

Justin Wilford Edited

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00:00 Allison Yacht: Welcome to The More Than 4-Cast. Thank you so much for joining us today. I'm Allison Yacht. As you probably know, we put together The More Than 4 Cast to help people share stories of pediatric cancer. My daughter was in the hospital in March with pneumonia for two weeks, and I was amazed at how the cancer experience came right back for us. When she was going through treatment I found the whole experience to be very isolating, even at times when it didn't have to be. It is easy to strike up a surface conversation with the mom sitting next to you, but no one ever talked about cancer. My goal with our podcast is for parents to be able to share, and more importantly, listen to other stories. I'm excited to welcome our next guest Justin Wilford. Justin, is the father of Max, an 11-year-old brain tumor survivor. He and his wife Audra founded MaxLove Project, a non-profit dedicated to improving quality of life and reducing long term health risks in children affected by cancer. He has a PhD in Geography and is finishing up a second PhD in Public Health. His research is focused on the power of online peer support and health behavior change. I hope you find our conversation helpful and interesting. Please stop by maxloveproject.org to see what he and his family are up to.

01:16 AY: Justin, thank you so much for joining us on the More Than 4 Cast. I'm really excited to have you and hear your story. So I'm just gonna jump right into it and ask you, how did you find out that Max had cancer?

01:30 Justin Wilford: Yeah. So it was a process, so Max was eventually diagnosed with a brain tumor, the official diagnosis was a mixed grade glioma 'cause they couldn't detect exactly what grade it was... Or it was a... The different samples came back with the different grades. So, in the spring of 2011, we started to see some strange things, like he wouldn't want to go downstairs. And there was particular... So, there was a set of stairs at this beach that we would always go to. We live in Southern California and remember one day he just didn't wanna go downstairs, and so this just stuck in our heads 'cause it was so strange, he loved going downstairs, he was four and a half at the time and would... Or he was four at the time. He'd turned four in the February and would constantly run around and jump on things and jump off things and make problems. And so we started to see small things like this, and then he would come home from his pre-school with a... With scraped knees more regularly. He would start to fall down more. It wasn't constant, some days were worse than others or sometimes in the day were worse than others. Finally, in the early summer we started to see it more frequently. We brought him in to the pediatrician. We had actually brought him into the pediatrician in the spring because he was having a lot of colds, a lot of sinus infections.

03:23 JW: And I remember one time when we brought him in the spring, I said, "Can you look at his balance?" And the pediatrician said, "No, looks fine." And then we brought him in to... For the pediatrician to again look at his balance in probably June of 2011. And he did a whole work up, and he had him walk down the hall, and do different exercises and all the stuff and he said, "No, I don't see anything. I've checked his eyes, his ears, throat and everything. He looks totally fine." Then we continued to see the stuff... Again, the scraping knees at school, not wanting to go downstairs. And so we brought him back in, and then we finally got a referral to a ear, nose and throat specialist. They thought maybe 'cause of the sinus infections in the spring something was up. And then we got a call from his pre-school one day, they said, "We really don't know how to tell you this, but he's on

the playground right now, and it looks like he's kind of drunk, he can't walk straight, and he's kind of falling over, and he's laughing about it. It's not a big deal, he's not upset, but it just... " And by then we had seen the balance issues, and so had they, so I go, "Oh, alright." So, called the pediatrician again and said, "We need to see whatever specialist you're gonna... Needs to see him sooner."

05:01 JW: So that appointment was moved up, and then I couldn't get him to Dayton, because eventually by late July there was definitely more concerns... Had to have been around late July, we were like, "Alright, we need to move this up." And then one morning, this had to have been August 1 or 2, he was sleeping on a bunk bed, and he had fallen off when he was trying to get out of the bunk bed in the morning.

05:33 AY: Oh.

05:34 JW: He fell off... He was on the floor and was unable to get up. He just couldn't coordinate himself in such a way as to get up and this of course really frightened us, so we were like, "Okay, this is really serious." So we called the pediatrician that morning, we said, "This is what happened. I don't think it's an ear, nose and throat problem." And so, the pediatrician said, "Okay, let me call you back." And within a pretty short time he called back, he said, "Okay, I've scheduled an MRI for tomorrow, bring him in, and then we'll see what's up." At the time we did not have any experience with the medical world, so we thought, "Okay, cool, we'll have an MRI tomorrow." Now that we have had countless MRIs, we know that it is really hard to get an MRI tomorrow. [chuckle] And so the pediatrician must have been absolutely frightened by what we told him and then everything he had seen before. And he was probably putting it together by then like, "This is not good." But we didn't know, and he was really calm and cool with us. And so the next day I had to go teach up in LA. And so my wife Audra, had planned...

06:54 JW: I dropped off our daughter with friends up in LA while I taught, because she was going to... She had to take him into the MRI early in the morning. And then after the MRI, they were gonna go out to see a movie and go on to have lunch and go on a date. They should have this great day planned. And so, I get up to LA, drop off Maisie and start teaching the class, it's a three-hour class, we take a break halfway through, and she texts me she's... And all I see is, "It's a tumor. We're in an ambulance on the way to CHOC Hospital." And so it's... MRI was at a different hospital in South Orange County. CHOC Hospital is more in North Orange County, which is where... So they found a large mass, and that's all that they would tell her and with severe swelling as well, and they thought he would need to go in for emergency surgery and so... Sent him in an ambulance up to CHOC Hospital, and the neurosurgeon was able to take a look at him and say, "I think we could wait till the morning." But it was that kind of urgent.

08:16 JW: And so that stuff, so after we discovered... I cancelled class and fighting back tears I talked with my teaching assistant. I said, "You need to tell the class that there's a medical emergency, and we have to cancel the rest of class." And then I drove down from Los Angeles as fast as I could and yeah, I mean that... That day will always be burnt into my memory. And so the next morning, he went in for variance in the brain surgery, and the amazing neurosurgeon at CHOC, Dr. Bill Loudon, was able to get I think it was about 80% of the tumor, but he couldn't get any more, because the tumor was on the brain stem. And so he... He just couldn't get any closer without

potentially causing severe damage. And even with the surgery... Even with what he was able to get, when Max finally came up, he was kept unconscious and intubated for a couple of days, because they wanted to do some more MRIs to see if it was possible to go back in and get more of the tumor.

09:44 AY: Right.

09:45 JW: When he finally did wake up, I think it was on Monday, he couldn't speak, he couldn't use the left side of his body, he had a hard time moving other parts of his body. And we had... It was... We were in the hospital for almost a month as he was recovering and we... We couldn't leave until he was able to get out of bed and use the restroom. It took that long for him to be able to simply get out of bed and use the restroom. But even when he came home, he was not able to walk, at least not on his own. And it was a long, long road to recovery. Still today, where we're just over seven years out, and there are still balance issues, there's still physical coordination issues, but he continues to improve every single year. It's really amazing to continue to see the slow improvements, and I'm happy to talk about that later as well.

10:56 AY: Perfect. Oh, that's great. And what grade is he in now?

11:00 JW: He just entered into sixth grade, which in California is middle school. And so he is now at a big kids school where he changes classes every hour or so, and he's doing great. He finished fifth grade last year working at about grade level in both math and language arts, and that has been our goal all along, is to get him up to grade level, and he's just about there. And we are so incredibly proud of him.

11:41 AY: That's awesome. Oh, that's really nice to hear. Did you guys start treatment while you were still in the hot... Tell me about his treatment. Was there chemo?

11:51 JW: Yeah, so... Right, so with his mixed grade histology, they were gonna treat it as if it were a higher grade tumor. They had a whole chemo protocol set up. They didn't wanna start him on chemotherapy until he was out of the hospital.

12:19 AY: Oh, God.

12:19 JW: They didn't feel like it was super urgent. And so we were able to recover enough. And he was also... One of the issues was he was still dealing with hydrocephalus. And he was still dealing with swelling, and so they had to do a couple of more surgeries to attempt to deal with this issue. So yeah, they wanted him to be healed and out of the hospital. We started chemo therapy, at least in my memory, we started it immediately after... A couple of days after we left the hospital.

13:08 JW: And my wife knows all of the names, so I know throughout he did Ginepriston, Carboplatin, Irenotecan, but I don't remember when he did and what was the exact protocol at the time. So my background is in academia and in the social sciences, so I didn't know anything about the medical world. And I... Going through academia, I have a healthy respect for expertise, for domain-specific expertise, and so I was happy at the time to just let the experts do what they were

gonna do. And I didn't pay super close attention at the time to protocols, and I just thought, "These guys are the experts. They went to school for this, [chuckle] I'm gonna let them do their work." Yeah.

14:06 AY: Right, good, and then tell me about... We talked a little bit about long-term effects of... Of treatment on your child, and I'll come back around to that in a second. Tell me about how your family dealt with him under treatment of...

14:27 JW: Oh yes, I... Just a... And I didn't fully answer your question before about treatment. He did a year-and-a-half of chemotherapy, then he was off chemo for six months. Then he relapsed. The tumor size started to grow again and... But we were also dealing with hydrocephalus again. We went through a bunch of surgeries and eventually a shunt placement, and then he had 30 rounds of conventional radiation.

15:00 AY: Oh, wow.

15:00 JW: And then... Yeah... At the beginning, they would have done the radiation at the beginning, but they wanted to hold it off as long as possible. So they were just saying, "How old can we get this kid before we expose him to cranial radiation?" And so he eventually in the spring of 2014 had his lifetime dose of radiation, and then the tumor started to grow again about a year, over a year after that, and then he went back in for... Oh, what was it? Two years after that follow...

15:44 AY: True.

15:44 JW: And then he... And then we did gammanized radiation, which worked extremely well. Through that as well we did specific dietary therapies that we can talk about later as well, that we believe were really effective.

16:00 AY: Yeah, that's... Let's... Perfect, let's talk about diet now I think...

16:06 JW: Oh, sure.

16:07 AY: And go ahead, you were saying something else.

16:10 JW: Oh, I was just gonna go back to your question that I interrupted, but I'm happy to talk about the diet.

16:18 AY: Tell us about the diet, and then we'll go back to about your family.

16:22 JW: Yeah, so the diet... Thinking about food and diet started really day one in the hospital. I mean, when Max was still intubated, Audra and I were just a mess, just tears and friends and family just coming in and out. And everyone's just in a daze. And that first weekend we were just... We were supporting each other, like she would go to these crying jags, and then I would support her. And then I would go through those. And finally on... It was, I don't know, a Tuesday or Wednesday after the surgery, we both at the same time just kind of looked at each other, we're like, "No, we're

gonna do this, and we are going to do whatever we can within our power to help our kid thrive and to do as well as possible. We don't know what the ultimate outcome is, but we know there's got to be tons of stuff that we can do outside of the hospital, and we know that diet is important. We don't know why, we don't know how." We didn't know anything about it, but we were like food is probably really important. We started to think about it right at the beginning. And so the first thing that we did is we said, "Alright, we need to cut out sugar." And we didn't know any of the science behind it, but I had read an article in the New York Times Magazine, the spring before, by Gary Taubes about about how sugar are... All of the negative effects of sugar.

17:55 JW: So I said, "Well, that's just gotta be a good thing to do." You know, whatever else. We started there... Was not a whole lot of understanding but I being an instructor at the university at the time, I had access to a big medical library. And I was able to start researching dietary therapies, different foods, different food constituents, and then also, I think one of the things that I got out of my academic training was information literacy. I was able to go online and sift through what was nonsense and what wasn't and then finding... If I found a blog page of an academic researcher, I know that guy or woman was going to be more trustworthy than another site where the person doesn't have any formal training. And so I was able to start to piece together some doctors and researchers and some pathways that were promising. And by the time, I would say by October or so of that year we had decided that we should cut out sugar, and that we should focus on colorful vegetables and high quality animal protein, healthy fat, and it was just a general healthy approach.

19:41 JW: Early on, still in the hospital, Audra came across a bunch of vegan-focused cancer and diet blogs and websites. And so, that was the thing that we considered for about a week, and then looking into the science, is like the science isn't really there for this. And so, yeah, so the approach that we settled on, probably by October, was whole foods, lots of colorful vegetables, high quality animal protein, healthy fats, and cutting out sugar, as well. So this approach develops over the next year or two. We also started a non-profit during that time. Audra used to be a professional cook, and she went to culinary school way, way back in the day.

20:41 AY: Oh, wow.

20:43 JW: And so this was the thing that she was able to dive into, food, and so we started to hold cooking classes for families, and we started to meet dieticians who shared our view on diet and cancer. Not all dieticians do, but we were able to meet some who did, and they were able to help us with the cooking classes. And then we started a parent support group, where we shared recipes, and we talked about food and food science, and I would share scientific articles. And we started to have parents in the group who said, "You know, we need... Are there any dietary approaches that aren't just going to support good health, which was our goal, we didn't think at the time that any dietary approach could actually fight cancer, but our goal was to support overall health, and that we wanted to have our kids thrive during treatment and then also afterwards. And so this is really that quality of life. And so we had some parents who were like... Who had kids whose diseases were not responding to treatment or relapsed and going back into treatment, and they said, "We need dietary approaches that are gonna fight cancer." And at the time, I thought there's not a lot of good evidence for any dietary approach that is actually going to fight active cancer.

22:22 JW: But then I came across the work of, it was Dominic D'Agostino at the time, or no, no,

no, it was Adrienne Scheck was the first researcher who I came across, I mean, I came across several others who had been doing preliminary research in mice on using a ketogenic diet to inhibit tumor growth. And this stuff was just like, it was like the clouds parting and the angels. It was like, "Oh, wow. You mean a dietary approach might actually be able to fight cancer?" Now all of their work was done in brain tumor model, so this was only something that we were willing to talk, advocate for brain tumor kids, but we started to... We found a dietician, a ketogenic dietician who was willing to work with families because the ketogenic diet is used and has been used since the early '90s for epilepsy.

23:31 JW: So there are a lot of hospital dieticians who are well versed in ketogenic diet, and so we found one who was willing to work with cancer families and through our non-profit we funded several families to get this ketogenic diet consultation and help. Those families found the diet to be extremely difficult, and there I can... We could go into the reasons for this later, very different to do it for cancer than for epilepsy. And so the ketogenic has been, the spring of 2013, that we were funding this dietician to work with families. At the time, Max's tumor sites were stable, it was about 10% of the original tumor sites were left, and they were stable, they weren't growing, and so we weren't considering the ketogenic diet at all for us. We thought maybe things will stay stable forever.

24:43 JW: In July of 2013, we had an MRI that showed potential tumor growth, and so that's when I go back into the ketogenic diet stuff and even more intense way and talked with the dietician and reached out to other researchers and tried to learn as much as I possibly could, because I thought this is our next step, this is exactly what we're gonna do. Our oncologist at the time was absolutely against it. She thought it was ridiculous. And so, I found every scientific article, every peer reviewed scientific article that was out there. I printed them off, and I gave her a huge packet, and I said, "Okay, here are all the studies, yes, they're all on mice, but the basic biology is... It's really fascinating. And the diet is being used for kids with epilepsy, so we know that it's safe for kids. We... So, why not?" So a couple weeks later, her assistant called us up for a different purpose, but then at the end she said, "Oh, by the way, your doctor is all on board for the ketogenic diet." She, so...

26:01 AY: Oh, wow.

26:02 JW: Yeah. [chuckle] And so we're like, "Yeah, this is great," because we told her like, "We're gonna do it, and we would love for you to support us, but we're gonna do it." And so it was just great to have that support. I went on the ketogenic diet myself or a ketogenic diet in August. 'Cause we said if he was going in for a follow up MRI, and if the follow up MRI shows for sure that there is... That the tumor sites are growing again, then we're going on the ketogenic diet. So, in preparation for that follow up MRI, I went on the ketogenic diet, then Audra went on a ketogenic diet, a couple of weeks later. By September 1, we were both in full swing with the diet, and the MRI came back that yes indeed these tumor sites were growing.

26:53 AY: Wow.

26:53 JW: And so we put Max on the ketogenic diet on September 1, 2013. So they'll be... Have that date. But I didn't think it's like, "Alright this is a massive change." If anybody is listening to this

who has done a ketogenic diet, and you know this is a really big change from the... From even just a normal healthy way of eating. So we have him... Also, I should say for anybody who's listening, a ketogenic diet, I don't say the ketogenic diet because there are many different ketogenic diets. And ketogenic just means this is a diet that forces your body to produce ketones, and ketones are basically fats that are broken down into smaller molecules and are easier for certain tissues to use, especially the brain. So evolutionarily, we have the ability to go into a state of ketosis, because it's what we do when we don't eat for a couple of days, our body starts to break down our own body fat. And some of that fat gets turned into ketones. So, we... Oh, and the diet is typically or ketogenic diets are very high in fat, very low in carbohydrate or sugar, like Max is limited to under 20 grams a day. And so, all you need to do is look at the side of a rice crispy box, and you can understand how low 20 grams of [chuckle] carbohydrates is for the entire day. And then a moderate amount of protein. So, you don't wanna overdo the protein on a ketogenic diet 'cause it will lower the amount of ketones that you have.

28:49 AY: Gotcha.

28:49 JW: So, we started that, and he took to it. It was no problem, we... Because of our visibility in the culinary sphere, she was able to whip up just amazing keto desserts, and he had ice cream and cheesecake like every day.

29:07 AY: Wonderful.

29:09 JW: He was totally fine with it, [chuckle] and then we had another follow up MRI, because we were dealing with hydrocephalus as well, we didn't know what to do, but we had another follow up MRI in the first week in October. And so, he had been on the ketogenic diet for a month, and the MRI showed continued tumor growth. And we were like, "Uh." But we know the [29:35] we're just gonna keep on going and regardless, what's our alternative, just to go back... Let's just continue on. So we had another MRI in mid-November, because he had gone in for surgery to do some procedure that was gonna avoid putting in a shunt. And they did an MRI during that time, and the tumor growth had stopped.

30:01 AY: Wow.

30:01 JW: And from everything we had heard, to when the tumor growth occurs, when it starts back up again, it doesn't stop unless there's been a treatment given. And there had been no... That we had not done radiation at that time, there was no new chemo, there was... We had done nothing except for the ketogenic diet. So, I'm like, "Okay."

30:25 AY: Oh, wow.

30:25 JW: "It's working." And then we had another MRI, so we eventually had to put in a shunt in February, we had another MRI then... And again, no tumor growth, it had just stopped.

30:38 AY: Wow.

30:38 JW: Now, it didn't shrink, but it had just stopped, and we were like, "Wow, this is for real." So then there was a study, one of Adrienne Shceck's studies on the ketogenic diet showed that it works really, really well with radiation.

30:54 AY: Oh.

30:55 JW: There aren't really a lot of studies that show ketogenic diets work on their own that particularly well. So we were really thrilled to see that it at least stopped the tumor growth, but it works really well in conjunction with radiation and chemotherapy potentially. So we had radiation scheduled for March and April, and we thought, "Alright, this is great, let's keep him on this diet and let's see what happens during radiation," and he flew through radiation, never missed a day at school, he was in little league at the time.

31:35 AY: Really? Oh my, gosh.

31:35 JW: And he just was... Just flew through it. And then we didn't have a follow up MRI. I feel like it was maybe four, five months later that... 'Cause, with radiation it takes a while to see if it's actually gonna work.

31:54 AY: Sure.

31:54 JW: And we decided to keep him on... To continue on with the ketogenic diet and the MRI... The next follow up MRI we had showed that he responded as well as our oncologist had ever seen a kid respond. And then we continued to see decrease in tumor size for another year after that MRI. Every time we would go in, it just continued to decrease and decrease and decrease. And so...

32:27 JW: We had, yeah... So finally, I don't remember the exact dates after this, but we had decided, "Alright, Max was getting tired of the ketogenic diet," so we took him off the ketogenic diet again, and I wanna say this was in 2014. Was it 2014? It would've been maybe the spring of 2016 or the winter of 2016 we said, "Alright, you can take a break from the ketogenic diet." We didn't go crazy, but he just wanted fruit. Apples, bananas, sweet potatoes, [chuckle] all the things that he... It's really cool when a treat for your kid is apples and bananas, right?

[laughter]

33:12 JW: That is his idea of just going crazy.

33:16 AY: I love it. That's awesome.

33:17 JW: And so we did that for about six months, and then in the summer of 2016, the tumor sites that had shrunk and were looking really small and great, started to grow again. And so it was like, "Oh, wow. We've been off the diet for six months. Like, what the heck?" You know. And so we said, "Alright, we're hitting the diet again." And so we went back on, and this time it was even easier because at the time we were friends with some people at a company that were producing a lot of ketogenic foods. And so he was having all these awesome keto foods, and we did gamma knife, I

guess then in the fall of 2016. And he responded brilliantly to the gamma knife, and in the six-month follow-up to the gamma knife, the neurosurgeon said that his MRI looks as good as it ever has.

34:30 AY: Wow.

34:32 JW: And it has continued to look that good since then. We now have him on what we call a modified Atkins, or not what we call, actually this is what dieticians call a modified Atkins diet. So a modified Atkins diet is, it allows for a lot more protein and basically the same amount of carbs. I would say on a typical day, he has around 20 grams of carbs a day. But we also will have free meals, so maybe once or twice a month, we'll go out and he can have a bowl of spaghetti or [chuckle] these other things too. So that's where things stand now. And we've kind of reached this point with him where he's okay with the general diet now, as long as once or twice a month he can have a free meal.

35:30 JW: And so we're gonna continue to do this for as long as possible. There are a bunch of other benefits to ketogenic diets as well that are emerging in the literature or have emerged, so there's a lot of evidence to show that it is neuro protective. So we think that Max's school and his cognitive development has been so good because through all of the radiation especially, he was in ketosis, and we think there's probably benefits for him to continue to be in ketosis, at least intermittently, for brain health. And there's some data that also suggests that it lowers markers of inflammation that are important, so we're gonna continue on and we're gonna see how long he... As he starts to grow up and he gets into adolescence and young adulthood, we're sure there's probably gonna be some pushback, but for now things are good.

36:42 AY: Right, right, yes. I think that does start to happen with more than just food, probably.

[laughter]

36:50 JW: Right, we're just bracing ourselves.

36:52 AY: Exactly. And I know you mentioned you have a daughter, how did she do through all of this, and how is she doing through all of this?

37:00 JW: Yeah. We had... One of the benefits of having this non-profit and connecting with thousands of families, is we've been able to hear so many stories, and early on, we were seeing a pattern with parents saying the sibling or siblings are having a lot of problems. And just...

37:24 AY: Right.

37:24 JW: There's issues. And so relatively early on we focused a lot on Maisie, just making sure that she had her own special time. There were things that we would do just with her, there would be special days just for her, because Max got so much attention. Especially in treatment, I mean, Max would just constantly... Friends and family bringing toys, and everything was about Max. And then of course, there's MaxLove Project which is our non-profit, there's no MaisieLove Project. And so

it's just... She knows that, or it's not irrational for her to think that she's getting the short end of the stick here. And so we have paid a lot of attention, and we still see that she is... I mean, this is true for, we've seen this with other non-cancer families as well, but she is very attentive to any little thing that Max gets. She wants to make sure she gets that exact same thing.

38:33 JW: And I remember in... I don't remember exactly when this was, but at one point Max had to go get a pokey for I don't know, taking blood or what it was. And he was gonna get a prize for getting the pokey, and she flipped out. She said, "I want a pokey. I want a pokey too!" And, and so it was like really she just wants to make sure she gets every little thing that he does, no matter what, and I think things are good. She's very... She's still very attentive to anything that he gets. But I think for the most part, things are pretty good.

39:17 AY: Good, I'm glad to hear that. Siblings... It's so hard to be a sibling of a kid who is sick. That has gotta be a very difficult thing. [chuckle]

39:27 JW: Absolutely. We've just so many times, and we see it with Maisie, too. She will have these meltdowns and these emotional outbursts that we think, "Wow. Where is that coming from?" And then we think, "This is really common in the childhood cancer world." We don't need to worry about it. [chuckle] You just need to continue to show her love and attention, and it's gonna be okay.

39:53 AY: That's exactly it. Oh God. Well, tell me, let's see. Tell me about... So, I know you guys were in the hospital for a month in the beginning, did his chemo require him to be in the hospital during treatment or during medication?

40:12 JW: Yeah, we were able to do out-patient. It was about a year and a half that we started chemo. I feel like it was the first week of September in 2011. And then we had our last chemo infusion the first week in January of 2013. And so it was all out-patient. Yeah, we never had to go in-patient for chemo.

40:39 AY: Gotcha. And how... Did he lose his hair? And how did he deal with it?

40:44 JW: Right, so... Yeah, so he actually did not lose his hair during chemo. So, we were told with the dose and the type of chemo that he would get that he may or may not. And so it's not a sure thing. And he didn't. But he did lose his hair for cranial radiation. And so, we decided to... Oh, actually before that. Leading up to radiation that year, we had just all these surgeries to deal with hydrocephalus. And so he had tubes, and scars, and everything on different parts of his skull. And we ended up... They had to shave his head for certain parts. And it just looked ridiculous. We were like, "Dude, we just gotta shave the whole thing."

[chuckle]

41:36 JW: So, his head was shaved before radiation started. And then when radiation started, the little he then started the patches were just bald. And so then we decided to just continue to shave during radiation because he just had these patches. Some of the patches have grown back, but some of them haven't. So, it's all in the back of his head. And he's able to... He is obsessed with having

longer hair I think because of everything he went through. And so he wants the hair to cover it. But, yeah. We did a lot of talking. We also had to shave his head at the beginning too because of the surgeries. And so we did a lot of talking about how awesome scars were. And we watched a lot of Harry Potter movies, like scars are a source of power. And they're really cool. And so he's not, he's not afraid to show his scars. And he's fine with the scars. But yeah. He is kind of obsessed with having longer hair. He doesn't wanna shave it again.

43:10 AY: Yeah. I can totally understand. Absolutely. Oh gosh. Well good. Let's see. And I guess I'll ask you our last questions. Tell me if there has been good that has come from cancer, silver linings. Talk about that a little bit.

43:30 JW: Yeah. I... Sometimes when I think about this, I feel a little guilty because I feel like Max's diagnosis has brought nothing but good things. Except for all of the hassle and stuff that he's had to go through, but even so, I feel like all of the challenges that he's had to go through have made him into a very resilient, strong kid. And so I feel guilty, because he had to go through more than most kids. Now, not most cancer kids, because we know so many cancer kids who have worse treatment and worse delayed effects, but he's had to go through so much. And so I think was it all worth it? All I know is that Audra's life changed completely for the better for it. My life changed completely for the better. I know Max would say in a minute, he would never... He would absolutely want cancer to be gone and to have never had to go through this stuff, but I think that it has made him into a really amazing young adolescent boy. And...

45:12 JW: One of the things that I've talked about before, when I go give talks about our non-profit, where it came from, why do the non-profit, and why focus on the things that we do as quality of life and all these health behavior changes. And I remember when Max was diagnosed, or I'm sorry, after surgery we were in the hospital, and it was extremely tough. He wasn't able to walk and there were all these issues. He could barely speak, and we didn't know what the future held, and I remember there was a pre-season football game for my favorite football team, the Arizona cardinals, that's where I grew up, and I remember in the pre-season game the kicker, the starting kicker for the Arizona cardinals had kicked the ball off, and he was the first... If you know anything about football or anyone listening, it's rare for the kicker to be the first one down the field and to tackle the guy with the ball. Usually the kicker kinda hangs back and is like the last person, but for whatever reason he ran down the field, he was the first one to hit this guy, and he had a really good hit and a really good tackle. And I remembers I was listening to the post-game interview, or I might have read the post-game interview, but in any case, he said the interviewer asked him, "How did you learn to tackle like that? That was a really great tackle, you're a kicker. That doesn't really happen that often."

46:50 JW: And he said, "Well I learned early on that tackling is not about skill, it's all about desire, and you just have to want to, and if you go in and you wanna make that tackle, you will make it and you won't get hurt, but if you go in and you're hesitant, and you're not real sure about it, then not only are you not gonna make the tackle, you're probably gonna get hurt as well," and so I don't know if it was because I was in the type of emotional state, or what it was, but it just hit me, I was like, "That's what we're doing, we are treating cancer like this kicker is treating tackling, like we're just diving in head-first, and we have to want to be here, we have to want to do this stuff." If we try to avoid cancer and say, "Oh, when is this just gonna be over?" And, "Oh, I don't wanna be doing

this." Then it's going to be a totally terrible experience. We're probably not going even make the tackle, like we're probably not going to do the things we need to do, and we're going to probably become depressed in the process, and so it's just kind of an epiphany that we need to run head-first at cancer and do whatever we can.

48:03 JW: And so that way of getting into the diet and then eventually physical activity, and then sleep. We totally geek out on sleep. And then all of the other things that we focus on meditation, social support, acupuncture. We just go head-first into all of these things, and if there's anything else that we can do to improve Max's quality of life, his cancer outcomes, his long-term health risk, then we're gonna dive head-first into it. And that has kind of changed our lives in really good ways. Audra and I healthier today in our early 40s then we were when Max was diagnosed seven years ago. So yeah, it's a pretty unequivocal thing. Cancer has been absolutely a blessing, and it's something that I say with reservation, 'cause I know that there are there's a lot of complexity there, and no one would wish this on their kid. They'll say, "Well, I'm glad my kid got cancer, so now we can all be happy," that's a terrible way to look at it, but I have a hard time coming to any other conclusion than the diagnosis has been absolutely good for us.

49:34 AY: Well, I think that is a perfect way to end this interview. Justin, thank you so, so much for speaking with us. I'm...

49:43 JW: Absolutely. Thanks.

49:46 AY: Perfect.

49:46 JW: Thank you for having me. It was a pleasure, and I always love to talk about the stuff. It is still a major part of our life, and there aren't really many other things that I enjoy talking about more than this.

50:02 AY: Well, lovely. Well thank you so much.

50:06 AY: Thank you so much for listening to our latest episode of The More Than 4-Cast. I related so much to Justin's story. I hope it helps you all with your journeys. I have to do a quick plug for BraveHoods, who is the sponsor of this podcast. BraveHoods gives comfort to kids fighting cancer. We do this by gifting lightweight, super soft hoodies with inspirational messages. We also give to siblings, because as you heard in the interview, sometimes they feel left out. We know everyone loves a hoodie, so we sell our shirts, and for each one sold, one is donated. If you'd like to check out our cool BraveHoods, please visit bravehoods.org and consider buying something for yourself or for a loved one. We will donate a BraveHood to a kiddo fighting cancer on your behalf. Thank you again for listening, and thank you for supporting us.

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