Transcript: The Prescription Drug Playbook, Part Two

Dan: Hey there. Let's meet Jeanne Chamberlin from North Carolina. She regularly talks with folks who take like 15 different meds every day.

Jeanne Chamberlin: You are like, oh my gosh. And literally the retail costs are $20,000 a month.

Dan: Jeanne's an expert, twice over. Since retiring from a career managing hospitals and medical groups, she's been helping her fellow seniors figure out how to manage what they pay for health care -- as a county-level volunteer coordinator for a program called SHIP.

Jeanne: And SHIP stands for Seniors Health Insurance Information Program.

Dan: Actually in some cases it stands for State Health Insurance Assistance Program.

Whatever you wanna call it -- It's a federally funded program that helps seniors with all things Medicare. Every state has its own version of SHIP.

During the busy season -- that's in the fall, when people can pick new insurance for the coming year-- Jeanne says she and her team speak to more than a hundred people a week.

And one thing that comes up in basically ALL of those conversations: Can I change things to get my meds for less next year?

She says one year, her team added up the impact of those conversations. Half of the people changed plans, and on average, they saved 300 dollars. Not bad…

Jeanne: But there were many, many people who saved a thousand, 2000, even $10,000 by changing from one Medicare plan to another based entirely on the cost of their drugs.

Dan: Jeanne's gonna tell us how she helps people get those kinds of savings-- with strategies that aren't just for people on Medicare.

And Jeanne is just one person who wrote to us when we asked for you, our listeners, to tell us about your tactics and tricks for dealing with the high cost of prescription drugs.

The result: two podcast episodes-- this is number two -- and four installments of our First Aid Kit newsletter.

In this episode, we're gonna hear from Jeanne and three other *incredible* sources who came to us with crucial insider knowledge. Knowledge that -- now they we have it-- we have to share with you.

Jeanne's gonna help us get set up. She's gonna share what she tells those seniors, and how it can apply to anyone, at any age.

... Then, a pharma insider is gonna air an open secret.

An employee benefits advisor -- a kind of scout for deals -- will tell us where she'd send someone struggling to pay for meds.

Finally, we'll meet a battle-worn hospital caseworker. And beyond the specific tip she wrote in with, her work – and life story – are gonna bring us some deeper perspective.

These people kick ass.

And for all their advice, there is, of course, a BIG caveat:

like we said last episode -- your mileage will vary. There is no one solution for everyone. This is a set of patches, workarounds, bandaids.

To be honest, a lot of them are actually weird byproducts of the profit-making machine. Which is a big reason they're so patchy and unreliable.

We deserve SO much better. But in the meantime, we can help each other. That's what this project is about. Including the four newsletter installments I mentioned. And we'll link to those from wherever you're listening -- so: you don't need a pencil and paper here. We've got you.

Our hope is that you walk away from all of this armed with a *little* more knowledge that could help you or someone you care about get the meds they need. A kind of leg up. An Arm and a Leg-leg-up.

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 the job we've chosen on this show is to take one of the

most enraging, terrifying, depressing parts of American life, and bring you something entertaining, empowering, and useful.

So, first: Jeanne wrote to us about what she knows from helping people enroll in Medicare. But she also had an instructive personal story to share. Because even experts have to scramble sometimes.

A while ago, when Jeanne's husband had a gut infection, he got prescribed two antibiotics. His insurance coverage meant one was gonna cost him thirty bucks. But the other one? His plan didn't cover it And... .

Jeanne: It was $1,200. For a 14 day supply it was just obscenely expensive.

Dan: So immediately, Jeanne says she went into problem solving mode. And her order of operations provides a great template for any of us.

Step one: Google for discounts. Just taking a quick first pass at the kind of thing we talked about in our last episode. Maybe that's GoodRx. Maybe that's a coupon from the drug maker. Results for Jeanne: Not great.

Jeanne: I could get it down to $800. It's like, still, you're like $800. Really?

Dan: So, on to step two: Tell your provider there's a problem and ask for advice.

Jeanne: We went back to the doctor and said, is there something else that you know you can do?

Dan: Jeanne was thinking: Maybe the doc could recommend another antibiotic -- one that insurance would cover. Or help them fight her husband's insurance to get this drug covered.

But actually, the doc's proposal was much simpler.

Jeanne: She said just take the other one.

Dan: Just take the one Jeanne's husband could get for thirty bucks. Skip the second drug.

Jeanne: So he did, and he was fine!

Dan: END OF STORY. In this case. It's not always *that* easy. But the moral is: ASK. If your insurance covers a different drug, your doc can tell you if it's a good bet for you. If not… well… we'll come back to other ways your doc could help.

But right now let's move on to the biggest, most valuable advice Jeanne gives to seniors-- and that applies to everybody.

Especially anybody with meds they're taking long term, like blood pressure or cholesterol meds, or whatever.

And the advice is this: Look ahead, every year.

In the fall, when it's time to sign up for next year's insurance plan: Get a look at the list of which drugs your insurance will cover, and how much they expect you to pay for them. It's called the formulary.

Because even if you don't change anything about your insurance, your insurance could change the formulary. That can happen to anybody.

Jeanne sees it all the time with seniors, when their plans reboot at New Year's.

Jeanne: People come in in January and this happens every year, and say, I just went to the pharmacy and. They want $300 for my medicine. And last year, or last month in December, it was $30.

Dan: These folks didn't plan to change anything about their insurance -- but their insurance plan changed on them-- and stopped covering a drug they've been taking. Now they're getting charged sticker price.

And Jeanne's like, 'Man, I wish you'd have come to see us during the fall sign-up-- open enrollment.'

Jeanne: We could have probably found a plan that covered that drug still..

Dan: Now, it's true that folks on Medicare tend to have more choices than the rest of us here. In Medicare, drug coverage is its own separate plan -- called Part D -- and seniors in Jeanne's county have more than a dozen to pick from.

If you get insurance from work -- and maybe there's just one plan -- this thing of looking ahead is maybe even more important.

At some point, maybe a couple months before the new year, you should get a chance to see that next year's formulary

And it could say, "Hey, your drug is gonna be more expensive for you next year"

That's your cue to start problem-solving right away. Get a plan in place before that new price kicks in.

Step one: Check: Can you find discounts online that make this drug affordable? Cool.

No? Time to get in touch with your provider's office: start tapping their expertise.

Jeanne: The provider normally has a lot of people with your condition and probably prescribes this medication a lot.

Dan: And so, if your insurance company says they've got some other drug you could take, one they'll pay for-- your provider will know: could that drug work for you?

And if you've got a choice of plans -- but they all require a special approval process now for your drug -- your provider will know: Is one of them more likely to actually issue that approval?

Jeanne: Ask them about a plan where they have an easy time getting it approved for somebody with your condition where it always goes through.

Dan: And that's the plan you want to pick. And, speaking of getting your insurance company's approval:

We're about to move from Jeanne's advice-- plan ahead, get your provider to help -- to the next step. Because you can't plan everything. Sometimes you get sick, with something new. No planning for that.

And sometimes, your insurance is definitely not gonna say yes right away to the drug your doc thinks you need. And your doc thinks you need *this* particular drug. So, how ELSE can your provider help?

John: I work, uh -- work for an industry with an approval rating below Congress.

Dan: He's a pharmaceutical sales rep! He asked us to keep his full name and employer confidential.

He's also an Arm and a Leg fan.

John: I love it when, uh, I hear stories of average people just sticking it to the insurance company. It's nice when the patient wins, cause they don't get a lot of wins.

Dan: We reached John in his primary office -- also known as his car.

When we asked listeners a few months ago to share lessons about getting prescription meds without paying an arm and a leg, he wrote right in with tips.

And one, I love just for the attitude. Here's John reading from the email he sent us:

John: Step therapies. Uh, denials and price at pharmacy should be viewed as suggestions.

Dan: Suggestions. Perfect. The other is much more specific. As a salesman, a big part of John's job is prepping doctors for the fights they're gonna have with insurance companies, to get approvals for drugs. He does that because approvals for them mean sales for John.

Of course, approvals take time.

John: But one thing that you know doesn't care about time is diseases.

The disease of Crohn's or Bipolar disorder, whatever, isn't like, look, I'll hold off on affecting you until this prior authorization is done.

Dan: So here's John's advice: while you're fighting for that approval-- pushing back on the insurance company's "suggestion" that you try something else-- Ask your provider if they can get free samples from the pharma company -- from a rep like him.

John: And the provider hopefully will say, yeah, let me call the rep and we'll leave some at front for you.

Dan: Actually, your provider may already have some on hand. A study from a few years ago found that TWO THIRDS of primary-care practices had CLOSETS of pharmaceutical samples. Which, wow.

So, let's address something big: Like John joked about as we introduced him, pharma sales reps are NOT generally looked upon as model citizens.

The rap is: Some of them use less-than-scrupulous tactics to encourage doctors to prescribe expensive drugs… even to patients who might not get extra benefit from a specific drug. Or, in the case of opioids -- which got pushed really hard -- might cause harm. And free samples are part of that process.

So, some providers won't meet with sales reps at all. Some health systems don't allow any of their staff to meet with them.

But you don't have to approve of how pharmaceutical companies do their business to take advantage of John's suggestion. And neither does your doctor.

John says, to get free samples, your doctor might not even need to talk to anyone.

They can just make a request online, at the manufacturer's website. John says it definitely happens.

John: So even with providers or doctors that I've never seen in my nine years, I know that they've gotten samples before.

Dan: But here too, there will be limits.

John: Some manufacturers don't even do samples. So it really varies a lot.

Dan: But a lot of these samples do exist --

And the idea of using them as a stopgap while you fight to get your insurance to pay for the meds you need -- I had never thought of it until we asked you, our listeners, for your tips.

And you also sent us this: Could a local clinic supply the meds you need for a price you can actually afford? That's next..

This episode of An Arm and a Leg is produced in partnership with KFF Health News. That's a nonprofit newsroom covering health issues in America. Their journalists do amazing work. We're honored to be their colleagues.

OK, a whole new kind of expert here. Like Jeanne, who we heard from earlier. Cristy Gupton also lives in North Carolina. She works as an independent employee benefits designer. You're probably like, what the hell is that? Here's how she describes her work.

Cristy Gupton: Imagine you're a kid in high school, in shop class, and your teacher puts an old engine on the table, and says, take it apart and put it back together again and make sure it works.

Dan: Except, the machine is a health benefit program for workers. And-- back to the shop-class metaphor -- Cristy says she's the real gear-head in the room .

Cristy Gupton: By the time I put the engine back together, it works twice as good, but at half the cost.

Dan: Cristy says she does it by ditching expensive, off-the-shelf parts -- standard insurance policies from big companies -- for custom solutions. It's a WHOLE THING, and super-interesting, and worth going into.

For now, she's got one big tip that *some* of us could use to get access to meds at super-low prices. Basically it's this: Look for a community health center that offers a sliding scale. They can get drugs at extremely low prices, through a federal program called 340B.

How low?

Cristy Gupton: The drug Humira is one of the most prescribed drugs in America. And the list price is probably somewhere in the neighborhood of 5,000 a month. But a 340B covered entity could purchase it for a penny.

Dan: So we checked, and actually: Humira's list price isn't 5,000 dollars. It's 7,000 dollars. But YES, a 340B clinic can get it for a penny. Now, they don't get every drug that cheap, but..

And look: although this is all very much worth knowing about, it's not guaranteed to work for you.

340B is complicated in all kinds of ways. Here's my colleague Emily Pisacreta asking Christy about it.

Emily: Help me understand what 340B is.

Cristy Gupton: I'll give you my best, um, like only know enough to be dangerous answer.

Dan: After checking some actual experts, here's what we think you need to know:

A federal law from the 1990s -- section 340B of that law -- basically requires drug-makers to give some hospitals and health centers that serve low-income folks super-duper discounts on meds.

Those discounts don't always get passed along to patients. The feds say hospitals and clinics can take a profit, to subsidize their other work .

But the rules say: community health centers DO need to make drugs affordable to people with lower incomes. Specifically, to people who make less than two times the federal poverty level.

For 2025, that's just over 64 thousand dollars for a family of four. Not a lot.

But it's a lot of people: More than 28 percent of Americans qualify. And some clinics may have sliding scales for people with higher incomes than that.

So: There's a search tool. We've got a link wherever you're listening to this. Find a clinic in your area, call them, and see what the deal is.

One last thing to know: You've gotta actually be a patient at the clinic in order to use this program. And actually, if you meet the income requirements, all the clinic's services are gonna be super-subidized.

But if you don't want to engage too deeply with the clinic-- don't want to switch over all your care to a new team -- Cristy says, in her experience, you may not have to.

Cristy Gupton: It can be as loose as they just have a virtual visit. I mean, that's pretty simple.

Dan: Again, we've got a link to the search tool for finding a health center near you. Which of course...near you… not everybody is gonna have. Your mileage may vary, literally. But is it worth checking? Yeah, I think so.

OK we've thrown a LOT at you. I know, I know. And we do have one more set of expert tips. From someone we are really glad to have met. So here's Erika -- and her expertise is part of a lifelong project.

Erika: You know, as a child with Type one diabetes, I had a very dysfunctional household and I had to take care of myself from a very young age. I have learned that the skills that I developed as a child with a chronic illness are transferable into a career to help people be taken care of.

Dan: So now, she works as a patient navigator-- a kind of case worker, at a hospital in rural Oregon.

When my colleague Emily talked with Erika, they bonded a little.

Emily: I live with Type One Diabetes and I really wish that I had had a patient navigator, um, when I was diagnosed.

Erika: Yeah, I wish I had me as a patient navigator too.

Dan: Most of the patients Erika does work with are managing chronic conditions and other serious health problems, under tough circumstances.

Erika: For example, let's say a patient has an amputation and they're told on discharge to keep it elevated and keep it clean. Well if they're living in their car, that can be a challenge. So in that case, case management would try to find them a hotel for a couple weeks.

Dan: And of course, one of the most common problems she tackles: helping people get their meds at prices they can afford.

Erika: There are weeks where that's all I'll do.

Dan: For insured patients, Erika he starts with drugs-and-insurance 101: Helping them figure out which drugs their insurance covers, at what price to them, and coaching them before they call their insurance company.

Erika: I offer to be on the call with them if they want. And I will tell you right now that we're gonna be on hold with that insurance company for 30 minutes

Dan: Yeah, that sounds familiar. Also, for some patients on Medicaid, Erika runs interference with bureaucracies.

And, when there's no way that insurance will make the right drugs affordable for her patients-- including folks with no insurance at all-- Erika helps them explore one of the options she wrote in to us about.

"Patient Assistance Programs" based on income. Some are from manufacturers, others come from private foundations.

Erika: It's such a matter of somebody knowing who to ask and where to get the stuff.

Dan: And there are websites to find this kind of thing -- we've got links and guides for you -- and she says the applications aren't complicated.

But the people she works with, they need extra help.

Erika: A lot of my patients don't even know how to use a computer or to get onto the internet, or they don't have smart phones, they just have cell phones. So a lot of them, I meet with them. I take my laptop, and we do an online application. I help them fill it out.

Dan: And then hope it works. Some programs only give out so much assistance per year, so not everybody gets help.

Erika: It's a frustrating fight. I feel bad that people have to wage this, you know, to get what they need to be healthy. It's, it's not like people are asking for BMW or new clothing. People are asking for, oftentimes medications they need to keep themselves alive. It's, it's like asking for oxygen. Like what if you were told you you couldn't afford oxygen? That's the way people feel sometimes.

Dan: And that's why, even though Erika wrote to us about practical specifics, it's her approach, her *presence* that we especially wanted to share with you.

Erika: I advised all my patients to get a tattoo that says, be persistent. I mean, seriously, I don't expect them to get tattoos. But as a patient who manages a chronic condition, you just have to be.

Dan: Oh yeah. The ongoing burden of dealing with all this, it's a bear. And it came up again and again when you wrote in to us.

Erika: Yeah. Stress management, whew.

Dan: For Erika's patients, and for herself too.

Erika: I have to remember to like, stop, step away, do some breathing. And these are things I teach to my patients a little bit too. Like, okay, let's stop and do some breathing together on the phone. Okay.

Dan: She calls her strategy "self compassion." It's about helping people see how much they're already doing.

Erika: I encourage people to take a moment and appreciate that about yourself. Okay? you've been on the phone with your insurance company for 30 minutes.

You're trying to get this done. You really need to appreciate that you're doing that for your health. For your health. Feel good about that, at least.

Dan: You are taking time to listen to this podcast. We are here, right now, together, doing our best.

For the practical lessons -- all the things to try, that may or may not work -- we've done our best to write them down for you, and organize them so they're useful, in our First Aid Kit newsletter. Four installments.

You can find those newsletters -- and these episodes -- at Arm and a Leg show, dot com, slash, drugs.

That's the address where we first asked you to share what you'd learned by walking through this maze. Now we're inviting you to come and see what we've learned from you.

Arm and a Leg show dot com, slash drugs. There'll be a link wherever you're listening to this.

And you'll find one more thing there, too.

To honor the endless and ridiculous process that we sometimes have to go through to get our medicines... my colleague Claire Davenport, who has led the reporting for so much of this series, made an endless and ridiculous song. Well, with the help of an AI. Stay tuned after the credits for a little taste of that.

We'll be back with a new episode in a few weeks.

Till next time, take care of yourself.

This episode of An Arm and a Leg was produced by Emily Pisacreta and Claire Davenport with help from me, Dan Weissmann, and Lauren Gould.

And edited by Ellen Weiss.

Adam Raymonda is our audio wizard.

Our music is by Dave Weiner and Blue Dot Sessions.

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Zach Dyer is senior audio producer at KFF Health News. He's the editorial liaison to this show.

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Finally, thank you to everybody who supports this show financially. You can join in any time at Arm and a Leg show, dot com, slash: support.

And NOW….a little treat.

So: At one point, we were like, “What if we could make like a jingle to help people remember all the tactics we’re talking about?”

But when our producer Claire tried actually writing one, with AI supplying the melody and the band -- it just kinda showed us how endless and ridiculous the list actually is.

And we found that just adorable. Here’s how it starts…

AI Song: I am a prescription – medication. And as you might know, I’m Expensive in this nation. Getting me can be confusing. And often quite scary. Since when it comes to meds. The prices can vary. Luckily, there’s some tricks you can try. When you’re in this situation and the price is high...

Dan: Alright, I think you get the idea -- and if you want more, it’s all at Arm and a Leg show dot com, slash, drugs. Along with these podcast episodes and First Aid Kit newsletter installments, and everything we hope you’ll actually find useful. Thanks.