



## *Insured?* You're not immune from medical debt

### — TRANSCRIPT —

*Dispatcher: 911, what's your emergency?*

*Caller: America's healthcare system is broken and people are dying! (ambulance siren)*

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**.

In honor of Dr. Martin Luther King Day, we're looking at what injustice in health care looks like for insured people. How is it that even those with health insurance face crushing medical debt in America? What choice do patients really have when they find themselves fighting for their lives and unable to pay the exorbitant costs for their care? And what far-reaching impact can medical debt have? To find out, we spoke to Monique Davis, a non-profit executive living in Southern California. She was diagnosed with Amyloidosis, a rare medical condition in 2016 that required her to have several rounds of treatment and a stem cell transplant. She had health insurance but the treatments and multiple ambulance rides still left Monique and her husband with thousands of dollars of medical debt, relentless

harassment from debt collectors, and a ruined credit score. This is the first of two episodes featuring Monique's harrowing story.

(5-second stinger)

**Welcome to Code WACK! Monique.**

**Davis:** Thank you Brenda so much. It's great to be with you today.

***Q: Oh, we're so happy to have you. Tell us a little bit about yourself. Where do you live and what do you do?***

**Davis:** Thank you. So I have been a [houser](#), working in housing finance over the span of my career over the last 20 years, and the last 9, 10 years of my career has been in nonprofit, affordable housing. I live in Orange County, California. I live in the city of Buena Park and I'm married and I have two sons and three stepchildren who do not live with us.

***Q: You were diagnosed with a rare medical condition, I believe, in late 2016. Tell us about that and how that diagnosis affected you.***

**Davis:** So interesting how I found out about it is I'm a nonprofit executive, like I said, working in housing to build homes for folks that have experienced homelessness at the time. So I just got a big promotion to (chief operations officer) and my husband and I just happened to be at AAArenewing like a DMV registration or something, and I thought, 'well, let's go look at their insurance products' and so through the insurance process it was determined that there was something wrong that they had found in my blood work and so over the series of about nine months following that event in November of 2016, I was diagnosed with AL Amyloidosis. And so it affected us because I became very, very ill very quickly and required chemotherapy and a stem cell transplant so I had six rounds of chemotherapy, so that's about six months worth of chemotherapy treatment.

And then a stem cell transplant, which required that I would receive high-dose chemotherapy so I'd have to be hospitalized. They'd have to harvest my stem cells, have me go through the stem-cell transplant, and then I'd have to isolate for

about 30 days because basically what happens is you're shutting down your immune system, you're giving your immune system a reboot, and then for your immune system to start back up again, basically they give it sort of a jumpstart and it starts back up again and then you wait a few days and then you're released to go home from the hospital.

***Oh, wow. That sounds super intense.***

**Davis:** Yeah, so the only advantage to it is that when we all had to isolate for COVID, I was used to it. So <laugh>. Yeah, that was probably the only bright side <laugh>.

***Q: What was it like for you to go through all that?***

**Davis:** Um, it was scary because as a mom. I still had a son that had just graduated high school. I had an older son that was about 22 years old and you know, I was 48 years old when I was diagnosed, so I was fairly young. I thought and was surprised that something like that would happen to me. I was pretty active and at the prime of my life from a career standpoint, I was more surprised, but also prepared to do whatever I needed to do to survive so whatever my doctors told me to do, whatever appointments I needed to have, tests, treatment, I did it all. I did whatever they told me to do and as painful as it was, and as hard as some of the treatment was, it was difficult. The way Amyloidosis impacts you is basically your body's producing way too much protein, Amyloid protein. We all produce amyloid protein, but we can't dispose of it with Amyloidosis.

And so it starts to stiffen your muscles, your heart, your kidneys. It can get into your actual muscles, your digestive system. It can actually impact your brain so I was lucky enough that we caught it fairly early so I had minimal damage to my heart and to my kidneys, but my digestive system was just totally shutting down so I couldn't eat. I couldn't go to the restroom. When things got really bad, I started to vomit all day every day so I lost a lot of weight. There was a period of time where I actually went about three weeks before I could eat anything. I didn't eat a thing. I mean, drink water, do nothing. So the fact that I'm still here is, you know, it's a miracle. What happened is that at that time where I was starting to get really sick and before my chemo started, I got diagnosed November 4th

And right after that week, I was admitted into the hospital and from then on it was go from one hospital to the other. I'd literally been admitted to every hospital in Orange County, California until I started my chemo, which was the week of Christmas, December, 2017.

At one point I had to learn how to walk again because I had become so weak and, and frail and hospitalized so much that I just stopped being able to walk on my own. So I was confined to a wheelchair for about a year and then had to learn how to walk after that.

***Q: Oh my goodness. Sounds like your disease progressed quickly.***

**Davis:** Very quickly.

***Q: Monique, what health insurance did you have at the time?***

**Davis:** I've had an HMO for 20-plus years. We were insured with Aetna and then in the middle of the treatment, we shifted, my husband's insurance switched over to, actually, no, I think it was mine, mine switched over to Anthem Blue Cross.

***Q: And how did you get your insurance? Were you employed at the time?***

**Davis:** Yes, (I was) employed. My husband is also employed and I was double covered. So he had his HMO and I was covered under his policy. And then I also had HMO through my work. We were both covered under my policy.

***Q: Tell us about the debt you faced as a result of all of these medical expenses.***

Well, when you go into the hospital, there were a couple times when my husband and my sons had to call the ambulance to come pick me up because I had passed out. And so there's the ambulance cost, there's the emergency room cost, then there's being admitted and each time that I was admitted, I stayed in the hospital at least a week, no less than a week. So we're talking at least five days – so there was that accumulation and then when you have all of the mobility issues, there's equipment that has to be brought to our home, like wheelchairs, there's portable commodes that have to be brought to the house. I had to have sometimes

infusions at the home, either for fluid or sometimes it was other medications that needed to be administered through an in-home nurse. So that all costs additional money.

When I had my stem cell transplant, the drugs just administered, the stem cell stimulant medication was \$20,000 for, you know, a series of like six or seven shots. Eventually, the shots were covered, but we had to fight with the insurance company to actually pay the cost. So all in all, at one point we were looking at like \$75,000 in debt. Yeah. And that's even with an HMO. And so you have to, you know, spend the time to make the phone calls. My husband had to call when I started to get better, I made phone calls to make sure that they knew that we had insurance to make sure that they bill the proper insurance. Some of it went down, but it was still over \$10,000 in all that we owed. And so, you know, that's a lot of money that we just didn't have.

I was out of work for my treatment for at least a year – off and on after that, an additional year because of the treatments. So when you have an immune system that's compromised, I was constantly getting sick, like any and everything, every part of my body, right, I got eye infections. I had a cough that I couldn't get rid of, and that went on for at least a year. So I had to have immunoglobulin, so it's just basically antibodies to boost your immune system. I had to have five treatments of that so that was administered in-house. So someone had to come and do that and that was like \$5,000 and then the machine, the mechanism in which the infusion was administered, that was \$500. That was all at our cost. Right. Like it wasn't covered by the insurance company.

***Q: Uhhhh.. <affirmative>. Interesting. What was your biggest concern about your medical debt at that time?***

**Davis:** Well, you know, number one, I wanted to live. I had kids that needed me, a husband that loved me, and I love him. And I was young. I still have so much life to live, so I wanted to live. And so whatever treatment, whatever medications they said I needed, we took it right and we worried about the expense later, but we also questioned if they were generic drugs. We tried to have the most cost effective care provided. So we weren't asking for expensive, you know, top of the line care. We were just asking for what was going to be life sustaining. So that was

really my issue. But I wanted to just feel better, you know, I wanted to feel better. I wanted to have some level of quality of life, and if I did pass away, I didn't want to leave my husband in a lot of debt on top of the loss of me, you know, I just didn't want to do that.

***Q: Hmmm, that must have been so hard for you. Did you have any concerns about your credit and how this could affect it?***

**Davis:** Well, of course, I mean, you know, once I got better... the one thing that we made sure we paid (off) was our housing costs. We wanted to make sure that our utilities and our housing was covered, but if we lost cars or whatever, you know, at that time it wasn't really of consequence. Right. What was more important is that we had a roof over our head. So the medical providers would call, they would pressure me for payments. They would call my husband on his job. They would harass both of us at all hours of the day. Even if we were covered under the insurance, they would still call us and demand payment and, you know, instead of working with the, you know, if it was a hospital, they would still call us as opposed to just processing the billing. I was never offered a payment plan by any of the hospitals, none of them.

***Q: California has a mandate that general or acute care hospitals must provide free or discounted care to uninsured or income-eligible patients who have high medical costs.***

***Patients who can't afford their hospital care should apply for fair price discounts or charity care, which could prevent them from getting into severe medical debt.***

***What did they tell you when you told them you couldn't afford these high bills?***

**Davis:** They said that it was still my responsibility, for the medical equipment and for the nursing, the in-home nursing, they offered a payment plan. They asked me what I could do, but they only gave me like a six-month window. So if the bill was \$500, right, I'd have to break that up over six months. That's still a hundred dollars a month. And if I have other bills to pay, right, like it's, and I'm not working, you know, and where we live in Orange County, our rent at the time was like \$2,500.

So if I'm only making the max for disability payments, that's \$5,000, but half of it goes to rent.

***Q: Yeah, that's true. Were your sons living with you at the time or no?***

**Davis:** Both of them were, one of them was, my eldest son actually was in college, and he's put college on hold to stay home and take care of me. I know, I know. It's one of those things where I'm so grateful that he did and so he would help take me to doctor's appointments. One day because of the treatment, I went to the bathroom and before I could even make it to the bathroom, I passed out and so it scared him. He thought I had died because I wouldn't wake up.

**Davis:** So he had to call the ambulance, you know, and I'm grateful for that. He and I have never talked about the bill. We, he doesn't know, you know, I've not shared the financial impact, but I think he's just grateful that I'm alive and he was able to get me the care that I needed to get. So he was in school, he was going to college, and so he couldn't work because he became my primary caregiver.

***Q: Oh, right. So how would you describe your financial situation at the time?***

**Davis:** At that time?

***Yeah.***

**Davis:** At that time, yeah. I would say it was definitely paycheck to paycheck. I would say that we weren't thinking about the future in terms of saving. Like my husband and I have always invested in our 401k or 403B. But at that time it was just survival. It was just like everyone was focused. Everything, and every, every moment was about trying to get me better. So financially it was just make sure we have enough food in the house to, you know, make sure that I have something to eat and that they have enough food to eat to get us going for the next day, to start all over to do it again. There was no entertainment, there was no, you know, nothing fun. It was just, you know, even the holidays, it was just centered around treatment for me.

***Q: You mentioned getting calls at all times of the day from collections people. What was it like dealing with them at a time that you're trying to survive?***

**Davis:** It was hard because I found that they were very insensitive and then the ambulance companies were actually the worst. I mean, even when the hospitals would call, they were, they were at least polite, right? Like they politely demanded money, but the ambulance companies were rude. They would yell at us, they would, you know, say all kinds of awful things. And they would call at all hours of the day. And like I said, they would call at work and they would call frequently throughout the day. And so that was stressful. It was scary because we didn't know if they, and they would threaten us, like, we're going to take you to court, we're going to take your paycheck. You know, so we were just, we were scared, right? We didn't, we didn't know how to handle that other than to just, we didn't want to ignore it, but we, we just didn't know what to do.

***Q: So were you able to negotiate those bills down?***

**Davis:** No, to be honest with you, they ultimately just went to collections because we just didn't have the money, right? So our credit is impacted by it. Our credit's impacted by a number of the medical bills because even though some of them we paid off, some of them we just couldn't afford to take care of.

***Q: How do you feel about that, Monique?***

**Davis:** Um, I feel terrible about it. I feel like as a responsible law abiding citizen who works every day, who has health insurance, I shouldn't be in this situation and I shouldn't be in a situation where I'm, it's a decision of whether I file bankruptcy or I let it just sit on my credit, you know, and ultimately, you know, make payments on it over time and I feel like a failure. I feel like, you know, I've let my family down because we had dreams before all this happened, right? We had plans and before all of this, it was, you know, we were in a pretty decent situation around our credit and so it definitely set us back and it's been a huge financial impact and it's prevented me from getting, when I was able to go back to work, right, it prevented me from getting jobs because they would run your credit and they'd say, okay, well you, you know, even though I would explain what happened,



and they were sympathetic to that, they still were like, 'okay, well this is too much, right?

We can't get past it.' Obviously, I'm working now and I work in the non-profit space and the organization that I'm with, I explained... I was very transparent about what had happened to me. And, you know, the credit situations matched the timeframe that I spoke about. And so they were able to make an exception for it and so I was very grateful for the consideration, right? Like for someone to understand what I had been going through and what impact it had on my family, and that it didn't mean that I wasn't a responsible person.

***Well I'm so glad they did overlook your medical debt, because the truth is we're all vulnerable. You had health insurance, in fact you were covered through two different employer-sponsored health plans and you tried to get generic medicines whenever possible, and yet you experienced severe medical debt and being harassed day and night by debt collectors. We also know that existing programs for charity care at hospitals may not be advertised and often don't go far enough. Thank you so much Monique for sharing your powerful story with us.***

**Davis:** Thank you.

(5-minute stinger)

***Stay tuned next time when we continue our discussion with Monique about her medical debt and how she's doing today.***

***Do you have a personal story you'd like to share about our 'wack' healthcare system? Contact us through our website at [heal-ca.org](http://heal-ca.org).***

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