

The Importance of Supportive Care with Sheri Biller & Anneliese Barron

Welcome to the Sandwich Generation Survival Guide

Candace Dellacona: Welcome to the Sandwich Generation Survival Guide. I'm your host, Candace Dellacona. I am so happy today to welcome actually two guests. We're gonna be talking about a really important topic and one that is really going to be helpful to our listeners. We're going to be talking to today about supportive care, and we have two amazing women. Who have made it their life's work to provide us as caregivers, sandwich generation members, and our families, the patients, the people we care for with services and extra care. So I wanna welcome Sheri Biller of the Sheri and Les Biller Family Foundation and Anneliese Barron from One Family Foundation. Welcome.

Anneliese Barron: Hey, Candace.

Candace Dellacona: I am so glad to have you here.

Meet Sheri Biller & the Sheri and Les Biller Foundation

Candace Dellacona: I wanna give our listeners a little bit of background on each of you. So maybe what I'll do is I'll start with you Sheri. You are kind enough to reach out to me. As I mentioned, this is a platform where we try to provide resources to our listeners, and your foundation reached out to me saying, Hey, we want to make sure that everyone knows about these services provided. So can you tell us maybe a little bit about your family foundation and what the foundation strives to do, and then we'll toss it over to Anneliese and talk about the coalition and what you work on together.

Sheri Biller: Sure. I think first I have to just take quickly say a little bit about my story because my story is what led to the foundation. First. anyone who's listening, I'm an only child and anybody who knows anybody who's an only child knows how important their friends are to them, and I unfortunately lost my two best friends to breast cancer when I was in my thirties. At that time both of those families had terrible trauma happening to them because of the disease. And one of my girlfriends, both of her parents were doctors, very successful doctors in Los Angeles, and they, that family had just was falling apart. Including a child who committed suicide because nobody was talking to them.

Candace Dellacona: Oh gosh.

Sheri Biller: At that time I realized I was probably doing supportive care, not even knowing what the language meant, or had no words for what I was doing. I just jumped in to help take care of both of those families. And when I think about Sandwich, I think about, oh my gosh, sandwich, I was not only taking care of two other families with children and grandparents and parents, but also my own daughter, my own husband, and I was working at that time. And the idea of what happened at that time led me to talk to my husband often and would say if we ever had resources, we have to figure out a way to fix this, to help people with these life-threatening diseases and figure out how they have resources to be able to get through it without trauma, more trauma happening to them in the end. And so that's how we started our foundation.

Candace Dellacona: That is so remarkable.

What "Supportive Care" Really Means and Why It Improves Outcomes

Candace Dellacona: And just for our listeners, so that everyone you know is aware, supportive care is a term that's thrown around quite a bit with diseases, diseases of the aged cancer, and it's refers to a holistic approach that is supposed to help patients and caregivers receive emotional and physical and

sometimes practical support they need like, economic support. And I think what has happened is that studies have been done, and it's pretty clear that the more supportive care that the patients and the caregivers have in their lives in the middle of their illness, it will improve their symptoms. It'll improve their quality of life. It actually increases their chances of survival and for, those of us paying for this care reduces the cost of healthcare. So your Family Foundation addressing this and really framing it for us, Sheri is amazing.

Meet Anneliese Barron & One Family Foundation

Candace Dellacona: And that's sort of a perfect segue into your coalition partner here from the One Family Foundation, Anneliese Barron. And just to give Anneliese a bit of an introduction we were chatting earlier that I was so moved by Bradley Cooper's initiative with PBS and his documentary called Caregiving. And so our listeners should know that One Family Foundation is actually Bradley Cooper's Foundation, and that is why Anneliese is here to talk about the foundation and the partnership with the Sheri and Les Biller Foundation, as well as her supportive care initiative.

So welcome Anneliese.

Anneliese Barron: Thank you so much. Thanks for having me. I probably should have gone before Sheri, she is such a rockstar in this space and like you said at the top, that she's dedicated her life to this work. I'm newer in this space. I've been with One Family Foundation for about four and a half years. But the foundation was founded by Bradley Cooper after the passing of his father who had lung cancer.

And this was a way to honor him. And the work that we've been doing up until now has been, was really focused on cancer and helping low income families get through their cancer journey. We really honed in on the side effect of cancer being the financial toxicity. It's a term that I didn't even know about until I started doing this work, but it's basically, it's the severe financial strain and the related psychological distress that patients experience due to the high cost of treatment.

So we have patients that, they can't afford to pay for their treatment so that they miss their treatment. They don't finish it. They go into debt. They go into, they become bankrupt. And so all of those have an impact on the health of a person that's trying to survive cancer. And we know that these patients, that we've got loss of income. There's like higher non-medical expenses like childcare, transportation, things like that. That's like the work that we've been focusing on up until now. But we recently launched a caregiving initiative called Care Out Loud, and that's for not just cancer caregivers, but all caregivers.

Candace Dellacona: Absolutely amazing.

Building a Supportive Care Coalition

Candace Dellacona: So tell me how and Sheri, maybe you can answer this. You come in as a family foundation. How did you connect with the One Family Foundation and other organizations to provide this supportive care, and can you go a little bit more into the programs that exist for our listeners who are dying to hear this information so that they can make those phone calls and send those emails when they are done listening through the podcast?

Sheri Biller: I think we should also define supportive care.

Candace Dellacona: Yeah.

Sheri Biller: When we are all talking about supportive care, we're talking about all the needs of patients and their families and their loved ones and friends, the caregivers, all services that all needs except for

the clinical care. So we're talking about whether it's nutrition, whether it's needing a babysitter just to be able to reach an appointment, pay an electric bill all just alleviate a stress, any kind of issue that comes up for our patients, including pain, including psychosocial, including every, everything that one could need. And that's what we're speaking about. The coalition came together because truly it was the first time that all of the people involved in supportive care ever were in a room together. That means policymakers, that means insurance, that means providers, doctors. We brought them all together and put them in a room and said, we have this problem. How are we gonna fix it? Fortunately, Anneliese and her foundation wanted to help and that's how we came together. So we're all working together to get this work done.

Candace Dellacona: Which is amazing.

Why Supportive Care Is Finally in the Spotlight

Candace Dellacona: And what do you think it is that is bringing the concept of supportive care to the forefront because diseases and cancer and, dementia and all of the illnesses have been around forever. But why do you think, and maybe either of you can answer this why do you think that it's come to the forefront now?

What is it about what's going on in our society now that we realized how important it is?

Anneliese Barron: I don't know if it's that we didn't realize before that it was important. It's just that there wasn't a name for it and there wasn't anyone like Sheri who decided I'm gonna do something about this and take charge and spearhead an initiative to tackle it.

Candace Dellacona: Sometimes it does take one person, Sheri.

Sheri Biller: I think that the issues around what's happened in our healthcare system. Have brought this to the forefront a lot quicker. I think that the issues in society that are causing mental health crisis have also brought this more to the forefront. People realize they need help and nobody had the language to be able to say what this is, and I, whether it's cancer or Alzheimer's or any other disease, when we're looking at Supportive Care, we're looking at how to get people to live their best life, be it the patient, be it the caregiver, be it the loved one. We need to be able to give people, empower them to take control of their disease so they can get well. And so my feeling is it was just a situation that happened where everything came together and everybody became aware of, I can't do this by myself.

Candace Dellacona: I think you're right. I think there has been this sort of convergence of these topics and in many ways, the convergence while it causes a tremendous amount of stress for all of us, it allows for the smartest people and the people who are generous with their time and their own resources to help us come up with a solution.

And particularly here in the sandwich generation, while we're doing our best to raise our good humans and advocate for our aging loved ones, and somehow stay sane through it all. These resources are not only important, they really are vital.

How Families Can Find and Ask for Support

Candace Dellacona: And so what would the two of you suggest when a diagnosis is received? In general, when a patient is sick, they, they see their doctor, and in this case an oncologist and maybe a radiologist, and perhaps a surgeon. What kicks off the initiative for the supportive care piece for the family, the caregiver, and the patient. How does a family even know where to turn?

Sheri Biller: I think from this podcast just what you're doing is going to help that issue because we need to educate the public. We need to educate them and let them know what supportive care is. We need to help them ask for it. And resources are out there, but people don't know how to get it. So whether it's. Asking our friends using technology, asking your physician specifically, not being afraid to ask the questions. And that, that's always a, been a great concern. And when we think about the need for this, we have to think about rural communities where there aren't big hospitals. We have to think about people who don't have the resources and people who don't know even to think about this question that are out there and how to get the information to them. And so just what you're doing is so helpful and what Anneliese is doing is incredibly helpful.

Candace Dellacona: Yeah.

Financial Help in Practice

Candace Dellacona: Let's talk a little bit about the financial piece and what you're seeing with the One Family Foundation. Obviously Bradley saw the need for the economic support. Can you talk a little bit about that and what resources are available to those who are looking for assistance from an economic and financial perspective?

Anneliese Barron: Yeah, sure. And I will say first there's just not enough of it, so I'll just start off with that. There's just not enough support. But yeah. But one of the things that we're doing right now with One Family Foundation is we've partnered with the University of Pennsylvania to launch a guaranteed income trial.

So that's unconditional cash transfer. So we give patients that have advanced cancer and who have, they're under resourced. We give 'em a thousand dollars a month for 12 months, no strings attached. They get to decide, they have the dignity to decide what's best for their family.

We're not gonna tell them, you need to spend the money on this. They know their family best, not us. And so we give them that, that cash payment every month for 12 months. And then we're doing analysis after that to see how does this impact their treatment adherence, treatment completion, health markers emotional wellness, things like that.

Be, because the concept is if you have the financial security to go ahead with your treatments, you have a better chance of surviving. If you can't afford to do your treatments, you're not going to survive. And how does this impact also quality of life? So that's one piece of the work we're doing.

And we have a wonderful principal investigator, Dr. Meredith Doherty. She's just a master at all this, and she's a scientist. I'm not a scientist. I'm just a regular person, a regular caregiver.

Care Out Loud Resources

Anneliese Barron: But that's kind of like what leads us into the initiative that we started to Care Out Loud which is to help caregivers first identify themselves as caregivers.

Like I didn't even realize that I was a caregiver until I started doing this work. I have a 19-year-old son with Down Syndrome and I just always thought, oh, I'm mom. I'm doing what other moms are doing. But I think my refusal of calling myself a caregiver. It did no, did me no favors. I lost out on support, financial support, resources that I didn't bother to look out for 'cause I didn't think I needed them or didn't, I didn't think I was entitled to 'em.

I didn't think they existed. So I think it's really important for people to be able to even recognize that there are caregivers, that they're not just helping out and being a great daughter. So we're helping people do that. And then we are vetting and curating resources for them. You know, we're all so busy.

Who has the time to vet? There's so many resources that are out there. But it's just hard to tell, which of the good ones, which are reliable, which are up to date. And so we do that homework for these caregivers and we just hand the to them, kinda like here are the, here's almost like your starter pack.

You're gonna start somewhere. These are not all the resources that are gonna be available to you in your lifetime, but this is where, at least a good place that you can start. And it covers all aspects of care. Yeah, and we're coming from it from really, we just wanna be a caregiver's best friend.

We're not the scientist, we're not the clinician. We're gonna give you this information in a way that a best friend would give it to their information. Oh, hey, I saw this really great jacket on sale that I know that you love. Go grab it. Is that kind of language and tone and feel.

Asking for Help, Delegating, and Caregiver Guilt

Candace Dellacona: I would love to point out, too, that we're three women. And Anneliese, you just said you didn't identify yourself as a caregiver. You thought you were just being a mom. First of all, just being a mom. We have to work on our language. Right? It's amazing. You have three beautiful children and you're, they all have different needs and we're all trying to survive.

But I will say that it is something I think as women that we have a hard time doing, which is asking for help. And, once we get those offers of help, it's even harder to give up the task and perhaps even delegate because we I, and speaking for myself and I presume you each feel this way, Sheri, you went through it with your best friends and trying to pitch in. I think, it's hard to delegate. It's hard to ask for help. It's hard to even identify yourself as a caregiver. So the deck is stacked against us as women.

Anneliese Barron: Yeah, I agree. It's like we feel like failures if we have to ask for help. 'cause we see everybody else well, no one else is asking for help. But what we don't know is that they're all struggling silently at home. So podcasts like this, like doing such a great job of, raising awareness. Let's talk about, care and how difficult it is. It's beautiful, but It's also difficult and it can, it can be a very long journey for so many people. And the thought of having to shoulder that alone there there's no reason for that. We just, we don't feel like we have permission to ask or to talk about it, and we just deal with it because we're a mom, a sister, or a friend.

Candace Dellacona: Exactly. And Sheri, I think you're the perfect example of that. You are caregiver in action, so you know, probably looking back. Do you think that there were opportunities that you missed as being essentially a defacto, let's say, caregiver for your friends who were like sisters to you, they were your support network. Do you look back and think about how different it may have been if you knew of the resources at that time?

Reaching Underserved, Rural, and Non-English-Speaking Communities

Sheri Biller: Yeah, I wish I could say a lot has changed, but when I'm looking at it, it doesn't seem to me that much has changed. In fact, I think it's gotten even bigger because when I look at the screen, I see three intelligent women who all know to go online or to ask for help or try and get resources or know how to get resources. And this makes me even worry more about the underserved communities and communities of color. And what about if they don't speak English, and how do we get this information to them? And it worries me about how alone they all must feel. Then we think about how does that explode even bigger, I mean, in rural communities.

And so this conversation is so critical. How do we get it past a certain zip code? I imagine that your followers are all within a group, but how do we elevate it and get it out to even more people?

Candace Dellacona: Sheri, that is so important that, we, three of us sit here obviously with some level of privilege and I think I applaud you for bringing up the fact that, your socioeconomic status unfortunately, has significant impact on the type of care that you receive and the support of services that you receive. And I think, taking a sort of broader view of what's going on in the world right now and the way that perhaps certain governments are run and the lack of empathy that seems to be going on in the world at large. And then trying to perhaps change a system that is very solidly in place in the way that it has been back to when your friends were sick, Sheri. And it is. It feels really overwhelming. But Anneliese, one of the things that you said that I love is the community piece, and we're all sitting at home thinking we're alone in this and we're not. And so the work that each of your foundations are doing in identifying this crisis because it is a crisis. If you watch Bradley's documentary again, I'm going to give it a shout out. It was beautiful and alarming to me.

Sheri Biller: Powerful. So powerful.

Candace Dellacona: And absolutely. I think the statistics are clear. One in four of us are in the sandwich generation. We will either need care, give the care, or be the caregiver. I think Rosalyn Carter eloquently said it much better than I ever could.

And so having these resources and bringing awareness to foundations like One Family and Sheri and Les Your Family Foundation. And the good work that you're doing.

How to Connect with Care Out Loud

Candace Dellacona: And so can we talk a little more about Care Out Loud and perhaps how we can connect our listeners with Care Out Loud and the initiatives that you have going on behind the scenes, Anneliese?

Anneliese Barron: Yeah, of course. Our website is, wecareoutloud.org. And then we also just recently launched social media. So we're mostly active on Instagram. Just like the grassroots way of things. And you know what's interesting is that we post different kinds of content and the content that we wanna share is very different than the documentary, which was long form storytelling.

These emotional gut wrenching stories that are so important and a lot of the history behind how do we get here today, like this caregiving crisis that we're in. What decisions, what policies were made decades ago for us to arrive in this spot, and where do we need to head? So Care Out Loud is the complete opposite.

It's more for someone who's probably won't watch a documentary or just really says, browse in their phone. We're, that's what Care Out Loud is for that audience. And so we wanna grab people where they are, which is, on their phones. So our content is very short. Very trying to make it relevant to pop culture, the trends on, social media.

We try to lean into those. But what I was getting at was that the type of content that we post, we do a lot of educational posting, like quick actions here's some easy ways for you to, do X, Y, Z. But we also post a lot of like shareable content, like memes almost kind of like, oh, the caregiver's guilt is that spiral is real, and having talking about if you've ever cried in the parking lot at Target, you're a caregiver. So that kind of content, like bringing a little bit of humor into it, but we're seeing the dms that we get and the comments that we're getting.

It's like people really resonate with that because they're like, they feel seen, they feel validation. They're like, finally somebody gets it. And it reminds us that we need to make caregiving more visible because caregivers carry so much. We don't get paid for it. We're not getting trophies for it, so we need some sort of validation that what we're doing is really difficult, but yet we still show up every day to do it anyways because we love the people that we're caring for.

Building a Movement

Candace Dellacona: And one of the things Sheri, that you know is very apparent with your foundation and talking about supportive care and the emotional and practical and spiritual piece of all of that is the concept of leaning out. Can you talk a little bit about what leaning out means to you and to the foundation and how you encourage caregivers and their families to lean out?

Sheri Biller: I think one of the things that you mentioned, which I think is so important is that this is solvable, but it's gonna take a movement the three of us here are a movement, but we need a much bigger movement. And so we need for the messaging to get out there and people to come together and demand change.

'cause that is, in this time we, in the time we live in, that's probably the most effective way we can get the work done. So I invite people to come to the coalition website because they can see who all our partners are from all parts of life that are working together to get this done, get all the information they need, they can join us and come and help us and to get the word out. So leaning out has to be leaning out in a big way. I think anybody who understands, and no matter who I talk to, as soon as I talk about this, everybody understands, needs to pass the information on, educate whoever you need to educate and also to give a helping hand. Any way we can help anybody it's critical. And the other thing we have to do is train the young generation into what it means to be a caregiver because every single one of them is going to be a caregiver.

Candace Dellacona: That is such a beautiful way to summarize what your two organizations are doing. And Sheri, thank you for the reminder that it's more than just being there for each other. It's demanding that the system change because the current system is not sustainable. It's not sustainable for patients, the families or the caregivers themselves, even the ones who are employed, who are underrepresented and underpaid, and, realizing that the system overhaul is needed and it's emergent. And I cannot thank the two of you enough for being here and shining a light on this issue and providing such incredible resources and support, and we're gonna put all of this information in our show notes. And from the bottom of my heart, as a survivor of the sandwich generation, I am so grateful for your time and your expertise and the resources that you've used to shine a light. So thank you so much for being here.

Sheri Biller: Thank you for having us.

Anneliese Barron: Thanks for having us.