's still different. And you know, the anticipatory grief. And as much as we don't talk about emotions, we really don't talk about grief. Nobody wants to talk about grief.

Cynthia Hayes 44:21
You are so right. You know, cancer, in particular is all about loss. And if not, you know, we're not just talking about the loss of your hair, but every expectation that you had for your life. I've been challenged by this diagnosis, and however long it takes to get through treatment, whatever that might be. That's a period of your life that you're never going to get back. But at the end of that, you're looking at a life that's taken a very different trajectory from what you were anticipating, you know, the week before your diagnosis, and so that's changed for you. But yes, as you said, it changes for everybody else in the household as well. So it's I like to say that cancer is all about loss and grief. And it's, it's interesting how we all process it. And you know, for many people, the way they make sense of it is to do something, you know, positive in the extreme. So, you know, one woman I met in the process started at an International Cancer organization that's raising awareness and bringing support in developing countries. You know, as bad as it is here in the States, imagine what it's like elsewhere. You know,

another another woman that I met and was process has started an organization to bring cancer patients as volunteers to random parts of the world, doing things that can help them remember that they actually have a pretty good, even if they don't have it as good as they used to have it. So people, people go and do extraordinary things in the process of trying to make sense of it. But ultimately, what we have to do is get to a point where we accept that is a very different set of expectations for our lives now than what there were prior to that diagnosis. And so yeah, that's a it's a huge loss. And even if it looks like we stepped back into our lives, you know, the way they were, it's, it's different. It's different, you know, physically and emotionally, it's just different.

Rosanne 46:17
The big part and the underlying issue is, it's okay to ask for that help. It's okay. In there's no shame in saying, I need help to get through this. And to then access that help. It's it, you know, there, there just isn't, there just isn't any shame in that. And I think that that's a very important piece that people miss sometimes.

Cynthia Hayes 46:42
I think that's absolutely right. And we all do need help along the way. It's not, it's not just, you know, there's no shame, but there should actually be an expectation that wait, we need that help, there should be an expectation that we're going to ask at some point for, for support, because we all need it. And, and that was really, you know, as I said, What motivated writing the book and the blog and getting involved in mentoring. It's all about helping people understand that this is a normal, healthy process, this happens. And so let's just be upfront about it. And let's acknowledge that it's happening. And let's make sure that you get the support you need, in order to get through it.

Rosanne 47:26
Totally agree.

Cynthia Hayes 47:27
I think that just, you know, validating the experience of patients by letting them know that they're not alone and experienced, this is so important.

Rosanne 47:38
I agree. Totally agree. I would ask you, what you would have to say to someone who just received a diagnosis and their caregiver, but I feel like you just said it. But I don't know we can I can certainly,

Cynthia Hayes 47:51
You know, one of the interesting things that I've learned over over the past five years, six years, six years that I've been focusing on the seven years since my diagnosis is that time, the most important thing you can do is not say anything at all, but just listen. And I think so often, because we are uncomfortable having emotional conversations, because we're uncomfortable with the topic of cancer, we all sort of race and to try and solve a problem that hasn't yet been expressed. And so I think one of the most important things to say to somebody who is newly diagnosed is I'm I'm here for you. Tell me about it. What are you thinking and feeling? And allowing them to express their emotion, their needs, their fears, their desires? And then asking, How can I help? What can I do for you? And of course, you

know, there's a real trade off, some people say, Oh, don't ask a patient, what to do, just jump in and do. Because you can see, sometimes you can't see. And sometimes jumping in and doing takes the agency away from somebody who has already lost so much. And so I encourage people to really listen, and then suggest, would it be helpful if I did XY and Z for you? Because that person still wants control over their life. You know, when my when my mom was a mom passed away a little over a year ago, and she was in hospice. She was 95 years old Yeah, she's not a good long life. But we had hospice at home and she had a caregiver there who's with a 24/7 and she was sort of in and out of consciousness and she had had a Parkinson's like syndrome that made it difficult for her to communicate and so she really wasn't speaking. And she had her hands folded over her chest, and I could see that her nails needed trimming. So you know, I got up and I got the nail scissors when I came back and I was gonna set to work, and she took, glared at me and pulled her hands so For me, she didn't want what I didn't understand what she was praying. And yeah, 15 minutes later, she was done. And she was very happy to give me her hands. But I made the decision myself that this is what should be done as opposed to asking her? Is it okay if I cut your nails now? And you know, that just brought it home for me because I felt so bad after that for interrupting her prayers. But of course, you know, it's something that we all want to do. We all want to feel like we're being helpful. We all want to chip in and do something that is going to make us feel better to do something. And so we blindly go and do but What's better is to think through, well, okay, our children play together, you probably could do with a few hours of sanity, what would you think if I took your daughter on mine to the playground next week was meant to be helpful to you ask, and maybe, you know, maybe you'll both be rewarded by, you know, everyone feeling good about about that. But maybe, you know, the daughter is a follow up to the patient, and the patient doesn't want the daughter to disappear for three hours. So, listen, listen, listen, listen, I love that no matter how well we think we know the patient, we don't understand exactly what's going on unless they've told us so. We just need to listen.

Rosanne 51:23
I love that. That's fantastic. We covered a lot of ground today, are there any final thoughts you'd like to share?

Cynthia Hayes 51:28
I do just encourage everyone to remember that because we are all so different. We can't assume that my anxiety is the same as your anxiety that my fear is the same as your fear. And then my way of dealing with my anxiety and fear are going to be the same as your way of dealing with your anxiety and fear. And so, no matter how well we think we know, a patient or caregiver, no matter how close the relationship is between those people, we have to assume that there are things that are unspoken, and and therefore ask. You may not get the answer you want to hear. But it's always good to ask.

Rosanne 52:07
A big thank you to Cynthia Hayes for being my guest today. To learn more about Cynthia, her resources, her blog, cancer stories and her book, check out her website, thebigordeal.com I hope you enjoyed our podcast today, head over to Daughterhood.org and click on the podcast section for shownotes including the full transcript and links to any resources and information from today's episode. You can find and review us on Apple podcasts or anywhere you listen to your podcasts. We are also on Facebook, Twitter, and Instagram, at Daughterhood, the Podcast and on my blog heyroe.com. Feel

free to leave me a message and let me know what issues you may be facing. And we'd like to hear more about or even if you just want to say hi, I'd love to hear from you. Also a very special thank you to Susan Rowe for our theme music, the instrumental version of her beautiful song Mamas Eyes from her album Lessons In Love. I hope you found what you were looking for today, information, inspiration or even just a little company. This is Rosanne Corcoran. I hope you'll join me next time in Daughterhood.