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LOSING MIKE BUT KEEPING HOPE

Interview with Jen and Allie

“I remember sitting on Mike and just holding his head in the consultation room saying, I'm going to fix it. I don't know how, but I'm going to fix it. I'm going to find the treatment. I'm going to find the doctors. I'm going to fix this. Don't you worry about it?”

Celia: This is Messages of Hope and I'm Celia Fielke. Today I'm talking with Jen and her daughter Allie about coming to terms with losing Mike.

Mike was diagnosed with a brain tumour and initially an operation and treatment minimised the impact of the cancer. But after 3 years there was a sudden and dramatic change, something Jen couldn't fix. Mike's daughter Allie shares what happened.

Allie: He was going away on an ultimate frisbee weekend with his friends. And that Friday he was fine. He was dad, he was peppy, happy, could walk, could talk. He went away and then automatically when he came back, he was like, a whole new person. It was like seeing a stranger.

Jen: He would cry when he was happy, he would cry when he was sad. He would cry when he sees food. It was a lot of emotions, typical of a stroke patient.

Celia: So he had that stroke while he was away, how was it different supporting Mike now?

Jen: For us as caregivers, where before we had to just kind of guide him, at that moment we had to start doing things for him. Like picking him up off the floor, helping him to the restroom, helping him off the couch, even trying to help him eat.

Allie: I couldn't sing with him anymore. He's always been a big music person. So just to go from my dad being able to play the piano for me and help me practicing my songs to not being able to. I mean, for every little girl, they want their dad to be like the biggest guy in the world, they're the most amazing person. They're the king of your life. And then all of a sudden like we kind of swapped places and no little girl wants that because they want their dad to be the guy that threatens your boyfriends!

Celia: He's there for you.

Allie: There for you and then just to not have him be there. It was really difficult.

Celia: Grief and loss hurt at any age, and in lots of different situations. I'm Celia Fielke and this is Messages of Hope. Jen and Allie are sharing the struggle of grieving for the Mike they knew, while still loving and caring for him as the disease affected his behaviour and personality.

Celia: Jen you look like you're dealing with this really, really well on the outside and all together, and you're, you know, organized and calm. What's really happening on the inside for you?

Jen: Loneliness. I would say loneliness with knowing that the love, you know, my partner, we've been together since we were teenagers and feeling that loss, not knowing who that person is anymore. There's been so many changes and having to mold your relationship to those unwelcomed changes.

Celia: Do you feel cheated?

Jen: Very cheated. Yes, very cheated. You feel like, nope, this isn't supposed to happen until we're 80! Mike and I had these conversations early on in our journey with his illness that this would be so much easier if we were....it seemed like it was not age appropriate for us, it'd be so much easier if we were expecting it.

But I had God place a beautiful woman in our path and she was an 85 year old woman who was crying so much that I couldn't understand her and she had just the week before placed her husband in a care facility. She was going through the same emotions that I was going through at age 40 that she was going through at age 80. She taught me that it hurts at any age. There's disappointment at any age, and there's loss and there's grief at any age. So that was an important lesson for me that I maybe shouldn't feel cheated, but you still do. Yeah.

Celia: How about you Allie, what has been your experience of grief through this?

Allie: It's obviously not great but this whole situation has shown me the different sides of people. Where we'll have people that are super like, "Oh, I'm so sorry for you. You shouldn't have to go through this." And then there are people that are like, they're going to just do stuff for us.

Celia: So if I said to you, come on Allie, let's go to the movies. Let's go do something fun so you can...

Allie: Just get my mind off of stuff. That's better than people coming up to me and giving me hugs and saying, "I really feel for you," because after seven years of doing this, it does get really tiring to have so many people, like I don't know how to word this, like grieve for us and say how sad they are and...

Celia: Put that onto you.

Allie: Yeah, put that on to me because it's like, yeah, I know. It's sad.

Jen: Everybody is going to grieve a loss, whatever their relationship with that person is. So for some people, they're going through the stages that we've gone through. We've had seven years to grieve, they are just now learning about our situation or they have just had tragedy or trauma in their life.

So whatever stage they're at, we were probably there too and just because we're not there now I think it's important for us to be respectful of that as well. You can always return to that anger, grief, sadness, bargaining, all of those things.

Celia: Has there been bargaining?

Jen: Early on, yes, absolutely. Every single report, just make this Lord, make this be a good report, and I will X, Y, and Z. Right. I will never yell at my husband again. I will never discipline the children.

Celia: How'd that go?

Jen: Yeah, right, exactly! So there is a lot of bargaining, especially in the early stages, and then when the report would come back and it wasn't good, I remember sitting on Mike and just holding his head in the consultation room saying, "I'm going to fix it. I don't know how, but I'm going to fix it. I'm going to find the treatment. I'm going to find the doctors. I'm going to fix this. Don't you worry about it?"

Celia: When did that change from the fixing to the acceptance. Or are you still in the fixing?

Jen: No, I'm not in the fixing anymore. I'm not. I would say even a year ago when he was placed in the home, I think that now that's probably, like my best friend said, I can take the responsibility of fixing it to now just loving him through it. Being a wife, not a caregiver.

Celia: When you're dealing with the loss of a relationship, it can be overwhelming. Jen what helps you to get through those tough moments?

Jen: I wanted to have a girl's trip that we could all bond together because I also know that there are going to be some very, very difficult times ahead of us that we can always pull from those good times. And that's a technique that I use. Like if you're in the middle of something and it's difficult, if you can close your eyes and just breathe and go back to your happy place for even 30 seconds and then get back to what you're doing. Just take those little moments.....

Celia: Little reminders of what life can be.

Jen: And pull from that love and that happiness. So we were creating, intentionally creating wonderful memories.

Jen: We did a spring break trip this year and Naomi, my sweet little 11 year old, wanted us to call her dad. She took on the role of dad and she had a wonderful surprise for me when we were walking onto the cruise ship. She pulls out of her bag, her dad's hat that he wore on my first cruise with him 10 years ago, and she said, "I'm dad," and it was the most beautiful thing. She wore hawaiian shirts, buttoned them all the way up to the top.

Allie: She put the sunblock on her nose.

Jen: Sunblock on her nose

Allie: She'd walk around saying, dad jokes.

Jen: Yeah. So she was,

Celia: Creating memories,

Jen: Creating memories and she was,

Allie: She is the most personality wise, like our dad, like she always wants to make other people laugh.

Jen: Yeah.

Celia: Earlier we were talking about bargaining with God in order to fix Mike's health issues, Mike hasn't got the fix you so wanted, so how do you make sense of God in this?

Jen: I don't believe that God is creating pain for us. I don't think it's an intentional pain. It's a horrible, horrible tragedy that was never meant to happen. That's my belief. I think we have a loving God who supports us and loves us through it, but, you know, it's in the Bible, Jesus wept, you know, and that's very real. Um, I think there's pain that's not caused by God.

Allie: God isn't just going to be like, "Ha, I'm going to put him for a little twist. Let's give them cancer." Like he doesn't do that, but I feel like God has helped mom and I to have an even closer relationship through this because I mean, I know without her, I wouldn't survive, without me, she wouldn't survive. And so he kind of helped pull us together to help us through this moment.

Jen: If you have the moments where you're up and down, you're not flawed in that, and whether that's questioning your faith, questioning God, being angry, whatever stage of grief you're in or wherever you're at processing your tough moments. If you're not going to embrace the tough times, you're not going to grow from it.

Celia: Grief can be really hard. The gradual loss of the people that you love can be really challenging. It's worth looking for and hanging onto those moments of joy when they do come. God gives us his promise that we won't be alone.

Allie: His point of view with it is that something happens, so let's make them stronger through this. It's hard at the moment but in the end, there will be a brighter light.

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