KESSLER FOUNDATION Podcast Transcript

A Caregiver's Challenges - Resilience, Self-Care, and Love

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JOAN BANKS-SMITH: 00:09 [music] Welcome to another Kessler Foundation Podcast. In this episode, Jessica Ganga, our communications and digital media coordinator, and me, Joan Banks-Smith, creative producer here at the foundation, had the opportunity to speak with Ali Welch. Wife, mother, schoolteacher, and caregiver to her husband Pete, who was diagnosed with a traumatic brain injury as a result of a traumatic event. Listen in as Jessica starts us off.

JESSICA GANGA: 00:39 November is National Family Caregivers Month, highlighting the dedication, love, and care that family caregivers provide to their loved one with a disability. Some research studies here at Kessler Foundation look into programs and tools to provide support for family caregivers like Ali Welch. Ali and her husband Pete, who has traumatic brain injury, have participated in caregiver and TBI studies at Kessler Foundation, and we are very glad to have the chance to speak with Ali today. Welcome, and thank you for joining us today, Ali.

ALI WELCH: 01:09 Thank you so much for having me.

GANGA: 01:11 When you became a caregiver for Pete after he was diagnosed with TBI, how did your life change?

WELCH: 01:18 I think that overnight my life really changed dramatically from, one, that first and foremost, I never even really knew what a TBI was. I guess I had an idea of what a nontraumatic brain injury would be as in a stroke or an aneurysm, but I never really focused on what going through a TBI would entail. My husband did have a traumatic event, and actually he was my boyfriend at the time. We were 23 years old. We were dating about a year and a half. I don't think most 23-year-olds are thinking that anything like that will even happen to them, let alone how it would affect their life, even from the immediate next day to next week to next month and then nine years later to where we are today. There's constantly still ways that life is affected in dramatic ways.

GANGA: 02:10 And I guess going off of that, what has your experience as a caregiver been like since Pete's accident, through his recovery and to now being husband and wife?

WELCH: 02:19 Really for the first two years, our lives were really bogged down in the day-to-day, true, true caregiving. My husband was in the ICU for 22 days, and then he was inpatient at Kessler Rehab for about three months, and then he did outpatient at Kessler Rehab for close to a year through various programs. Each phase of that looked different. Also, we had a very unique situation because I was a girlfriend, not a family member. The immediate night of the accident, we called 911 and the police took me in the police car to the hospital and I was able to see him in the ER, but I wasn't able to get any medical information. I called both of his parents and they gave consent for life-sustaining measurements and things like that and for the surgeries that went on immediately, but it was very clear that I was going to have to continue to fight and advocate for my right to being his loved one in the area. We lived in New Jersey and Pete grew up in West Virginia, so his parents came from West Virginia. But at 23, it's this weird age where-- I remember saying in the moment, "If you go wake Pete up and for him to designate one person to make decisions and be his caregiver in a moment of lucidity, it would be me." Not just because that's what I thought, but because that was the relationship, but I had essentially no way to prove any of that. Now, eventually many months down the line, he signed off on a power of attorney for me to be his healthcare advocate as he continued in his recovery, so that I was able to have some true rights. Because like everybody else, there's always different dynamics to kind of go through in families and in relationships.

WELCH: 04:16 And so caregiving immediately looked with a lot of-- his family very, very much including me in decisions, but also I was just the girlfriend. His family came and stayed as long as they could, but there was a time when they had to go back to their lives and jobs. I stayed in New Jersey, was there daily, my family was there daily. Again, my family having no true caregiving rights, but actually being the caregivers. And similarly, as he moved to inpatient at Kessler and then outpatient, him coming home and kind of navigating through that looked a lot differently as a caregiver. Again, being 23, 24 years old, not really understanding what it entails and kind of the road that we had ahead of us. And then just kind of every single phase as the years have gone by, even though we think that life is this way, I'm still caregiving in these different unique situations.

GANGA: 05:15 Thank you for sharing that part of your story, because I feel like there might be people that are in a similar situation as you and may hear this podcast and feel a lot better to know that there is somebody that went through the same situation and can kind of relate.

WELCH: 05:38 I would love to help them, because in my experience with everyone that I've met through all of the different avenues of life, 95% of caregivers that I've experienced are either parent to child or spouse. And again, my husband and I got married when we were 25. So about a year and a half, two years after his accident, and really our wedding was just like a giant celebration of life, love and happiness, more than a traditional wedding would even really entail. Everyone was just really celebrating Pete's life. But I think it was very unique. So I hope that others can kind of feel solace in that, because I always felt alone in my caregiver experience. Especially being in my 20s, not quite an adult yet having a lot of responsibilities and that I never really thought I would ever do or definitely not looking long term, 10 years, 20 years, how that would continue to shape our life.

GANGA: 06:37 You participated in caregiver studies at the foundation. What did you learn about caregiving from being a part of those studies?

WELCH: 06:48 So I think what I learned is kind of twofold. I definitely learned that no matter how different everyone's situation is, there's still so many similarities that the caregivers have. And whether it be about their personality and the way that they carry themselves and the things that they interact with, no matter the age. The problems that crop up, the strategies that need to be put in place, I felt that there was this connection that was able to be formed through that study. I think the other big thing that I found, is that at the end of the day we are just all humans who care for each other, and no matter what happens in your life, at the drop of a hat for the people you love, you stop and you step into this role no matter what, right? That over-encompassing love surpasses any of the real part of the decision-making, and you know that you just have to do whatever without-- kind of having blinders on all of those other things, that if you stopped and paused, you might think like, "Ooh, this is really going to affect in a different way," or "Maybe 15 years later, this wouldn't have been the same choice if I knew all that I went through," but that love just pushes you forward. And I think no matter the caregiver, that's really what I've been able to connect with.

GANGA: 08:16 That's really beautiful. And what advice do you have to offer to people that become caregivers to their loved ones, either unexpectedly or they anticipated the situation? What advice do you have to offer?

WELCH: 08:37 I think that I would tell them that, like everything else in life, there are going to be really, really, really bad days, really hard days, really frustrating. You're disappointed in yourself, you're disappointed in your reactions, the things you chose to do in that moment, but you also have to just give yourself an added layer of grace that you're doing something that is really unexpected of you and not something that everyone can withstand and withstand the pressure of and the daily grind and the never going away. I think that anybody that knows my husband and I, would-- people we've met later in life past his accident, that didn't know whatever happened, they still know that I - for lack of a better way to say it - help him in things and that I'm always working to still [caregive?] for him, even though he doesn't have some typical things that people-- I think that the thought of what caregiving is, is the very physical caregiving and not the emotional and that mental load that goes along with the caregiving.

BANKS-SMITH: 09:52 One of the things that you don't realize until you're in a situation of being a caregiver, is it's not just the physical, it's the mental. What have you done for your own self-care or respite throughout these years?

WELCH: 10:05 Oh my goodness. This is so important and such a hard question. I think that this is another thing that all caregivers would right away giggle about, because 100 billion percent self-care in this type of situation is so important. Prioritizing my own mental health and personally going through therapy, grieving my husband's accident. It was a very traumatic experience that I went through personally, even though he went through it. Myself, the immediate people that were there, my mom and my dad, Pete's family who came hours thereafter, everyone has had to kind of grieve it and go through it their own way. So truthfully accepting that, that took many years to recognize that I need to really deal with that. Also, this is something that a lot of people don't talk about, in my opinion, but grieving the life that you would have had without being so hyper focused. But again, I was 23. There was whatever avenue that I thought my life would take, and the avenue that I did take. And just again, being honest and understanding and giving myself kindness that it's okay to have those feelings, many, many years of therapy of dealing with that. It doesn't take away my love and my care for my husband or the caregiving that I've done or the journey that's led us here, but I think that in an ideal world, yeah, getting alone time or vacation, all of that would be great self-care. I also channeled my energy into becoming a marathon runner, so I started running at 25, so a couple of years into Pete's time. And that was a time that I was able to really focus on myself and prioritize myself, set some lofty goals and achieve them and have the successes be about me rather than always about Pete and his successes, which were, of course important, but it felt like I was becoming my own self, so kind of channeling.

WELCH: 12:12 Not a lot of free time, but being hyper focused on what I could do in the small amounts of free time that weren't caregiving. Again, my husband doesn't have a lot of physical need, so I can definitely understand how for some caregivers listening right now, they're thinking like, "I could never dedicate hours to running a marathon," but my husband has a lot of mental need. And so I think that self-care is super important. I think every single caregiver would be like, "Self-care, what's that?"

GANGA: 12:41 As you said, every situation is truly unique to the caregiver, so I guess it's just finding what you need as a caregiver to make sure that you have yourself kept in mind.

WELCH: 12:54 For me, it always felt overwhelming. There's no way I could take this amount of time or even an hour a week for therapy, or I would spend my whole therapy time talking about the day-to-day monotony, right, but making it a little bit bigger and truly focusing on myself as self-care says, right? That was the way that I was able to really actually care for myself and be my own caregiver.

BANKS-SMITH: 13:18 Talking about self-care, you've talked about therapy for yourself. Did you find that being a part of a support group for caregivers was helpful, or did you join any?

WELCH: 13:30 I think support groups are incredibly helpful. Again, just that connection immediately. Everyone in that room knows what you're going through, even if the situation's unique, which of course, it will be. You're going to be able to find some threads and commonalities. I felt whenever I was able to interact with other people, it was comforting. I have definitely been here and there in finding different support groups. There's a great one through Kessler. It's a dual split group where they have the survivors meet and the caregivers meet during some meetings, and that has been really helpful, because again, you're able to make those connections. But I also find that because we're a little bit longer into our caregiving than some people at these meetings, I was able to kind of backtrack and give like, "Oh, these are all the things that we've tried. Some things for you to--" multiple strategies and things. So I think support is at the basis of what you need, because no matter how supportive your family and your friends are, no one gets it unless you're doing it.

BANKS-SMITH: 14:37 Thank you for sharing that with us. It's certainly beneficial to people to hear that there are others out there, and like you say, not everybody has the same needs, but still you're in this together. There's always information to share that will help you get through the daily grind.

WELCH: 14:53 Yes. Exactly. I'm sure lots of caregivers feel this way, but I wish that I could dedicate my life's work to providing caregiver support. I think there's a huge need for this in the country, like everything else. I think that from day one on, so many things that are confusing and you just don't even know where to begin, from Medicaid, Medicare, all these different actual government entities. You're on a phone that's ringing forever to ask your question. And yes, there are case managers and things and people in the hospitals and recovery centers to help with, but there's nothing like a real live person that you can connect with. And I always have said that I would like to take a team of caregivers and create this mini army that can go and share this information. Because the people who-- and actually it's almost-- I think probably five people in the nine years of Pete's accident of friends of friends or people that we personally know that have had TbI's themselves or a loved one has had a TBI, they've reached out, "Hey, I know you went through this. Can you tell me your experience with blank or this or what you would do for that," and it's just invaluable. Everyone is doing their absolute hardest to share certain information, but other things, it's just impossible to figure out. And so that's where, again, a support group is nice because you're able to share those little tidbits, but this is a much bigger need than I think people even realize. So I'm really thankful that this podcast is coming out because I think that caregivers need to be a little bit more focused on. Everyone focuses on the survivors, rightfully so, but. No matter your age, no matter your gender, no matter your relationship, it is difficult and it is a lot of work for a variety of reasons, and I think that anything that people can do to make it easier for others--

WELCH: 16:59 This is so silly, but I remember one time telling someone-- because my husband doesn't drive because of his accident, and there is a service in New Jersey run through the state where a bus will come and pick you up and take you to therapies and things. And so my husband was taking a bus to Kessler that was state run that we didn't pay for. And there were many people in the caregiver support group who is like, "What? We didn't know that was a thing," and that's something that everybody should be taking advantage of. That's absolutely nothing against the people who didn't pass that information on. There's just so much information that needs to be passed along, and so there really needs to be this frontline of caregivers who could be like, "Hey, well, these are things that I know," and just almost be special. I don't know. I have a lot of grand ideas. I know that there are case managers in the hospital who say, like, "Oh, apply for this, this and this," but they're going to visit how many hundreds of people because they're not just visiting the TBI people. That's why if there could be a small sector, I don't know. I don't know how it would work, but I just feel like there's so much missing information. My husband, all of his disability claims got denied to begin with for various reasons, and just the fact that we knew you could appeal in a successful manner typically, that's why he was able to receive the benefits that he did. But most people get that denial letter and they're like, "Oh, that's it." And having someone say, "No. No. Wait. Look at this part about appeal. Do that."

GANGA: 18:35 I feel like there's information all over the place and people don't know where to find it.

WELCH: 18:41 Yes.

GANGA: 18:41 Or they don't know that it's even there, as you said, to begin with. And then they feel like they reached the end of the road, and it's like, "No. No. No. You can keep going," but people don't know.

WELCH: 18:53 Exactly. And maybe someone thought that they did know. Well, it says it in the letter you can appeal, but maybe you have to appeal two, three times. There's just so many things, that having that advocate for the caregivers would be-- this is what I'd love to do. I'm an elementary schoolteacher and I love that job for a lot of reasons because I [caregive?] in a different way, but I just feel like this is such important work, that I hope in my second half of my life I can help with.

GANGA: 19:25 Well, you'd be the perfect one to do so.

WELCH: 19:27 Oh, thank you.

GANGA: 19:28 You sound very passionate about this subject. Very evident throughout the podcast. So, yeah.

WELCH: 19:34 Oh, I appreciate that. It's important work that caregivers do, and it's difficult work, so I really appreciate the help. Spread that word.

GANGA: 19:45 Well, thank you for your time. Definitely. And if you, the listener, are interested in participating in either one of our caregiver studies that are currently going on, more information is linked in our program notes. So the final question is, you and your husband donate to Kessler Foundation. Why do you choose to support the foundation and the research that is done here?

WELCH: 20:13 We do everything in our power to work alongside Kessler Foundation, because the work is just so meaningful. I think I say this every time I talk about Kessler Foundation, that Kessler gave us our lives back. The hospital saved Pete's life, but the life that we have is because of the work that the doctors and the nurses and the staff, everybody in Kessler did, and they directly helped because of Kessler Foundation. We have our life because of Kessler Foundation, before I even knew what Kessler was, right? We donate our time and our money and our energy so that we can help other people be given such a high-level of care and support, and the most innovative technologies and procedures and tools that they can give, because my husband is the level healed, the way that he is in his life, because of the care he received through Kessler.

GANGA: 21:17 Well we are incredibly thankful for people like you, Ali, and your husband, Pete. This is why we do what we do every day. [music] From my position to Jodie's to the researchers, thank you so much for your time today.

WELCH: 21:34 My pleasure. Thank you for having me.

BANKS-SMITH: 21:38 Tuned into our podcast series lately? Join our listeners in 90 countries who enjoy learning about the work of Kessler Foundation. Be sure to subscribe to our SoundCloud channel, Kessler Foundation, for more research updates. Follow us on Facebook, Twitter, and Instagram. Listen to us on Apple Podcasts, Spotify, SoundCloud, or wherever you get your podcasts. This podcast was recorded on November 16th, 2021 remotely and was edited and produced by Joan Banks-Smith, creative producer for Kessler Foundation.