



Season 4 | Episode # 16

The Caregiver's Journey: Surviving to Thriving **Susan Wahlers – Part 2**

Crystal Keating:

I'm Crystal Keating and you're listening to the Joni and Friends Ministry Podcast. Each week we're bringing you encouraging conversations about finding hope through hardship... and sharing practical ways that you can include people with disability in your church and community.

Susan Wahlers is the founder of Makers of Care, which is a nonprofit that provides resources for caregivers in need of support during a long-term crisis, and also equips churches to proactively serve them. Susan understands what many caregivers often face; exhaustion, loneliness, and discouragement wondering if life will ever be different.

On our last episode, she shared her story of caring for her husband who was diagnosed with early onset, younger Alzheimer's at age 55, and how this unexpected disease threw their lives into disarray as caregiving became completely consuming. Susan has come to recognize our need for each other and that for the caregiver, Jesus Christ is the ultimate source of endurance and companionship.

She joins us again today to share about her ministry and help caregivers go from surviving to thriving as they confidently support their loved ones. Welcome back to the podcast, Susan.

Susan Wahlers:

Hello, Crystal. Glad to be back with you.

Crystal Keating:

I'm so glad you're back again. So, let's jump right in. What led you to create Makers of Care and how did you discover the great need to train churches to better encourage the caregivers in their congregations?

Susan Wahlers:

Great question to start with. I love it. Basically, in a nutshell, there's a gap to fill and the gap is between when someone gets a diagnosis to when they would be ushered into the kingdom. And how do you do life in between that gap? And I think on our last episode, we talked a little bit about the "diagnose adios," and where doctors are giving families this diagnosis of some type of dementia, but then they don't tell you how to do life.

And so, what happened in my own story is, even before Dave passed away, I started getting phone calls from friends and family and they're like, we know somebody who's caring for



somebody with dementia. They're struggling and we don't know what to do. We don't know how to help them, but we're concerned for them.

So, honestly, I just kept getting phone calls. And then after Dave passed away, those phone calls kept coming and coming. The first year, I think I talked to 63 people. Oh, my goodness. It was a lot of phone calls. And what I was finding was people were in this crisis moment where they've gotten a diagnosis, but they didn't know what to do.

Or they were experiencing advanced symptoms in a loved one and they didn't know what to do. And so, they just needed someone to hear their story. They needed to know that with God that they're gonna be able to endure. So, I knew that there was a need for this. And also, I had a little bit of righteous anger in me because when I was hearing all of these stories of what was happening and, and something I didn't share on our last podcast together was when I placed my husband into a care facility, we didn't receive really good care.

In fact, there were lots of things that happened to my husband physically because of the lack of care he was getting. And that was a difficult thing to take care of. And I was going to the Lord in prayer and saying, God, I don't like this, like, how do we change this? Yes. And it's such a huge issue and COVID made it even worse.

Like COVID, you know, exposed many of the things that we already knew as caregivers that were there, but just made it worse because now we couldn't even get in to see loved ones and to advocate for them. So, there was a lot of heartache happening around all of this issue. It's a big challenge.

You're coming against a big monster there. And so, one of the ways in which I felt the Lord was leading me to help families was just to empower them, to empower them with encouragement and endurance, in and through his word. But then also to empower them with knowledge, you know, education. How do you advocate some of the practical things of caregiving?

And so that's why we started Makers of Care. We wanted to be that, and we wanted to offer faith-based support groups. That was the biggest reason. When I went to a support group to try to just see what it was like, for me, it was not a positive experience. And most typical support groups, they gather in a circle and you're sharing what's going on in the heartache, which is fine. You're connecting to others through their stories, and it is good to be with people who actually get what you're going through. You know that part is good. But the defining difference was my hope is in Jesus Christ.

And we need to be eternally focused. And when you have the author of hope missing, what, what do you have to offer people to walk away with? And so, most of the time, those support groups were good for people to get it out because they wanna verbally get it out, but it didn't leave them with any kind of hope.



And so, our support group, I mean, that's our goal. We wanna leave you with some kind of a nugget. Who is Jesus, where is God in your story and where are you in his story? And that's the reminders that we do for each other at our faith-based support groups is helping them with that.

Crystal Keating:

Well, that is wonderful. Yeah, you're right. It's very cathartic to be able to express yourself in the hard things that you're going through to others who understand. But once you've let that out, what's coming in? And if we're not being refilled with God's spirit and his hope and a perspective through our hardships, you know, God has so much more for us through those difficult times.

And I just love that focus for your faith-based support groups. You know, I'm wondering how churches have responded to your offer to come alongside them as they provide Christ-centered encouragement to caregivers who are often weary and burnt out. Are, are churches receptive of your offer, or what's been your experience?

Susan Wahlers:

It, it's been a challenge. And I think it's, it's not that they don't want to help caregivers. It's kind of a challenge from the standpoint, caregivers don't always identify as caregivers, first of all. You know, there's like 44 million unpaid caregivers. Wow. And most of that is made up of family and friends that are caring for a loved one. Right.

But when you're caring for a loved one, it's just what you do. You're caring for them out of the love that you have in your heart for them, or out of the type of relationship you have with this person because you see them struggling and you don't want to see them struggle. But most people don't really identify with that term "caregiver" until they're already into the journey several years. I mean, that's what happened to me. For the first two years, I was just a wife taking care of my husband. Right. I wasn't a caregiver. But caregiver is really more a role than it is identifying someone. It's a role that you step into. So, there's some challenges with that.

I have this church here in town, that's a very large church. They have a large congregation, several thousand members. And I had the care pastor say to me we have a lot of volunteers, but we don't know who to serve. And I said, well, who are the people in your congregation that are dealing with this?

And he said, well, I don't know. It's a very, very small number. And I'm like, well, statistic-wise across the country, it should be 20% of your congregation. Right. And I said I don't think that they don't exist. I think that you just don't know who they are. Hmm. And so really phase one of what Makers of Care is trying to do is really bring awareness to the fact that these invisible heroes actually exist.

Mm-hmm. And we need to try to make it comfortable for them to come forward and comfortable for them and embrace them. And that's the other thing is, let's face it. There's a lot of complex things happening in our world today. And pastors are being inundated. Yes, they are, from all angles. And so sometimes when I come to them, I could sense that they're like, oh, I can't open another can of worms because I can't do anymore. My plate is already too full.



Right. And I get that. And, and that's even Christians feel that way in our daily life. Like everybody's busy. Everybody's like, I can't deal with this. But the reality is these are people. This is why the church exists. This is the teachers of God's glory. Like if we see people who are in this position, as the teachers of the church, they will teach us even how to support them and how to come alongside them in sustainable ways.

I think people are really reasonable when it comes to that. So, we're praying about it. We're asking pastors to begin to pray about it and just open up their hearts to a conversation about it. But I think it just begins with sharing, sharing stories that this is happening, and what God is doing in those stories.

So, things that you do on your podcast are really important for that Crystal. And that's why I loved your podcast so much is because you do share those stories. And it just is letting them know that it's gonna be okay. Like we can do this. And as far as the body is concerned, oftentimes I think the American church in particular really sets a stage for passive Christians to come and just receive a sermon or, you know, that sort of thing.

Yeah. But now we're asking them to be active with this and in Romans 12, it talks about everybody has a place, a function in the body. Sometimes I think we just glorify certain gifts over others, but there's a lot of different gifting. And when we got to the point where people wanna step in and help us, you know, oftentimes they'll say, well, what do you need?

We'll say that to people in need. Well, what do you need? And I'm like, I don't know what I need. Right. Like, it's gonna change tomorrow. I don't know what I need. Yeah. And so, I encourage the body of Christ to pray about it and let the holy spirit be creative in and through you and then just offer, offer something to the person that you know, that you love, that you care about. So, we had, we had some incredible things. Can I talk about some of them? So, a friend called me, and I was very discouraged one day and feeling very isolated and, and depressed. And I said I am just so sad. I just told her the truth of what was going on. And so, it happened to be like the month of February coming up.

Unbeknownst to us, she did this list, "A Month of Love for the Wahler's Family." And she listed out the days of the month and she had people sign up for a day and they could do whatever they wanted to do. So, we got cards and gifts and dinner, and you name it every day. And she started it off on day one and she left a little package anonymously on our porch.

I think it had like a popcorn thing and movies and some candy and, and this little printout that said, this is the month of love and who took what day. And then every day we were surprised by whatever happened. That's the holy spirit.

Crystal Keating:

Amen. Because he wants to minister to us through the body. Absolutely. And love.



And that just speaks to what we say all the time. Be in relationship with other Christians. I know that's the desire of all of us that we know one another and that we are known to one another and as God shows us, hey, this is what you have to give. This is what they need.

It's just a beautiful expression of God's intention for the church today. I just love that.

Susan Wahlers:

Yeah, it, it really was. And, and my little church just did the same thing for a caregiver in our church who's struggling and they're in the hospice stage of caring for her husband and she was feeling very depressed. So, we just did the same thing for her. We made it a week and it wasn't the month of February, but we did it and it just lifted their spirits. Mm-hmm. And just letting them know they're not alone. So, community is so important. And even visiting, visiting is a huge gift.

Yeah. A huge gift to these families. I see a lot of people become bitter because it doesn't happen. And then they're like, oh, I'm just gonna give up on it and I'm not gonna do it. But you hit the nail on the head when you said community is important. It's, it's vital. It's vital to the body of Christ.

We had friends that would if they had leftovers, they would make frozen meals for me for lunch. There was a gentleman who made a, this is great. My husband was a biker, and I found this picture of a bike with a wheelchair in the front, and I couldn't afford it.

It was several thousand dollars. He made one for us out of parts that he got from Craigslist and out of the garbage. And I don't know, he, he made it and it was a labor of love. He said he is never doing it again. That is so creative. You know, it was, it was wonderful. And I was able to give Dave that experience when he could barely even walk at that point. So that was great.

Crystal Keating:

Awe, I love that. Well, so what are some of the key steps you share to help caregivers best advocate for a loved one in a medical system, that's often frustrating and filled with barriers? In our last conversation, you talked about a couple of things. Like it was hard to get a diagnosis. Um, mm-hmm, you know, maybe the doctors weren't doing all the testing that they could have done early on. They were just thinking it was, oh, this is just a natural part of aging. And then even what you were saying about being in a care facility that really affected your husband's physical wellbeing. Like how, how did people navigate this?

Susan Wahlers:

Yeah, it's a tough one. This is probably some of the biggest emotional impacting things that can happen because there's a lot of it that you can't control, and you just have to accept. And then there's a lot that you can. Most caregivers are women, which is interesting to me.

Over 60% are women. But that still leaves a big chunk, 40% that are men. But a lot of times personality-wise and, and the roles that we play in our relationships really impact on how we



can advocate for someone. Because we're always taught to be kind and, you know, don't push and don't even question authority.

And oftentimes doctors are looked at as an authority figure in our life. But when you're advocating for someone, you kind of have to push in this day and age. You gotta kind of push for the things that you need. But some of the things that are gonna be helpful for caregivers to understand is when you're advocating for someone, you are the voice for the person that you love.

So, if they cannot speak for themselves or think rationally like we talked about before, you have to become their voice. And it's very important that you play that role and you're not afraid of that. And so, if you're afraid to confront things with doctors or talk about them, it's good to get someone else to help you with that.

Mm-hmm. You know, I think a lot of it has to do with recognizing what are you capable of doing and, and what can you do? But a lot of these things you can learn too, as you go along. But you need to stay organized, and you need to have everything together. Doctors don't want you to waste their time, and you don't wanna waste their time either. But we'll go into these appointments unprepared for the goal of the appointment.

And so, it's always good to have a goal. Like, why are you going to the doctor? If it's symptom management, let's say, my husband had delusions and hallucinations. I had to go to the doctor and say, here's the biggest symptom we're dealing with right now is delusions and hallucinations. I need to know what are the options.

What do we have that can help us with this and asking them what you know is going on. And a lot of times their hands are tied due to policies, hospital policies. Insurance companies don't let them run certain tests, those sorts of things. So, you need to ask them, are there other things that you can do for us? Or if you can't do other things for us, can somebody else in your organization help us with this and just keep asking questions.

And if you don't understand something, keep asking until you do. Don't be embarrassed by that. You're not a medical person and they're there to help you. Most people are not trained in any of this. The other thing you don't wanna do is you never want to assume. I hear this all the time from caregivers.

Well, I just assumed that they were gonna do this, or I just assumed that this was gonna happen. And I said that's gonna get you in trouble when you assume because then you're gonna have expectations that can't be met. And you need to make sure that you speak any expectation that you have and make sure it's a legitimate expectation.

Something that they can actually help you with, or, you know, just don't assume that they're gonna read your mind. Yeah, that's good. And we use props. One of the things I tell caregivers is make a bullet list of symptoms that the doctor can look at and tell the story in a minute. Because



you want them to look at a bullet list and say, here are the things that are happening to my loved one, and just let them look at it and sink it in.

There's something about the written word in front of them. Yeah. And also, if you can't say sensitive stuff in front of your loved one, at a doctor's appointment, use the portals and have this list that you can give to the nurse ahead of time with a note saying, I need the doctor to explore this, or, you know, that sort of thing, but being very, very detailed about it.

Crystal Keating:

Those are practical pieces of advice. Thanks for sharing that. You know, as we think about various caregivers, it seems that they're in different stages of their caregiving journey. You, you had talked about it. You were just starting out.

There wasn't a diagnosis yet. You weren't even considering yourself a caregiver and then others have been caring for their loved ones for many years and might even be preparing to say a final goodbye to them. Mm-hmm. So, what are some of the caregiving stages you've identified and what are some of the unique challenges in each stage?

Susan Wahlers:

That's a great question. I didn't know that caregiver stages even existed. I got some training from a company called Carriers Academy and I became a certified caregiver consultant, like a coach. And part of that training that the owner Denise Brown came up with was she identified like these six stages. And it's helpful to a caregiver to identify kind of where they are on the journey.

Mmm. Because they can see maybe where they need to go, but also where they've been. So, it's an encouraging thing. So, the six different stages that she talks about are the expectant caregiver. So that's somebody who maybe is expecting that they're gonna have to care for like an aging parent soon or something of that nature.

And the key word for that stage is to ask, ask questions. What are their wishes? Get prepared with paperwork. Understand what's going on. You know, that's kind of like a first stage. A lot of people skip that stage though, and they go right into what the freshman caregiver is, what she calls stage two. And the keyword for that is find.

You're experimenting with this new role that you've taken on. You don't know what works. You don't know what's needed. You need to get your feet wet. You're trying to figure out how to do life. And typically, this is the Google stage where you're on Google, trying to find answers to questions you don't even know to ask.

And then the third stage is the entrenched caregiver. That's where you're in the thick of it. It's happening. Life is going on. Things are chaotic. A keyword for this stage is to receive. You need to find support and the strength to endure, and you need to receive. You need to receive resources, anything that you can find to help make life easier.



The stage four is the pragmatic caregiver, and that is where you kind of got into your routine now when you're finding a routine as an entrenched caregiver. The pragmatic is now you're gonna welcome in the joy with the sorrow. This is where you really pay attention to all of those little God winks, as people call them.

Where's God? What's happening? Where does my story fit into his story? What's going on? How can we give God glory and what's happening? And a lot of times I've found joy and sorrow are companions. They're not opposite of each other. They go together in the kingdom of God. And then the stage five is the transitioning caregiver. And this is where you're allowing yourself time to grieve and accept that closure's coming. There was a scripture talking about the body as the body was decaying, the spirit is growing. That's right.

So, every time Dave would lose his ability to do something, in this transitioning caregiver stage, I was saying, oh Lord, you're getting him ready for the kingdom. He doesn't need anything. He doesn't even need to be able to walk because you're gonna, you're gonna fully heal him. He'll be able to walk when he gets to the kingdom. So, he doesn't need it on this side of heaven.

And I kept saying, I'm gonna usher him into the kingdom. That was the stage where we really just wanted to usher him into the kingdom and do it in a way that honors God and honored him in his life. Wow. You know, and then the final stage, the God speak caregiver is when it's come to an end and your role has either ended or shifted in some way.

And that's when you get to treasure the moments in the memories. Mm. Yeah. And in the kingdom, endings are always beginnings, aren't they? That's right.

Crystal Keating:

Beginnings for your loved ones to live the life that God always intended, right? In freedom of their body and their soul. Amen. And a new life for the caregiver.

That in itself is a piece of Lord, who am I now? What's my role? What purposes have you been preparing in me for this next season of my life? That's a transition in itself, one that God will walk caregivers through as well.

So, Susan, I just love our conversations. This has been so good. Thank you. Oh, Crystal. It's been so great. It's been so great. You know, before we close, I just wanna give you an opportunity to share directly to that overwhelmed caregiver who may be listening today or the church member who wants to be a better support to the caregiver in need.

I would love if you could share some words of hope.

Susan Wahlers:

Oh, absolutely. Absolutely. To the overwhelmed caregiver, I see you. You know, we hear you. We care for you. You're not alone. God hasn't forgotten about you and there's purpose. There's purpose in the pain. There's purpose in what you're going through.



And he is telling his story through your story. I think that's so important to remember and you know, just keep the position of your heart eternally focused. I mean, this is not our home. This is not where we're gonna end up. And we just need to internally focus on who Christ is. And he's gonna show us glimpses of his glory all throughout the journey of caring.

And like my husband said, just make it count. Yeah. Make it count, cause Christ is worth it. And for the church members, I would say, go from questions to offers. Don't ask them how to help, offer to help. Hmm. And let the holy spirit lead you and be creative. And also know that respite, respite, respite.

Those caregivers need respite. Offer to just go sit with their loved one and let them have respite, respite, respite across a board. That's what every caregiver talks about is having people that are willing to step into their life and into their home and just be there, be present with them.

Crystal Keating:

That is good. Susan, thank you so much for joining us on the podcast today and our prayer for the weary caregiver is that God would be uplifting your spirits through everything that Susan shared, and that God would be meeting you today, that he sees you, he knows you and he provides the help and grace that you need.

Susan Wahlers:

Amen. Absolutely. Thank you so much, Crystal. It's been such a pleasure.

Crystal Keating

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