



From rage to gratitude: A mother's harrowing journey to save her daughter (and herself)

“It was (a) profound policy failure that we can change. But now when I think about it, in addition to the rage I feel, I also feel an overwhelming sense of gratitude.” - Rebecca Wood

911. What's your emergency?

America's healthcare system is broken and people are dying.

Welcome to **Code WACK!**, where we shine a light on America's callous healthcare system, how it hurts us and what we can do about it. I'm your host, **Brenda Gazzar.**

(music)

This time on Code WACK! This Mother's Day, we're talking about how our dysfunctional health insurance system affects moms. How far did one mother go to ensure that her daughter – born extremely premature – got the critical care she needed to thrive? How did our broken healthcare system push today's guest, **Rebecca Wood**, to delay her own health care for the sake of her daughter Charlie, with devastating consequences? And how has Rebecca's life been transformed since she testified before Congress in 2019 about the impossible choices she faced while trying to manage her daughters' care? This is the first of two podcast episodes featuring Rebecca Wood.

Rebecca, welcome back to Code WACK! It's so great to have you again on our show.

Wood: Well, thank you for having me again. I am excited to be here and excited to talk to you again.

Q: Thank you. We have a lot to catch up on. For those who may not have heard of you, tell us a bit about yourself. Who are you and what do you do?

Wood: I am Rebecca Wood. I had a pretty ordinary life up until my daughter's birth, I would say. I did all the adult milestones, went to college, got married, and then when I had my daughter, she was born at 26 weeks gestation. She weighed one pound, 11 ounces and that was the beginning of, I guess, a giant snowball of change in my life. It definitely launched me into the policy realm unbeknownst to me, her birth was the beginning of that. And now I'm currently a law student. I'm finishing up my first year of law school. I am a full-time law student, and I live in the metro west region of Boston.

Q: Awesome. Okay. So as you mentioned, your daughter Charlie, was born extremely premature and needed a whole host of therapies, treatments and advanced medical care to survive and thrive. Tell us briefly about the healthcare expenses you incurred and how they affected you and Charlie's father?

Wood: When she was first born, it wasn't too bad. We had insurance and it covered most of her NICU stay, which is phenomenal 'cause her NICU stay was over a million dollars.

Wow, that's the Neonatal Intensive Care Unit.

Wood: But when she came home, she lost the institutional Medicaid that kicked in while she was in the NICU for three months, so then we were starting to handle copays, deductibles, things that just weren't covered – exclusions – and it hit us hard. At first, we could handle the expenses because we were saving up to buy a house, but then after our savings were drained, we were scraping by. She had three specialists. No, actually she had more than that. <Laugh>. She had three therapists,

a feeding therapist, a speech therapist, and well, the feeding therapist was a speech therapist, an occupational therapist, and a physical therapist. And then she had a handful of specialists – an orthopedist, developmental pediatrician, gastroenterologist.

Wow. It's been over 10 years so I can barely remember them all, but I just remember the specialists and the therapy copays were \$40 each and she was going to at least three or four of them a week and that adds up over time in addition to the things that weren't covered. It crushed us, it broke us. So then our dream of home ownership just flew out the window.

Q: Got it. When Charlie lost institutional Medicaid, was that because she was no longer in the Neonatal Intensive Care Unit?

Wood: Yep. So at the time, we were in Virginia and after a child is in a facility, in our case it was a hospital, over 30 days, then institutional Medicaid kicks in and it worked as our secondary insurance. So it took care of a lot of the expenses we otherwise would've been saddled with.

Q: But then when she left, when she came home, she lost it?

Wood: Yep. And then she did not get a Medicaid waiver for about a year and a half. And when she did get her Medicaid waiver, there was a 10-year waiting list for the waiver she qualified for and so she got a lesser waiver. And so we missed out on a lot of services that would've been provided.

Q: So you had to dip into the money you saved to buy a home?

Wood: Yes.

Q: And didn't you also have to delay graduate school?

Wood: I did, yes. I was hoping to go to graduate school for Global Health and I was looking into schools when I was pregnant. And then after she was born <laugh> I realized that that wasn't something that was gonna happen, so I put that off.

And then I was having to make choices between my health care and hers. And at first it didn't seem so bad I would not get my asthma medication just so I could pay

her expenses and I did end up in the ER a few times because of that, but it still seemed manageable. But then things really came to a head when she had a speech therapy payment due. And at the time her speech was finally emerging. She was three and a half and she wasn't really talking, and all of a sudden she started talking and at the same time, the therapy payment was due. So I didn't wanna miss that window of opportunity and not pay the therapy bill.

So I paid it ... while I needed a root canal and crown and <laugh>I put off the root canal and crown and ended up getting a massive infection that spread through my entire mouth and jaw and it ended up costing me all of my teeth and parts of my jaw. And in fact, the last time we talked, I still had these really bad dentures that were too big for my mouth and I really wasn't able to eat. I had to drink a lot of Ensure and applesauce, <laugh> and scrambled eggs and refried beans and stuff. Well, since then, I did like a GoFundMe and I've had \$10,000 worth of reconstructive surgery and a new set of dentures made and it has really made a difference for me.

Q: What an awful ordeal! And then dealing with reconstruction. So are you done with all of that?

Wood: There is more that can be done, but I've kind of drawn the line. Each time, it's incredibly painful and the pain management hasn't been great. So I've reached the point where (it's) good enough, <laugh>The last time I had my jaw opened and they smoothed and scraped my jawbone so that the dentures would set right after all of the work was done. And <laugh>, it's as horrifying as it sounds. But afterwards they told me to take some Advil <laugh>.

Oh no!

And so then after a weekend of that, I decided, 'no, I can't do it anymore. I can't.' And I cried each time I was in the dental chair. It was awful. I like, I'm tearing up just thinking about it <laugh>. So I'm at the point of good enough <laugh>.

Q: I'm so sorry, Rebecca. You shouldn't have had to sacrifice so much - including your own health - to give your daughter a chance at the best life possible.

Wood: I was angry for a very long time, and I think if I still think about it, I can still feel that rage. But now when I think about it, I think about how lucky I've been. I

didn't die when I had that massive infection. I had somewhere to go in the midnight hour. I was able to raise all that money on the GoFundMe to have the reconstructive work done. And you know, there were just so many moments of I guess good fortune <laugh> that outweighs the bad. So it's a mixed bag of emotion and yeah, it didn't have to happen. It wasn't necessary. It was (a) profound policy failure that we can change. But now when I think about it, in addition to the rage I feel, I also feel an overwhelming sense of gratitude, which is kind of an odd combination <laugh>.

Q: Right, gratitude and rage can coexist absolutely at the same time. And often it's rage that fuels us to fight for change.

Wood: That's exactly when I get so burned out in law school. 'cause It is like a marathon. And I feel like, 'oh my gosh, this is so much work, I can't do it.' I remember how angry I am <laugh>and that propels me through it. All of a sudden it goes from, oh my goodness, I can't do this to 'let's go!'

Q: Right, so let's circle back to your medical expenses and how else they affected you.

Wood: So I'm trying to remember back when she was younger, because our story has changed quite a bit. When she was younger, it broke us and we had to scrape together whatever we could. And I applied for scholarships to a lot of her therapies and things like that in order to get those for her. And some of them came through, some of them didn't. You know, you just <laugh> you throw out a wide net, and hope you get something. And then later on, my husband and I, we separated and got divorced and suddenly I was a single mom and the first six to eight months were absolutely awful. I had to find a way to work without childcare and you know, she was little. So I drove for Uber Eats with her in tow, and at that time, I just could not afford my asthma medication, even like the minimal asthma medication.

I had to go to the ER with her in hand sometimes in the middle of the night. And I asked her recently if she remembered that, and thank God she doesn't, but she does remember when we drove for Uber Eats and then later on, after those six to eight months, I ended up moving to the Boston area where I was a single mom again and the healthcare expenses in addition to our rent – in the Boston area,

rent is pretty high – in addition to our rent just killed us. And things like the school meals or school lunches, we didn't qualify for free or reduced because on paper it looked like my income was good <laugh>, but it didn't take into account my rent, my healthcare expenses and between Charlie and I, we were just a bottomless pit for healthcare expenses <laugh>. And so actually I started working on universal school meals in Massachusetts because I struggled with school lunch debt and we ended up winning it last summer so that was exciting. <Laugh>.

That's amazing. Congratulations!

Wood: Yeah. I would rather have universal healthcare, but we'll get there too. <Laugh>. But yeah, and it snowballed. What started as healthcare expenses also had me see how interrelated all of these issues are. I didn't think about food insecurity, but because of my high healthcare expenses, I realized after we got universal school meals that holy wow, we were a food insecure household. Like I was always counting like, how many cans of beans did I have in the cabinet? And if she got sick and needed medication or something like that, then I would have to think, 'okay, if I get this medication, what does that do to my grocery budget? Do I have enough food at home?' And I always had this running count in my head of how much food we had, and I never thought anything of it until afterwards when I didn't have to think about that anymore. And I thought, 'wow, we were food insecure.' It was so surprising to me, <laugh> and then how they run hand in hand with health care or even housing for that matter, all of those things.

Q: Right. Choosing between medicine and food is a choice no one should have to make.

Wood: Mm-Hmm. And then when the student loan payments kicked back in, you know, it's do I pay for health care or do I pay my student loan payments? <Laugh>. And again, all of 'em <laugh> (are) interrelated. And it's so frustrating to me that these are solvable problems. These are all policy failure problems.

Q: You mentioned that you separated and divorced from your husband. How much do you think that the expenses for health care played into that or did it at all?

Wood: You know, I think about this a lot. One of the things we haven't talked about in this interview yet that <laugh> you know about is that I did a lot of political work

when we lived in Virginia and beyond. Clearly if I worked on universal school meals in Massachusetts, it continued, but I think about this a lot. Exactly. At what point did we break because we did break when I was probably deepest into doing the political work I did. However, when I think about it, and I really critically think back, I think it was in the NICU, we broke. I think about this all the time.

When she was born, one of the things we struggled with, I remember being in intensive care and trying to decide how do we announce her birth. You know, we were both so scared at the time. And he said, 'well, let's not announce it.' And I said, 'no, she deserves to be loved and celebrated no matter how long she is with us.' And I honestly feel like that's the moment we broke, because after that I was all in for her and he was just kind of always on the outside and it continued that way until eventually we really broke.

Yeah, I'm so sorry.

Wood: It's life, you know, <laugh>, there are good things and there are hard things.

Thank you Rebecca Wood. Stay tuned for next week when we continue our discussion with Rebecca about all the ways our broken healthcare system has impacted and transformed her life.

Do you have a personal story you'd like to share about our 'wack' healthcare system? Contact us through our website at www.heal-ca.org.

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