

Our Normal

A MinneStory

Ashley and Jeremy share how taking things one day at a time has helped their family maintain a “normal life” after their son, Carson, was identified with cystic fibrosis through newborn screening.



Ashley: Our son has cystic fibrosis. It is a lung disease. I remember that day like it was yesterday, and when the doctor called us in, or took us back to a room, she just said, "I'm sure you're wondering why you're here, and the reason is we got Carson's newborn screen results and he has cystic fibrosis." And it just hit me like – hit me like a wall. I just – I was in shock and disbelief, and I was – I started bawling to the doctor, and I said, "He's fine." It just wasn't what I was expecting. Like I said, it just went over my head. And so, I just kept staring at Carson in his car seat, and just thinking like, "Oh, my gosh." And I – we still really didn't really know much or, you know...

Jeremy: I cried a lot when you told me. The guy I was working with, "It's going to be okay." And I just cried. I just like – "I just want to get out of here." He's strong though...

Ashley: He's been through a lot, but like I said, he always – he's just your happy little boy that no matter what he's going through, he just always has a smile on his face. CF is a part of our life. It's not taking over our life. And we're not going to let that happen. We're still going to raise our son just like your – anyone would.

Jeremy: Let him do whatever he wants, whatever his heart desires. He's my little buddy. I feel like he's the spitting image of me, just with how he acts and he's uh, he's my best friend. I think he would say the same.

Ashley: What advice would you give to other families dealing with this condition?

Jeremy: Just stay positive. For me, I didn't – I just wanted to take it all day by day. I just always try to stay positive and not think like he may have to get a lung transplant someday.

Ashley: Take it day by day.

Jeremy: Yeah.

Ashley: The first year was probably the scariest for us. We just kept being told, "Don't Google. Stay away from Google." But I'd say that...

Jeremy: You were on Google all the time.

Ashley: ...that's everyone's first like – that's just what you want to do. You wanna learn about it. You want to know what to expect. I agree, looking back now, that Google probably wasn't a good thing, but...

Jeremy: We were curious.

Ashley: ...just weren't sure what to expect.

Jeremy: We found out though that like we're probably in the best state to be in.

Ashley: ...to have..

Jeremy: ...to have this disease he has...

Ashley: We have the best care here in Minnesota out of a lot of other clinics all over the world. So, I tend to forget the whole CF thing. It's so like, it's in our routine, the breathing treatments, the

medications, the doctor visits, the lung infections, the coughs, the coughing and the colds. It just...

Jeremy: It's all normal to us.

Ashley: I hope that other families can feel at ease after listening to our story, and just stay positive and live your life like normal.

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