



Season 4 | Episode # 15

## **Alzheimer's Disease: Help and Hope for Caregivers**

### **Susan Wahlers**

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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.

At the age of fifty-five, Susan Wahler's husband, Dave, was diagnosed with early onset, younger Alzheimer's and it threw their lives into disarray. As they struggled to adjust to the ever-increasing impact of the disease, friends faded into the background. Caregiving became completely consuming and Susan wrestled with loneliness, discouragement, and exhaustion as she struggled to navigate the complexities of life. Feeling alone and without support, she didn't know if things would ever change. But God authored a transformation in her life as she continued to care for her husband. When Dave passed away in 2019, God ignited a fire in her to help caregivers with the support they needed.

Susan joins us today to share her story and help caregivers find strategies for better living as they support their loved ones with Alzheimer's and dementia. Welcome, dear Susan.

Susan Wahlers:

Hello, Crystal. Thank you so much for inviting me today. Really appreciate the opportunity.

Crystal Keating:

Absolutely. I'm so glad to have this conversation. For a couple of years now, I've really wanted to speak to people whose lives are being affected by Alzheimer's and dementia, and especially the loved ones who are caring for them. So, I'm really thankful that we're gonna have an honest conversation. You know, maybe we can start by thinking back to the beginning stages of your husband's conditions.

Susan, did you have any clues that something was changing in him? I mean, did you notice anything that indicated something is just not quite right?

Susan Wahlers:

Yeah, that's a good question. A lot of people always ask me that, like, what were the signs? You know, what did you see? And initially, we didn't notice as much like not big things.

And so, it was like the little things that were happening all the time, but just like life is, you just learn to adapt to a lot of those little changes. So, some of the common things like the memory



loss and like that just forgetting keys or losing things or misplacing things, sometimes just overlooked as like normal, normal aging things.

And you just learn to adapt to it. But looking back, I can see signs there that we didn't see at the time. But usually, what happens is some kind of a crisis hits the home. Something pretty major happens. And that's kind of what happened in our life, is we kept seeing all these little things.

And he would go to the doctor, and he would say, yeah, I'm, I'm struggling to have some issues with my memory. And the doctors would just say, well, that's normal that you know, we all fit things. They just kinda didn't really take it seriously, that symptom. But what happened with Dave is, it really started to affect work life. And he started to get comments from his colleagues like Dave, you know how to do this. Why are you asking this question? And things like that. And I started noticing he started becoming very disorganized and he was an organized man. This guy had a file for everything and all of a sudden, he was just so unorganized. His office was in our house and typically there was a place for everything that I would walk in and there would be files everywhere. It was just kind of a mess.

Crystal Keating:

Do you think, and he recognized something was happening in him? Did he have a self-consciousness about that? Okay.

Susan Wahlers:

Yep. He absolutely did. And that's something that's really interesting about Alzheimer's and dementia is they do know that changes are happening. Okay. They don't always want to admit it. Right. But they do know that changes are happening. So, with him, what happened was the big crisis that hit our house was their company had gotten bought out.

And so new management came in that didn't have any history with him. He was in sales; a sales rep and they sent him to learn new software. Oh, nice. And there was about thirty to forty people in the classroom to learn this new software and Dave could not get it.

And rather than have kindness towards that, or even seeking to understand, they basically made him the laughingstock of the class.

Crystal Keating:

Oh, that's horrible.

Susan Wahlers:

It was horrible. And he came home from that trip just in tears. And, uh, that was hard. Yes. That was really hard to see my husband so tore up like that. And, but that's when we knew that something was going on and we had to take it seriously. It just wasn't like him. So, he made another appointment with the doctor, and I decided to go, the bulldog in the family, I guess. The advocate. And so, to advocate for him and, and to say, hey, no, you need to listen.



And what's really interesting is, we knew that we were praying and we're like, God, we don't know what to do here. And we said, what should we do? And I'm not kidding you, two days I think it was before the appointment to the doctor, Dave got what they call a lipoma on his forehead, which was just like a little raised bubble thing on his forehead. And so, when we went to the doctor, we mentioned it cuz they started to do the same thing as they always do.

They weren't paying attention to the memory loss. They weren't paying attention to the symptoms that he was presenting to them as being anything big. And finally, that lipoma that was on Dave's head, he goes, oh, we can just remove that with surgery. That's no big deal. But the doctor was leaving the office.

I said, well, his brother had just died of a brain tumor at age forty-seven. That is so young. Yes, it was terrible. Oh. And so, we had already gone through that caregiving situation. It was a quick thing with his brother. But, that made the doctor turn around and come back into the room and say, what's going on?

And so, they did some testing at that point, and then it just led to more testing and testing and testing. And then we finally got a diagnosis, which for us was actually a miracle because since then I'm finding, it takes about an average of five years for people to get a diagnosis with any kind.

Crystal Keating:  
Oh, that is too long. Why? Why is that the case?

Susan Wahlers:  
That's a good question. It's a confusing disease. I think a lot of doctors, it's not something that they can give a diagnosis on that's actually like a hundred percent, you know? And so, some of it is guesswork and some of it is okay, you know, you gotta rule out a lot of things, other things that it could be.

And when you're talking about someone as young as Dave, at this point, he's fifty-five years old. This is not something that they see that young people get, but it is. And it's just not widely accepted that younger people get it. And when you say early onset, Alzheimer's a lot of times people think that means early stages of Alzheimer's and it's not. It means diagnosed younger than sixty-five.

And it's, unfortunately, a growing area. But it's also an area that's ignored for any kind of diagnosis and symptom management and resources and things like that. So, we were kind of thrown into a big chaos, all of a sudden. Oh yeah.

Crystal Keating:  
What were you experiencing at that time? I mean, even just you feeling so discouraged for your husband after coming back from that business trip where he's learning new software and then becomes the laughingstock of the company. Like, what are you thinking at this point, especially when the doctors finally give him a diagnosis?



Susan Wahlers:

I was concerned obviously for him more than anything, like what's going on. We didn't even know that you could get Alzheimer's at this age. Like that wasn't even in our, our realm of thinking at all.

And so, we were just confused. We were looking for answers and I am the type of personality that will dig and keep asking questions and, and push and say, no, we need to know what's going on. He was a little bit more easygoing, you know, not, not wanting to maybe push as much as I was.

So, we made a good team when it came to that. But he was concerned as well. We were both concerned, and we had young daughters still. We still had a daughter at home who was sixteen in high school and another daughter who is just starting her adult life, so to speak at nineteen. And so, we were still parenting.

We were still active. We were socially active. We were involved in our church. There was a lot still going on with life and it was a very confusing time for us and kind of a little overwhelming because we didn't know what it would mean. Yeah. The one thing, when we got the diagnosis, we call it the “diagnose adios.” The doctor gives you a diagnosis and then you're out the door.

Cause they don't really tell you what to do. And so, I remember we went out to the car and Dave looked at me and he goes, well, what do we do now? And I said, I don't know, but whatever we do, we're gonna do it together and we're gonna do it with God. Amen. And he said, well, just make it count. Let's just make it count.

Crystal Keating:

Oh, I love that. It's like, Lord if this is it, use it, use it. Yeah. And multiply it and don't let it be the adios. Let it be an open door for something much greater.

Susan Wahlers:

That's exactly was our attitude. Maybe that's the grace of God in our lives and the knowledge of who Jesus was as you know, our king in our life.

But that's, that's the attitude that we decided to take right from the very beginning, is just make it count. And those words kept coming up all the time throughout the whole journey that lasted six years.

Crystal Keating:

Wow. That is God in you, the hope of glory, the hope that he is gonna work all things together for good when it does not feel good, and it does not feel what you expected. So that, that is God's grace. Well, you know, maybe we can talk a little bit more technical. A couple questions I have, and I know people have asked these questions too. Like what's the difference between Alzheimer's and dementia and how can we distinguish between normal symptoms of aging and abnormal symptoms? What are the red flags?



Susan Wahlers:

Yeah. Great questions, really great questions. I was confused on that even in the beginning. But basically, the best way to describe this is, dementia is kind of the umbrella term for a set of symptoms where you're recognizing that there's some things going on in your brain and underneath that umbrella of dementia are all different types of dementia.

Alzheimer's is just one. It's probably the most common about sixty percent of the people that are diagnosed with dementia have Alzheimer's dementia. But there's several others too. There's frontotemporal dementia, vascular dementia, Lewy body dementia. I've lost count of how many different types of dementia there are.

And you can have mixed dementias where you have more than one. So, that's kind of the overall view of it. And so, dementia is not actually a diagnosis. It's an acknowledgement that there's symptoms that there's something going on with the brain. But a lot of people will tell me, well, my loved one was diagnosed with dementia.

And my first question to them is what kind of dementia. And oftentimes they don't know, and the doctors haven't said anything to them. But it's important to know that because it helps when it comes to resources. It helps when it comes to different medications and behavior modifications. Then you kind of know what to look for when it comes to symptoms.

So, like normal and abnormal, that's a tough one, because that, there's a saying that, that says, if you see one person with dementia, you're seeing one person because everybody has different personalities. Right. You know, and everybody has different things they bring to the table that kind of affect their behavior.

And so, I think the best way to think about it is if the person that you love is experiencing things that are uncharacteristic to them. So, it was uncharacteristic for my husband to be uncoordinated. Yeah. You know, he was an athlete. He was six foot -nine, Crystal. Oh, my goodness. Not, not a short guy. He played basketball.

And so, he came out of an athletic world and was very coordinated and he started doing things that we just not characteristic of that. Right. And had a small car accident where he was at a four-way stop and he saw the car going and he just ran right into the side of the car. And that was on a business trip that he was on.

And, and I was like, you did what? And he goes, I don't even understand why I did it. Yeah. And so, it was just things like that. So, I would always look for uncharacteristic things. And that's what I always tell people, you know, cuz they'll call and they'll say they're so mean they're so angry and I go, is this normal reactions for them?

Or is this something that you're seeing that's different? Are they reacting to situations and circumstances that are different than they normally react to? And so those are some of the things. But one of the key things I would always say is if you are suspecting that there's something going on with a loved one, start documenting some of these things.



Good advice. You know and writing them down because you do forget. And a lot of times they know changes are going on. They're not at a place where they wanna recognize that or accept it. Yeah. And so, it's good to kind of document.

Crystal Keating:

That's really good. Well, can you recommend strategies for coping and communicating that might help improve quality of life when living with these types of memory issues? I'd love for you to share a bit about the language of dementia that you've learned for improving communication. What is it and why is it important for us to understand?

Susan Wahlers:

Yeah, there's like three things that I think are really important. It really helped me in being able to care for Dave and to be in a place where I could accept some of the changes that were going on. And one of the things that was told to us was you need to enter into their reality. So, when you have a diagnosis with any kind of a dementia, no matter what it is, shifting their reality of what's going on. And oftentimes, it's our natural instinct to want to pull them into our reality. Yeah. Yeah. And a lot of these things don't come naturally. I will tell you that. There are things you have to learn. But entering into their reality is really important. So, if they say things like, this person is doing this to me, you don't argue with them about it.

Okay. You just say, tell me more about that. Or that's not very kind of them. Or even if you know, it's not true, you just need to go along, if it's their reality. Because if you fight that, they'll argue with you. And because to them, it's real as you and I. It's, it's very real to them. And it's funny how the brain works, but some of those things are very, very real to them.

And it's not one of the symptoms as the disease addresses, hallucinations, and delusions, and they will see things that are not really there. They get more tunnel vision, so things can really scare and frighten them. So, entering into their reality is really key to being able to just make things calm. And the second thing that I wanna mention is they typically shift from a rational thinker to an emotional thinker. Emotions become their way of communicating, oftentimes, which is really interesting. So fascinating. Yeah. Yeah, you have to become kind of an investigator.

So, when you talk about the language of dementia, it's understanding that if you can't use words, how would you communicate what's going on with you? Mm-hmm right. And so, they oftentimes use their emotions to express what's happening to them. So, for instance, if they're in an area where they're confused and they don't know where they are, they, they could feel very unsafe, which will make them start to act out into, like, I gotta get home. I gotta get home.

You hear people all the time say that their loved one wants to go home. Yeah. Oftentimes what they're trying to express is that they feel unsafe for some reason. And it could be that everything is just new to them, and they need time to settle in.



It could be that there's some real threat there and you need to, you know, pay attention to that. But you, you investigate the emotions to try to understand. Do they have any unmet need? You know, if they're cold, they can't always express that.

Maybe they're hungry. Maybe they have pain. All of those sorts of things are usually expressed through emotions with someone who has some type of a dementia. And so, it's always good to start with, are there any unmet needs? Are there any threats? Are there any safety concerns for them?

And then if you've gone through all of that, then you can look at it as maybe it is a symptom of what's happening and then you can address it with the doctors. But a lot of times you know, you just have to approach things differently.

You can't come in and say, what do you want for lunch? You're asking them to think rationally at that point. It's better to come in and say, we have a turkey sandwich or a ham sandwich, that's it. Give them two choices and let them choose, so they still have dignity and honor in their choices as a person. But you're not overwhelming them with things. And using less words, using less words is really key. You don't always have to use complete sentences when you're speaking to someone with dementia. Wow. It's better to just use a few words at a time. Instead of saying I'm gonna go to the bathroom, do you need to go, you could say let's go bathroom. Hmm. It's simple. And because, you know, more words means they have to connect more dots.

Crystal Keating:

Okay. That is so, that's so helpful. Mm-hmm well, and the caregiver has to really ask for God's grace as they are so attentive to the person, cuz they're really giving themselves to this process.

Susan Wahlers:

It's sacrificial giving, right? It definitely is. And you have to understand that they're not always giving you a hard time. They're having a hard time. And I think that's a helpful. Yeah. And so, I always tried to remember that. And it's hard and sometimes you blow it, let's be honest.

We're all human, right? We all have limits some days and you know, so you have to have grace for yourself too. Like you're not gonna be perfect every day. You're not gonna get it right every day. But the idea is as believers we can sacrificially love this person. Yes. As best we can. Amen. And with God's grace.

Crystal Keating:

Amen. We are not alone, even though we may feel that way sometimes. Well, thank you for clarifying how to communicate better and how that's better for your loved one with dementia. So, you know, we received a really interesting question a couple months ago, and I wanted to ask it to you.

We heard from a precious wife whose heart really is to respect her husband who's in the early stages of Alzheimer's and she was writing to us saying, you know, I'm unsure if I should tell my

friends and family of my husband's diagnosis to explain for some of his bizarre behavior, especially if we're in public. I really want to honor him.

And I'm sure she's not the only one facing questions like this. So, Susan, when you encounter couples who are unsure of how to best honor their spouses, what are some key principles to keep in mind? What are you hearing?

Susan Wahlers:

That's a great question. My heart goes out to that lady. It's really hard.

It's a huge emotional burden that we constantly carry. And it's a very common struggle for many. And there isn't really a one size fits all answer to this. Cause there's many factors that play into it. And let's face it, invisible disabilities are hard for people to, you know, to explain, and oftentimes, others' responses after you do explain it can be unpredictable and even judgemental. So, you know, a lot of times people don't wanna say anything cuz they wanna protect that. I guess the best way to answer this is just kind of share our story and what, what we decided from the beginning because we had to face that same question.

Do we tell people, or do we not tell people? And we decided that the key biblical principles and truths that we stood on is we have to know who we are in God. And we also said, you know, disease doesn't change who we are in God. We're still beloved. We're still a child of God and we're still image bearers of the King. And as an image bearer, we have a responsibility to be, to teach the world, to demonstrate the character of God, to teach the world that our King's way of doing things. And the world's desperate for hope.

There was a verse that really spoke to us, and it was 1 Peter 2:9. "You are a chosen race, a Royal priesthood, a holy nation, a people for his own possession." And it goes on to say that you may proclaim the excellencies of him who called you outta darkness and into the marvelous light. So, a lot of times when we stay secret about these things, it becomes a really heavy, heavy burden to maintain.

It also, it kind of blocks others to be able to see God work in your life; in and through it. And so, everybody has to decide for themselves if and when they're gonna talk about it. But we have found, and then all the support groups I do and most of the people that come to our group have found there's a lot of freedom and a lot of relief in being able to share this with family and friends, and even strangers.

You know, and most people have been really gracious about it. They have as many questions about it as we do, you know. We become the teachers actually to them and teach them, you know, about this disease, but also just about caregiving, about our lives, about how God's entering in to become the comforter, to be there with us to give us endurance, to give us surrender when there's no solutions to really tough things happening.





So, it's really a great way for us to tell God's story through our story. You know, we just kept saying, we're just gonna tell God's story. We're gonna keep telling God's story because we are his possession. We exist for his glory.

Crystal Keating:

That is a wonderful identity to keep in mind and to pray. Maybe some are listening today and think, I don't know how to do that. And so even just inviting the Lord. Okay, if this is true about us, that we are to proclaim the excellencies of God, help me, Lord, help me to know myself in relationship to you.

Help me to turn this difficult situation to something that speaks of your praises and shows others who you are. I just love that picture. We need to show the world who is our King, and we get to do that as his representatives. I love that.

Susan Wahlers:

Yeah. And also knowing we have an enemy, an enemy that doesn't want us to do that, an enemy that wants us to stay in darkness. Yes. You know, an enemy that wants to pile shame on us. And we have to fight that. We have to say, no, that's not who we are. That's not who we are as citizens of the kingdom of God. We are not those people.

Crystal Keating:

That's right. That is right. Well, perhaps someone listening, maybe feeling their loved one is declining. So how do we know when it's time for palliative care or hospice? And maybe you could talk a little bit about the difference between the two.

Susan Wahlers:

Absolutely. Yeah. It, it is a question that comes up a lot. And typically, if you're asking about it, that's the time that's, you know, always a good time to at least explore it.

And a lot of people think that hospice, you have to be basically bedridden. You know, there is the requirement, usually, they'll say that you're gonna die within six months. Obviously, no one knows when anyone's gonna die, except God. But it's really good to understand that hospice is there to really help and support the family.

So, I'm not a total expert in this area, but the way that I understand it is, all hospices are not the same. So different companies, you know, and so some of the services vary per hospices. But palliative care is where they're gonna come in and let's say you have a long-term illness, and you're thinking that you might possibly be cured from it and you wanna maintain doing your treatments for that illness, but you need some extra support, or your family needs some extra support. So palliative care is really for that time. But usually, that's meant you're gonna transition at some point. You're either gonna transition out of the care because you got better or you're gonna transition into hospice care because it's progressing.

Crystal Keating:

Okay. That's helpful.



Susan Wahlers:

And so yeah. A lot of people are afraid of hospice because it feels like you're admitting to the final end coming, which in some sense you are. So, it's really dealing with the emotional impact of that. But what most people find is when hospice steps in is what, what a wonderful thing they are and the support that they offer.

We had hospice the last three months of Dave's life. I wish I would've had them the last year. Because the biggest thing that caregivers need is respite and they don't always help tremendously with that, but they help a little and a little is better than nothing. Absolutely. Every bit counts. Every bit counts.

And also, it was just really nice to know that they were really focused on keeping him comfortable and keeping me comfortable honestly, and in our whole family. And so, it was nice to know that they were there twenty-four seven. I could call them if I had a question about something I was seeing in him that I wasn't comfortable with. And then the last three months of his life, we did transition him into a care home, and they went with us to the care home.

So, it was more eyes on the situation when I wasn't there. They came in and helped with bathing, which is a big deal for people with dementia. A lot of people really struggle with that task. He was six foot nine. And so, it wasn't easy to bathe him. Right. So, it was just good to have some, some extra help with that, and they also give medical equipment, Hoyer lifts, beds, wheelchairs, things of that nature. So, they were very, very helpful and it didn't cost us anything. It was paid for by Medicare. He was on Medicare at that point and so, it was really, really helpful to us.

Crystal Keating:

That's good. You got a lot of support. Mm-hmm. Yeah, so, well, how can someone look ahead and intentionally prepare for the next stage of the disease?

Susan Wahlers:

I guess the thing that I would say is always just pray. You're gonna start with prayer. You're gonna pray every single day and ask God to give you the grace. And then also educate yourself on the disease.

Like, invest a little bit of time. There are a lot of YouTube videos on dementia. There's a couple people that really, I think are doing a great job at educating people with the practical symptoms and ways in which to care for someone with dementia. A couple of the helpful ones is Teepa Snow. It's T E E P A and then her last name is Snow. Okay. And she has a lot of YouTube videos in really help teaching families and even professional caregivers, how to care for someone with dementia.

So that was something I spent a lot of time in doing. I didn't have the energy or time to really read a lot of books. Right. But I found YouTube videos easy. Podcasts, there's a lot of different podcasts that you can listen to, you know when you're in a car driving those sorts of things, but education is good.



And, you know, talking about these things before they happen, like your wishes, sorts of things. You know, do power of attorneys. Get all of that in place, cuz that really helps caregivers. It's a gift to family really to have all of that in place. And so those things and just remain flexible.

It's gonna change and we used to say flow with the glow. Just let God do whatever he is gonna do. And I love that, you know, and just kind of go with it. Yeah. So, flow with the... And don't forget, you're telling the story of God's glory. And so, just be present in the moments. Those sorts of things are really important.

Crystal Keating:

Well, Susan, on the note of flowing with the glow and just allowing God to tell his story through us, how can we spiritually encourage our loved ones who are living with the effects of dementia, and what are some of the ways you found particularly uplifting and impactful?

Susan Wahlers:

Great question. One of the things I learned is validation is a big one. You need to validate what they're going through. It doesn't mean you always have to agree with emotion or how they're handling things. But validating the reality that their life has been turned upside down is okay. It's okay. You know, and we always used to say in our house, don't deny - let's testify.

And so that's, I'm the one-liner girl today, aren't I?

Crystal Keating:

I like it. Mostly I remember those things.

Susan Wahlers:

Yeah, yeah. Let's not deny - let's testify. Sometimes people wanna cover up what's happening. When in reality, going back to what I said earlier, it's really God's opportunity to step in and he's gonna show his power in your life and he's gonna transform your life through it.

So, validation, I think is a big one. And then reassurance, just reassurance that they're not alone, that you're gonna walk with them, that you're gonna be there with them. I think that was really helpful for my husband to hear from me and from others. The reassurance was a big one. You know, isolation happens. There's not a lot we can do about it. The world shrinks and their world grows smaller when you're in dementia. So, we basically have to bring everything into them, into their world.

And for the caregiver, for me, you know, I'm a social butterfly, extrovert being around people and all of a sudden, I couldn't do that. I couldn't go do any of the things that I normally did. I couldn't leave him alone and go even run to the grocery store. And so, isolation is a big one. So, I think for families and friends, it's just recognizing that that's a huge issue for people who are caregiving and when they isolate, they tend to get depressed and they, they don't wanna reach out which they won't.



And so, you have to be a little bit more proactive. And also, another big one, too Crystal, is grieving and lament is a natural response to loss. And a lot of times we wanna call it depression, but it's not. It's not like a clinical depression. It's, you're grieving. You're grieving and lamenting about the losses in your life.

Yeah. Even though you have somebody you love present with you, we lost a lot of things. We had to move in with family to help me so I could go to work, and they could watch days and help care for him. So, we lost our, our way of living, you know, loss of time, loss of energy, and then loss of dreams.

There's just so many losses that happen. And we need to recognize that grieving and lament is gonna be a natural response to something like this. And it's okay. It's okay for people to experience that. Sadness isn't a bad emotion. Mm-hmm. It's a real one. Yeah.

Crystal Keating:

So even acknowledging that and allowing God to speak into that, into the pain, into the loss, into the grief is where we find our hope.

Well, Susan, this has been such a practical and uplifting conversation. It's a really hard diagnosis and I really would love to talk more about how caregivers can go from surviving to thriving, even talking about loss and feelings of grief and even depression that people face. I know that is so real.

So, I would love if you could join me again next week to share about your ministry, Makers of Care, that provides resources for caregivers and equips churches to proactively serve them. Would you be willing to come on again?

Susan Wahlers:

Absolutely. Crystal. I would love to.

Crystal Keating:

All right. Well, Susan, it's been a wonderful conversation and I do thank you for joining us on the Johnny and Friends Ministry Podcast.

Susan Wahlers:

Thank you so much, Crystal. Really appreciate it.

Crystal Keating

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