

Transcript: The Insurance Warrior, part 1

Dan: Laurie Todd calls herself the Insurance Warrior. She says she's fought and won more than 200 appeals, life-or-death cases.

And the first appeal she won was her own. So the story starts with a medical nightmare. Of course.

Laurie was in her mid-fifties, working as a massage therapist. She was in good shape. And then...

Laurie Todd: I started to feel really exhausted. I mean, so exhausted that you fall asleep in your chair.

Dan: Her doctor ran a bunch of tests, didn't find anything weird.

Laurie Todd: she said, you have nothing to worry about. You're the healthiest 55 year old on the planet.

Dan: But Laurie kept feeling worse. A few months later she went back to the doctor's office. She could tell the nurses were freaked out the second they put their hands on her enlarged abdomen.

They ordered an emergency CT scan, told her to come back the next day. She did.

Laurie Todd: The doctor, the first thing she did was to push a box of Kleenex across the desk.

That's how you know,

The doc says cancer. Maybe she's got a few months to live.

Laurie Todd: So I went home and I was kind of in a state, I piled up like nine or 10 trash bags of all these belongings, my backpack. Like, am I going to be climbing mountains in the next few months?

I gave away my KitchenAid standing mixer. Am I going to be baking bread? I don't think so.

Dan: She has surgery right away. They take a big tumor out of her abdomen. And when she recovers, they tell her: You better meet with the head of oncology, right away. Your cancer isn't exactly what we thought it was. It's actually ... this pretty unusual cancer, of... the appendix.

Laurie Todd: I walked in there and sat down and I said, so I have appendix cancer.

What's the treatment for that? And he goes, there is no treatment for your disease. And even if there were, they wouldn't pay it.

Dan: And Laurie's like, HUH. "Even if there were, they wouldn't pay for it." Hm.

Laurie Todd: that told me that there is a treatment and he knows about it

For me, that's like waving a red flag in front of a bull.

Dan: Because Laurie Todd did not want to die. But she ESPECIALLY did not want to be treated like a chump.

This is An Arm and a Leg, a show about why health care costs so freaking much, and what we can maybe do about it. I'm Dan Weissmann. I'm a reporter, and I like a challenge, so my job on this show is to take one of the most enraging, terrifying, depressing parts of American life-- that's right, I'm claiming it. I see you there, climate change, I said what I said-- and bring you a show that's entertaining, empowering and useful.

And of course, talking about our incredibly awful health care industrial complex can leave a lot of us feeling hopeless. What the hell are we going to do? How can we protect ourselves, and each other, from this crap?

Laurie Todd has some lessons. And even if you're not in a life-or-death situation right now-- and I hope very much that you are not-- her lessons for us have BROAD application. As she'll tell us, they go beyond health care.

So, back to her story. We should actually rewind to a couple days before she meets with the oncologist. We start with that call where they tell her she's got a cancer of the appendix.

Laurie Todd: I said, okay, give me the full name. He said, pseudo myxoma peritoneal . So that was Friday. I immediately got on the computer, I went straight to pub med and started reading scientific articles. And by the time the weekend was over, I knew what I had, what treatment I needed and what the chance of, beating this cancer really was.

Dan: So when this oncologist tells her, there's no treatment, she already knows better.

Laurie Todd: he was giving me percentages of recurrence and how long it be before it grew and all this. And I said, so how many appendix cancer patients have you treated?

And he goes two. And I'm thinking "You're making all these prognostications from a population of two? I don't think so."

Dan: She goes home, gets back online. Finds 20 surgeons around the country who actually do the treatment she needs. And she writes letters to all of them, lays out her whole story.

Laurie Todd: I said, surely, you know, more than these doctors in Seattle, can you help me?

And two days later the phone started to ring

Dan: It was those surgeons. Sixteen of them called her back.

Laurie Todd: I learned something important that I could write something and make things happen.

I also learned that there are two different kinds of doctors, the ones who worked at my HMO and didn't give a rat's patoot and the ones who would talk to me for an hour for free.

Dan:Very first one was a guy from North Dakota

Laurie Todd: this doctor said to me, let me tell you, he says, if you do what the HMO told you to do, let me tell you what's going to happen to you.

Dan: Their plan was: Nothing. Wait and see. He said, you do that, your cancer's going to come back. It's gonna require another surgery in maybe 8 months.

Laurie Todd: And then it will come back faster. Eventually you'll wind up with a huge abdomen bowel obstructions, and you'll die of starvation in the nursing home. I didn't really need to be scared straight, but you know, it helped it's the truth.

Dan: She also heard from the surgeon who invented the treatment she needed. Paul Sugarbaker in Washington DC. They scheduled a consultation.

She was broke-- hadn't been able to work since that first surgery-- so she borrowed frequent-flyer miles, flew to D.C., met the doc, and scheduled surgery for six weeks out. That gave her six weeks to get her insurance to pay for the surgery. Which she knew was gonna be an uphill climb.

Laurie Todd: I had probably the crappiest cheesiest insurance plan you could possibly have . I had an individual catastrophic plan with a \$16,000 deductible.

Dan: And it was an HMO. Stands for Health Maintenance Organization-- it's insurance where, basically: You pay them less every month, but in general, you only get to see providers that are on their approved list. Laurie's insurance did not exactly have the longest list.

Laurie Todd: it was a funky local HMO and they had no intention of paying for any kind of surgeon in Washington, DC.

Dan: So, yeah. Uphill climb. Friends came over to console her.

Laurie Todd: Nobody thought that I would win. These friends, sat around like making big puppy, dog eyes and, and, crying and everything.

Dan: Not Laurie. She was like: Figuring this out is my job now: Write the document that's gonna save my life.

Which was actually something she had done a version of before. Not actual life or death, but she'd been up against a wall. This was twenty years earlier. She'd been married, and her husband had died after a motorcycle crash. He left a \$50,000 life insurance company.

Laurie Todd: And, you know, after he died, I could not deal with that money. It seemed like blood money. I just couldn't do it.

Dan: And the insurance company said, hey that's cool. We'll hold onto it for you. And we'll send you interest on it every quarter. They did. After a year, Laurie withdrew the money, and invested it somewhere else.

And the next quarter, she got another interest check.

Laurie Todd: So I called them up and I and I said, I've withdrawn my money. Why are you sending the interest? And somehow she said, no, no, that's yours. You're supposed to keep it.

And of course I was very poor. You know what I mean? I went, I was really dirt, poor. I really needed that money. So I kind of okay. And kept it. This went on for an entire year.

Dan: She called them every quarter. And every quarter, they said, no that's yours. You keep it. Until...

Laurie Todd: the last day of the year, I got a telegram. Saying, we paid you \$5,000 by mistake. You must pay it back immediately. I mean, I didn't have it

Dan: She started by looking for help.

Laurie Todd: I went to a local lawyer in a box, you know, just a lawyer office on the street.

And I explained the situation and he, he laughed at me. He said, what do you want me to do to tell you how to pay the money back? It's not your money. And that had the same effect that, that chief oncology saying there is no treatment and they won't pay for it.

I am offended. You are not going to do this to me. So I had no idea how I was going to pull this off, but I came home and wrote a letter.

[MUSIC]

Dan: And she knew she was a good writer. She'd been valedictorian of her high school class. Phi Beta Kappa in college-- without, she says, studying a whole lot. She knew she was good in a pinch.

And she'd been a teacher-- so she had experience convincing people-- young people, determined people, unreasonable people-- to do what she needed them to do. She had all that.

And she had something else: Ammunition from the calls she'd made to the life insurance company.

Laurie Todd: Here's the key. I kept a record of who I spoke to and when I spoke to them

Dan: Yeah. She had that. So she put everything to work in that letter.

Laurie Todd: I kind of balanced it between being a grieving widow, so vulnerable.

And also this person on this day told me I could keep it. That person on that day told me I could keep it. And I got the call a few days later and they said, you can keep the money.

Dan: I just love this so much.

Laurie Todd: And I shouldn't have won it. It wasn't my money. And I filed that knowledge away.

And that's where it started.

[MUSIC OUT]

Dan: So that trigger was, this kind of, arrogant contempt.

Laurie Todd: yes. Or was just treating, treating me like a chump or treating me like an idiot or, you know, and I realized I was smarter than that guy. And I was gonna prove it..

Dan: And here was this doctor, the oncologist, telling her the same thing. Bah! You'll never beat this. There's no treatment, and even if there were, they would never pay for it. She was not about to let that guy win, and then fucking die.

Laurie Todd: I would have felt like the world's biggest chump. Cause it didn't have to be, I could let that happen either.

Dan: So, getting this insurance company, the HMO, to do what she needed them to do. That was now her job. And she went at it full-time.

Laurie Todd: I went to the library and sat on the floor and read an entire shelf of Washington state insurance regulations. I learned everything there was to know about this HMO cause they were my worthy opponent. .

[MUSIC IN]

Dan: And here's one thing she learned: Her funky local HMO was connected with a much bigger outfit: Kaiser Permanente.

When Laurie found Kaiser in the mix with her HMO. She had an idea: Had Kaiser ever paid for this surgery she needed?

Laurie Todd: That's what we call precedent.

Dan: And Laurie wasn't a lawyer, but she knew she had to think like one.

Laurie Todd: I had to build a case, proving that they needed to pay for it for the terms of the contract.

Dan: She got back online. Went to the patient groups for people with her kind of cancer. And found three people who had gotten Kaiser to pay for the surgery she needed. That was it.

She wrote it all up. Her whole story. 23 pages. She hit them with science: Why this treatment was necessary. Why this doctor had to be the guy to do it. And with the precedent: Kaiser had a history of saying yes to this procedure. Why should they treat her differently?

Laurie Todd: I found a few important people to send it to at the HMO. And three days later, they called me well, or, um, we decided to pay for it. So a few weeks later, I borrowed frequent flyer miles again, and flew to Washington DC for my surgery.

[MUSIC OUT]

Dan: And as far as she knew at the time, that was IT. And that was plenty. The surgery was 14 hours. The procedure includes chemo, add that to the wear and tear.

Laurie was in the hospital for six weeks after surgery, she calls it the cancer gulag. And lucky for her she had friends who took her in.

Laurie Todd: when I came out of the hospital, I was like the a hundred year old woman in a wheelchair, too weak to brush my teeth.

I thought, I think I'm gonna be sitting in front of their television, watching home and garden channel for the next five years.

Dan: That's what she was doing, at home, in her pajamas, when something happened.

Laurie Todd: This guy called me on the phone. His name was Bob

Dan: He'd heard about her victory from an online cancer support group, wondered if she could help him.

So Laurie wrote up a big document, and Bob lost. But: He still had one more shot. An in-person hearing.

Laurie Todd: I said, you know what? I'm going to write you a speech and I'm going to teach you how to give a speech. and a speech is like the Gettysburg address. You know, it has to make them feel something.

Dan: Now, Laurie had never actually GIVEN a speech. But she'd been a teacher. She'd worked a room.

She wrote Bob a speech. She ran him through it-- all on the phone, Bob's in Pennsylvania. He calls her just before he goes into the hearing. She waits by the phone, pins and needles. And he calls her on the way out.

Laurie Todd: And he said, Laurie, I went in there with my head, held high.

He said, I saw a little tear in one of their eyes. He said, I knew I had him.

Dan: Four hours later, she says, the approval came through.

[MUSIC]

And after that, there were just a lot more people where Bob came from, people with her kind of cancer, seeking the same treatment she'd gotten.

And for the first year and a half, she didn't charge anybody a fee. Even though she was just barely keeping body and soul together. It took months for her to get disability -- that was its own appeal process. Her sister gave her a few hundred bucks a month. She drew on savings.

Eventually, she started charging what she calls a modest fee. She wrote a book. "How to fight your health insurer and win." Got a foundation grant to cover the publication costs. Learned to get herself booked as a speaker at local libraries. She got a fee, and she sold books there too. Built a website.

Soon, it's not just people with her particular cancer who are calling, looking for her help.

Laurie Todd: I've written appeals for brain tumors, organ transplants, cranial facial surgery for babies. One of my favorites with a super high tech artificial limb. And , it isn't even just for diseases. these are just strategies to hack through a bureaucracy.

I've used these strategies, against the bank, the IRS, the store, social security disability, you know, they should be taught in every high school in the land.

Dan: So we should get into what some of her strategies ARE. That's right after this.

[MUSIC OUT]

[MIDROLL]: This episode of An Arm and a Leg is produced in partnership with Kaiser Health News-- that's a non-profit newsroom that covers health care in America. Kaiser Health News is NOT affiliated with the health-care giant Kaiser Permanente. We'll have a little more information on Kaiser Health News at the end of this episode.

So, OK, what are Laurie Todd's strategies? She's now been doing this for more than 15 years. She's written a second book. It would take a whole season to outline everything. Which I would not mind doing.

But for an overview, a sample, we should start where she starts.

Laurie Todd: the first thing that I say to people when I'm working with them, as I say, no appeal was ever meant to lead to an approval.

This is not a good faith process

Dan: She says: No tips or tricks will do you any good unless you understand this first.

Laurie Todd: If you think it's a good phase process, the first person you ask for help is the insurance company.

Dan: Yeah, no! The insurance company is not there to help you. They are your worthy opponent. Don't take anything they tell you at face value. Don't accept their rules.

So, that's one.

And if an appeal isn't a good faith process, what is it?

Laurie Todd: every insurance appeal is a contractual dispute. They don't care if you need the treatment. It's not anything clinical, it's a contractual dispute. And the only thing they care about is do we have to pay for it for the terms of your contract?

Dan: Thinking this way was part of how she won her own appeal, right? Not by being a lawyer, but thinking like one. And to dig a layer deeper here, she says the contract isn't just your benefits booklet.

Laurie Todd: It's the denial letter. It's their medical policy statement for the treatment. It's, every word they say to you on the phone, if you've got their name and the date, every word that comes out of them is part of your contract.

Dan: Let's not lose this part here: It's every word they say to you on the phone if you've got the name and the date. Remember, this is part of how she won with the life-insurance company all those years ago. If you've got the name and the date, they're on the record.

Laurie Todd: And the cool thing about it is they spew out so many words that you have a whole lot to take issue with.

Cause they're not as smart as I am.

Dan: Yeah, that laughter, that confidence. They point to Laurie Todd's next principle about the nature of this conflict. She calls it a GAME.

Laurie Todd: It's a strategy game. they have strategies and my strategies have to be better than their strategy.

Dan: One strategy she used in her own case and now uses every single time: Go straight to the top.

Laurie Todd: There's no law that says that you can't find the higher ups and contact them directly.

And all of a sudden you're a VIP.

Dan: Getting to those people, hacking the bureaucracy, takes work. It takes strategy. She writes about it a LOT in her second book.

Laurie Todd: Like how you ferret out, these people and how you approach them.

It's part of the fun really.

Dan: I mean, I love this, but that kind of confidence doesn't exactly come naturally to all of us. She says when she works with people on their appeals, she often has to coach them into it.

Laurie Todd: I say you don't have to feel that way. Just pretend you're that way. I said, if you're that scared to get on the phone, Pretend you're somebody who pretend you're me.

I'm not scared of these fools

Dan: I asked her. Were you always this fearless? She said absolutely not. She knew she was smart, but she wasn't fearless. Until she needed to be.

Laurie Todd: I had a lot of insecurities, but somehow just the whole experience of the crazy scary, cancer . The insurance company is definitely not going to pay no money, no resources. And somehow this whole thing rose up in me that I'm just going to do everything. And as it turned out, I wasn't afraid of anybody

[MUSIC - NEW PIECE]

Dan: That's not exactly a tip. But it is also kind of the whole thing. Laurie Todd says her favorite thing anybody she's worked with ever said about her is: This isn't about insurance. This is about life.

She hears from people who worry they'll never master the all the tricks in her 300 page book.

Laurie Todd: live and I'm overwhelmed. And I can't do that. If you only did 10% of what I do, you'd be much more likely to win it

Dan: I don't think we've gotten to ten percent of things here. So we'll be coming back to Laurie Todd next time.

And she will bring us back to an idea we talked about last time. This giant, open secret that Laurie Todd calls the biggest scandal in health insurance. Because....

Laurie Todd: not usually really fighting insurance companies. I'm fighting employers

Dan: That's because-- like we talked about in our last episode-- if you get your health insurance from work, the insurance company probably isn't really insuring you.

Your employer is paying them to "administer" your insurance plan, but it's your employer who's actually paying out. And as Laurie Todd says, that means they're ultimately deciding which bills to pay.

Laurie Todd: you have to know that, or you don't know who's making the decision.

It's like, you're barking up the wrong tree.

Dan: Next time, we'll hear how she LEARNED that. And what she did next.

[MUSIC OUT]

But I've got a piece of news today: Right now, in November and December, we've got a big opportunity. We get to be part of a project called NewsMatch: The Institute for Nonprofit News has pulled together a fund to MATCH any donation you make to this show, from now through the end of the year.

And if you make a MONTHLY donation? They will match a whole year's worth. Pledge five bucks a month? They will give us twelve month's worth of that, sixty bucks, upfront. It's a huge deal.

We got to be part of NewsMatch last year, and thanks to your generosity, it's made a huge difference. For one thing, it allowed me to bring on Emily Pisacreta, first as our intern and now as our associate producer. Emily's work behind the scenes allowed us to make our reporting a LOT deeper this year.

And for another, it's allowed me to create a project I'm SUPER excited to tell you about. One thing we get asked for a lot is: Can you pull together the practical things we've been learning, all in one place?

And I've always been, like: YES. We should totally do that. Gaaah, when am I going to do that?

And the answer is: NOW.

[MUSIC - less joyous/still driving/not gloomy]

Starting this week. In our newsletter. Which is getting a new name: First Aid Kit.

Because with our awful world of health care-- what we really need is like a Level 1 Trauma Center, or at least a well-staffed ER. Which we're not getting.

But what we CAN have is a first-aid kit. And training on how to use it. I hope you like it, and I hope you're going to pass it around. Even if this isn't something *you* need, you probably know somebody who could use it.

First Aid Kit will come out on Tuesdays, starting next week. If you're not on our list, I hope you'll sign up at arm and a leg show dot com slash newsletter. And tell a friend.

And we're able to do this -- I've been able to hire an editor to make it happen, been able to pay Emily to do work that allows me to take time to write it-- because you've been supporting us.

And we've got big plans for next year. If you like what you're hearing, if you like what we're doing, I hope you'll take this opportunity to help make it happen-- and to let NEWSMATCH pitch in to double your contribution. And if you make it monthly, they'll give us 12 months worth of match. Holy moly.

That's arm and a leg show dot com, slash support.

THANK YOU!

Till next time: Take care of yourself.

This episode of An Arm and a Leg was produced by me, Dan Weissmann, with help from Emily Pisacreta, and edited by Marian Wang.

Daisy Rosario is our consulting managing producer. Adam Raymonda is our audio wizard. Our music is from Dave Winer and Blue Dot Sessions.

This season of an arm and a leg is a co production with Kaiser Health News. That's a nonprofit news service about healthcare in america, an editorially independent program of the Kaiser Family Foundation.

Kaiser Health News is not affiliated with Kaiser Permanente, the big healthcare outfit. They share an ancestor. This guy, Henry J Kaiser. He had his hands in a lot of different stuff.

Really different. He paved roads. Built a big chunk of the U.S. cargo fleet for World War II. Made cars- including the Jeep. Made aluminum foil.

When he died more than 50 years ago. He left half his money to the foundation that later created Kaiser Health News. You can learn more about him and kaiser health news at arm and a leg show dot com slash kaiser.

Diane Webber is national editor for broadcast and Taunya English is senior editor for broadcast innovation at Kaiser Health News. They are editorial liaisons to this show.

Thanks to Public Narrative -- a chicago-based group that helps journalists and non-profits tell better stories-- for serving as our fiscal sponsor, allowing us to accept tax-exempt donations. You can learn more about public narrative at www dot public narrative dot org.