



Better off dead? The unbearable burden of 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**.

This time on Code WACK! What would you do if you were faced with thousands of dollars of medical debt? Would you file for bankruptcy or let the debt go to collections? What help is out there for people facing such difficult dilemmas? Would Medicare for All protect patients from the hassles and financial burdens that ill patients face?

Today, we're continuing our discussion with **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 poor credit score. This is the second of two episodes featuring Monique's harrowing story.

Welcome back to Code WACK!, Monique.

[\(01:11\)](#):

Davis: Thank you Brenda.

[\(01:12\)](#):

Q: *So you had to make this decision, either file for bankruptcy because of medical debt, or let the debt go to collections. You chose not to file for bankruptcy. What was your thinking behind that?*

[\(01:24\)](#):

Davis: Honestly, after 2007/8, I worked in the mortgage industry and that's a whole nother podcast. Right. Because of that, we actually did file bankruptcy, so we didn't want to do it again. We had just done it in 2009, as a matter of fact coming out of the mortgage crisis and so that's why we didn't want to do it again.

[\(01:46\)](#):

Q: *Okay. In a Public Law Center report that mentioned your case, you were quoted as saying "At times I thought maybe it would be better if I had died, then my husband would not have the added stress and financial burden of me." Can you tell us about that?*

[\(02:01\)](#):

Davis: It's still a thing today, right? Like we had come out of 2008, we were doing much better. Like I said, I had the dream job, I was making more money and we were just doing better and here we are again. Right? Like not only the emotional burden, but the financial burden that I put on my husband. You know, he's somehow got to come up with more money to cover the medical bills, right? And it's just if I die, right, like there's life insurance, right? There's some, because now that I've been diagnosed with this, I can't get a policy. Like I told you before, I found out because I was trying to get more life insurance to make sure that we were covered, right? And you make more money, right, there's more risk of losing your income. So because of that diagnosis, I can't get life insurance.

Now I'm covered through my husband's company and now that I'm working again, I have life insurance through my employer, but it's a limit. It's a minimal amount. So that would still help my husband. And so there were times where I just thought this whole thing is just a mess and then maybe it would just be better if I had passed away. So, you know, my husband and I, obviously he doesn't agree with me and didn't agree with me and it's challenging.

[\(03:14\):](#)

Wow. That really kind of shows how desperate you must have felt at that moment.

[\(03:19\):](#)

Davis: Yeah. You know, just to even be in the hospital a month, right? There's a max that you have to pay, but it's still a max, right? When I got my treatment the way that it works is an HMO contracts with a provider cuz the stem cell transplants are a pretty specialized procedure and not all the hospitals actually have services to provide for them for Amyloidosis. They don't have providers that can actually treat for it. So we were contracted with UCLA so that meant that we had to leave Orange County and drive to UCLA three and four times a week. Right and so that's the gas, it's the parking fees cuz every day you go in it's a \$14 fee to park. So you know that in itself and if you're doing that three or four times a week, times four or five Right. Given the weeks and the month, you know, that went on for months. And then just so you know too, after I had my stem cell transplant and was released, I had to go back to the hospital for a couple more stays because

of my immune system, right? They had to give me more antibiotics. So my digestive system stopped working. So I had to have like, I was fed through a feeding tube so it's all of those expenses.

[\(04:31\)](#):

Q: Right, that's a lot. If you think about gas and the time being spent and the fact that your family has to either take off from work or from their studies, it adds up for sure. Yeah. At one point you asked the Public Law Center for help. What happened?

[\(04:47\)](#):

Davis: So we reached out to them cause I just wasn't really sure in terms of what to do. We couldn't afford an attorney to file bankruptcy and I wasn't really sure what my options were and because of all the phone calls, I just out of frustration reached out. I had met some people that worked at the city that was helping with the Community Resource Center and they actually referred me to the Public Law Center and so I reached out and they started to offer me support and help.

[\(05:14\)](#):

Q: Did they help with the collections agencies at all?

[\(05:16\)](#):

Davis: They gave me direction on how to handle them and what to say to them and so that was incredibly supportive. It was incredibly empowering if nothing else, right? Because I figured that, you know, now I started to understand that I had rights and that's how I found out that the hospitals were required to set up payment plans so we started to do that with some of the hospitals.

[\(05:36\)](#):

Q: Oh good. Monique, how are you doing health wise today?

[\(05:40\)](#):

Davis: Thank you so much for asking. I'm doing better. My numbers are great. Obviously I'm back to work and I'm good. I mean, I think the biggest issue for me is I had to learn how to walk again so there's still some mobility issues and it's really just like climbing the stairs are really hard. So I can climb, you know, maybe four or five flights of stairs before I get, you know, to a point where I'm just so exhausted I can't continue. So I did my physical therapy for that and then the two main things are just the fatigue and my digestive issues.

[\(06:10\):](#)

Q: *Do you think the digestive issues and the fatigue will heal?*

[\(06:13\):](#)

Davis: They've gotten better, but I just, so before my treatment it was severe constipation. Now it's severe diarrhea. Like I have to be really careful cause everything... I have to take medication to help with it, just to keep food in and to process it normally. There's that and then just the fatigue from chemo, right? And a stem cell transplant, you just feel tired all the time. It's just, it's really exhausting. Mm-Hmm. You just feel really tired. So I have to make sure that I exercise to build up some endurance and then I have to be really careful about what I eat and drink and then the only other thing is neuropathy. So the cramp, I have cramps in my feet, they're painful. Mm-Hmm and it's usually at night. So usually when I rest and I lay down at night and that's when they start <laugh>.

[\(06:57\):](#)

When it's time to go to sleep, it'll start. But other than that, you know, I'm grateful. I'm really grateful that I'm alive. And I had, you know, I will say this. UCLA, once I was assigned to them and I started to meet with my oncology team and you know, I had a number of doctors. They were incredible. They really were. I mean, they saved my life. They were great to my family and supportive and kind and every step of the way, they were really just great for us. So I'm glad that once we got there, things started to happen in a positive sense. Yeah.

[\(07:31\):](#)

Q: That's great. How has the whole situation affected your trust in the healthcare system?

[\(07:36\)](#):

Davis: I think, you know, the most important thing, and I'm a pretty smart individual, at least I think is that it was so hard to navigate. It was hard to understand, first of all, the medical part of it and then there's the advocacy part that you have to to really try to get the best care and make sure that you understand and ask the right questions and there's things that people just aren't gonna tell you, right, from a medical standpoint. But then there's the whole financial component that's coupled with the medical procedures that you're receiving and at the time, you know, when someone says, okay, well you have to take these drugs and this is how frequently you're going to need it you don't ask, well, how much is it? Right? And then you have to start asking the questions because then you need to like, make sure that you understand how much you have to pay.

[\(08:22\)](#):

And there were times where they would tell us how much, and then we would still get an additional bill on top of the other bill because there's the specialist, there's the nurse, right? Like there's the other things that they're not billing for, but they're just contracting some of the part of the services out. And so, you know, with one medical procedure, there could be three or four other bills on top of it. And so, you know, it's not transparent. It's just not transparent and it's really confusing and I mean, I understand that we have great care in terms of the medical providers, but the business side of it is really complex and it, you know, there's no school for it.

[\(09:01\)](#):

That's true.

[\(09:02\)](#):

Davis: So I mean, you know, it's difficult and it makes you feel like a failure. Mm-Hmm. <Affirmative>, it makes you feel like a failure. It makes you feel very vulnerable and I don't trust, I don't know necessarily that people are set out to hurt us cause I don't think people get into the medical field to hurt anyone. But I do think that if it's lack of automation or lack of transparency, either way it's not for everyday people to navigate, which it's supposed to be for us to help us. Right. And it's just not set up and it's not designed for us for the person that's receiving the care.

[\(09:36\)](#):

Q: *Hmm. Because it's too complex to navigate.*

[\(09:39\)](#):

Davis: It is. Yeah, for sure.

[\(09:40\)](#):

Q: *Really good point and to have to deal with these issues when you're at your most vulnerable, it's almost a crime.*

[\(09:46\)](#):

Davis: Yeah. I mean, you know, there were times Brenda, when I couldn't even speak. I couldn't talk. So my husband had to do it for me or my mother-in-law and my father-in-law had to do it or my son had to. And you know, my son's at the time, he was 21 years old. How's he going to navigate for his 48 year old mother? It's too much to put on someone else. Right. So I was incredibly vulnerable at that time and so when you're getting like that level of care, it's more important I think to be transparent.

[\(10:17\)](#):

Right. Exactly.

[\(10:19\)](#):

Davis: And have options. Cuz those options aren't provided to us either. Right. Options in terms of here's types of treatment that you could receive, but the price tag's not connected to it.

([10:30](#)):

Q: Right. And then you get surprised by the bills later on.

([10:33](#)):

Davis: Yeah. It's not disclosed. And I mean, I don't know if doctors should be, you know, sharing that information at the time that they offer the care or the options, but it needs to come pretty quickly after you've had the conversation with your doctor.

([10:45](#)):

Q: I think the burden is on the patient now to call your insurance and figure out what's covered and that's a maze to navigate too. With single payer Medicare for All, we wouldn't have to worry about surprise bills or fight insurance companies to get our health care covered. All medically necessary care would be covered and paid for directly by the government.

([11:04](#)):

Davis: And then trying to do the reimbursement part, that's where it gets really sticky because then you have to fight with the insurance company.

([11:12](#)):

Right, wow. Monique, I'm so glad you were able to get through this.

([11:15](#)):

Davis: I am too. I will tell you, you know, I did go through a, what do they call it? Survivor's guilt. It's a real thing. And I did go through PTSD. I had a case worker that helped me. She did some therapy with me afterwards and I went through some like cancer, post-cancer therapy. And by the way, I had to advocate for that

as well because what I have, it's technically, it's not a cancer, but you receive cancer treatment and so when there's other therapies that are out there or therapists that specialize in cancer for cancer victims, that was not considered what I have. Amyloidosis was not considered one so I literally had to fuss at the <laugh> the potential therapy organization that worked, that partnered with UCLA to, to give me, you know, some therapy sessions because they just didn't see it. That, you know, that I kind of fit in that model.

(12:03):

Q: So you had to advocate for yourself and thankfully it worked.

(12:06):

Davis: Yeah, it worked. It definitely worked. So that's how I know they told me that, you know, survivor's guilt is a real thing. And I will, the reason why I'm telling y'all this is because I had, I wanna say there were at least four or five people that around the same time that I was diagnosed and going through my treatment, they were also diagnosed or going undergoing chemo treatment and they didn't make it.

One of my son's college friends, just last week, his mother was diagnosed with breast cancer and she, same thing. She went in the bathroom, passed out and she didn't wake up. Oh. So, you know, it's, it's one of those things where I'm incredibly grateful, right. So I don't, I don't want to, you know, send this message that like, oh, you know, I'm complaining, let's beat up on the medical providers. That's not the message that I want to send. But it is one of those situations where it could have been a lot easier and the stress and the anxiety and the pressure mm-hmm. <Affirmative> to like pay the bills. I probably could have been healing a lot faster. Right. I could be less of a burden on, you know, taxpayers because of the stress and the mental, you know, anguish that goes along with all of this.

(13:07):

Q: Yeah. Thank you for sharing that. California passed Assembly Bill 1020 in 2021 to improve its charity care law and help close some of these gaps. Time will tell

whether this law is working as it intended. Do you have any thoughts on the passage of that law?

[\(13:24\)](#):

Davis: I think it's great. I'm glad to hear that it passed and I'm glad that, you know, California is open to doing the right thing and trying to protect, you know, patients. Sorry, I'm, I'm glad about that. I really am.

[\(13:36\)](#):

Q: Yes. We think it's a step in the right direction, but of course much more needs to be done. With single payer Medicare for all. We wouldn't have to deal with any of this. Everyone would get the health care they need without getting into medical debt and the vast majority of families would end up paying less than they currently do for their health care. Is there anything else you want us to know?

[\(13:56\)](#):

Davis: I just want to say thank you for the opportunity to share my story and what happened. And if anything else, I hope that you know, I can help someone else hopefully understand and navigate through the system and, and be aware of some things that I didn't know, you know?

[\(14:13\)](#):

Q: Right. Like you can contact the Public Law Center and get help dealing with collections agents.

[\(14:19\)](#):

Davis: And they were wonderful by the way. They were wonderful.

[\(14:21\)](#):

So glad to hear that. It's been an honor and a privilege to interview you, Monique. Thank you.

[\(14:26\)](#):

Davis: Yeah, you too.

([14:27](#)):

Thank you Monique Davis.

(5-second music stinger)

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.

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