

Transcript: Wait, is insulin cheaper now?

Dan: Hey there. Right after the holidays, I got an email from a listener named Brianna. It started, “Happy new year Dan! I was just reading the news about the price of insulin going down to \$35! Is that for everyone?”

And I was like, Huh. I had a sense that there was some news about the price of insulin, but 35 dollars a month for everyone? That sounded like a BIG reduction. And big news. I googled the latest stories, and I was... not totally sure what I was seeing.

I was definitely seeing some new stories about people paying 35 bucks from here on out. And there seemed to be some federal law involved, and politicians were patting themselves on the back. But it just wasn't totally clear: Was insulin now 35 dollars for everyone? Did the outrageous price of insulin get solved while I wasn't looking?

And I mean, I've kinda been looking. We've done a couple of episodes about the price of insulin already -- because insulin is iconic. It represents the wild cost of prescription drugs in this country. More than 8 million Americans take insulin to treat their diabetes -- and for some, going without it could actually kill you.

And its price got jacked up so much -- huge multiples over like ten years -- -- that one in four of those people who couldn't go without... took to rationing: Seeing how much they could go without, short of actually dying.

So I asked our senior producer Emily Pisacreta to take the case.

Emily: I feel more like the senior insulin correspondent, which is fine with me as the resident type 1 diabetic! And a lot has happened since the last time we talked about insulin on this show. We really do need an update.

Dan: This is an Arm and a Leg, a show about why healthcare 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 our job here is to take one of the most enraging, terrifying, depressing parts of American life, and bring you something entertaining, empowering and useful.

Today we have a question: what's going on with insulin? Is it \$35 now?

Emily: Well, there have been some BIG improvements -- bigger than I thought when I started reporting. A lot of people can get their monthly supply of insulin for just \$35. But it is oversimplified to say it just costs \$35 now. And the people who have been fighting to lower the price of insulin over the past decade? They're still very pissed. So let me walk you through what changed, what led to those changes, and what's still unresolved.

Dan: OK!

Emily: For years now, there's been a giant push from people with diabetes to get the federal government to do something about the high cost of insulin. In 2022, finally something came through. I'm talking about a provision in Inflation Reduction Act.

Dan: Yes-- I remember this-- the Inflation Reduction Act was a big infrastructure bill that included, like renewable energy subsidies, and-- honestly, this is the reason that I remember the bill, because we did an episode about this part-- letting medicare negotiate some drug prices?

Emily: Exactly. It said people on Medicare would be able to get a month's supply of insulin for no more than \$35 out of pocket. But of course that left a big gaping hole. BECAUSE that's cool for people on Medicare, but what about the rest of us? And the pharma companies were feeling the heat. Here's President Biden in his State of the Union last year:

President Biden: big pharma has been unfairly charging people hundreds of dollars, four to \$500 a month making record. Record profits. Not anymore. Not anymore.

Emily: By the way, those pharma companies? There's three of them who make insulin.

That's the American company Eli Lilly, the Danish company Novo Nordisk, and the French company Sanofi. OK so: not long after Joe Biden talked about their record profits, the insulin makers were back in the news. ...

Eli Lilly was the first to announce they were going to slash prices on several of their most popular insulins, and limit out of pocket spending to \$35 a month.

Fox News: This is a big story.

Next, Novo Nordisk and Sanofi made similar announcements.

CNN: Millions of Americans are affected by this major news this morning for millions of people suffering from diabetes and high prescription drug costs.

Basically, the insulin manufacturers all said hey, you're not covered by this Medicare thing? We're going to bring your copay down to \$35 ourselves. So if you have commercial insurance Print out this card, take it to the pharmacy, and your copay will be no more than \$35 for a month's supply of insulin.

Dan: And what if you're uninsured?

Emily: Well, they have a card for that, too.

Dan: OK so what I'm hearing is you need a card.

DAN: Yes. How do you get one?

Emily: The insulin makers set special phone numbers you can call. Or you can visit their websites, fill out a little form, and download the card.

Dan: Sounds simple, unless I'm missing something?

Emily: In all honesty, I had no problem with those steps. But I wouldn't assume that's the case for everyone. And I'm also not rationing insulin right now.

Zoe Witt: when you are rationing insulin, maybe you aren't even fully rationing insulin yet, but you don't know how you're going to get Your next prescription, your next fill of insulin... You are in crisis. Like, you, you do not have the capability to sift through these websites. It's very confusing. It's very overwhelming.

Emily: This is someone who frequently speaks to people struggling to afford insulin.

Zoe Witt: my name is Zoe Witt. I work with Mutual Aid Diabetes.

Emily: Mutual Aid Diabetes. That's an all volunteer group that has banded together to help diabetics get what they need, when they need it. They help people with cash and with free diabetes supplies, including insulin, no questions asked. That means Zoe knows the ins and outs of every obstacle to getting insulin.

Zoe Witt: our healthcare system is like a whack a mole from hell.

Emily: And Zoe reminds me: if you're not taking enough insulin, you probably feel awful. Maybe not even thinking straight. And it can affect your eyes, making it hard to read.

Zoe Witt: It just is unmanageable

Emily: Zoe says they talk with people all the time who are too stressed out or too debilitated to download these cards and use them. Diabetes folks walk people through the process. And once someone has the card... Mutual Aid Diabetes gives people the 35 bucks, too, if they say they need it. Because \$35 can be a barrier for a lot of people. And it's actually \$70 sometimes if you use 2 types of insulin at once, which lots of people do... myself included.

Dan: Wow. OK. But then once people have the cards they typically have no problem?

Emily: Well, your pharmacist has to know what they're doing, too. So sometimes it means a patient having to educate their pharmacist-- or even bring the doctor in to help troubleshoot -- which is no picnic. And people with diabetes are *always* having to deal with insurance roadblocks at the pharmacy, so I don't want to make anything sound simpler than it is.

Dan: It's like a whack a mole from hell!

Emily: Exactly! And the cards don't solve everything. Especially this: if you have insurance, these cards only apply to the insulin your insurance plan already covers. If you normally need a prior authorization to get the right insulin for you... that is still the case.

Dan: Right. Okay. like prior authorization is this roadblock to getting all kinds of treatment, that you and your doctor agree that you should have, and your insurance company can say, we disagree. We're s not authorizing this. And then you're stuck.

Emily: Right.

Dan: But in terms of what the pharma companies. can do to kind of offer you a deal. They're basically doing it. Is that right?

Emily: I think that's fair to say.

Dan: That's super interesting. All right. So it's not solved, but this is a big step forward. And what's not solved is: some people are still on the hook for the list price for insulin -- the price without any discounts or insurance or whatever. But you found big improvements there too, right?

Emily: Yes! When the companies announced all these discount cards, they announced a whole other big change, too. Slashing the list prices of a bunch of different insulins by up 75%. So a vial that once was north of \$300 is now being listed at around \$70.

Dan: OK, that sounds like a big improvement.

Emily: It's a big, big deal. Actual price reductions are what diabetes advocates have been demanding all along. And... while these are still the highest prices in the world for these same insulins, to see them drop from triple to double digits, it's wild.

Dan: I sense that there's a "but" here.

Emily: Well, the Big Three didn't lower the price of every type of insulin, only ones that have been around since the 1990s or early 2000s. Newer insulins that work faster or last longer are not included here.

Dan: And I'm guessing not all insulins work the same way.

Emily: Right. Some people can switch between types or brands of insulin easily. For other people, there can be allergies or one works better with their body with another kind. It's complicated. It's medicine! AND... there have been some issues with pharmacies actually stocking lower list price insulin. That is a whole 'nother saga... an episode for another day. But the important thing is... a bunch of insulin is a lot cheaper now.

Dan: Wow. Emily, you said right at the top: The changes here are bigger and better than you realized before you started reporting.

Emily: Yes but there's still a lot more to say.

Right. After the break, we'll hear from you about why these changes happened NOW. And what it means for people with diabetes and really all of us...

[midroll]

So. We have seen some big changes in the last year -- including DRUG COMPANIES expanding their discount programs and lowering the sticker prices on insulin, dramatically. Why now? I'm guessing this wasn't because they had a big change of heart.

Emily: I can't speak to what's in pharma's hearts. But I did talk to someone who knows a lot about pharma's brain.

Ed Silverman: my name is Ed Silverman, and I work at Stat News, a health and life sciences website,

Emily: I'm a big fan of Stat News

Dan: Me too, man! Their reporting is great.

Emily: And Ed Silverman. He's been covering the pharmaceutical industry for almost 30 years. He thinks activism from people with diabetes over the years created political pressure that played a big role in the decision to slash prices. But there was also something kind of hidden at work.

Ed Silverman: It's not altruism, here was a real mechanism, government mechanism in place that helped change the equation and therefore the thinking back at the companies.

Dan: OK... what is he talking about?

Emily: So, Dan: do you remember the stimulus bill, the American Rescue Plan?

Dan: I'm starting to feel like this episode is a quiz on recent-ish legislation. And I think I'm gonna do pretty well here..The American Rescue Plan was a trillion dollar stimulus that Joe Biden got passed right after he got into office-- am I right?

Emily: OK, hotshot. Do you remember how in part 8 section 9816 they sunsetted the limit on the maximum rebate for single source drugs and innovator multiple source drugs?

Dan: Um, busted. No.

Emily: Ok so here's the deal: it's obviously kinda wonky so I'll simplify-- in that little section Congress made a tweak to Medicaid, basically raising penalties on drug-makers for jacking up prices too far, too fast. So if you're a pharma company who has raised the price of a drug by a lot very quickly, which is true of insulin, and a lot of people on Medicaid use your drug, which is also true of insulin, then you have to pay a big penalty. In the case of insulin, that penalty would be more than you'd make selling the insulin to Medicaid. A LOT more: So, unless you bring the price back down, you're going to owe Medicaid a lot of moolah. And those penalties were set to kick in January 1st 2024.

Dan: So you're telling me: Part of what the pharma companies did here came right out of a small part of a giant federal law from 2021.

Emily: Yep. And there's another big wheel turning in the background here. Novo Nordisk and Eli Lilly, two companies who really got their start by selling insulin, now make other diabetes drugs -- drugs that are now increasingly used for weight loss. And it's a bonanza.

GMA: It is literally the hottest drug in the country right now.

Fox News: all people are talking about these days is Ozempic, we'll go V. Oh my gosh, this person lost 20 pounds. This person lost 50 pounds.

Ozempic Ad: Once weekly Ozempic is helping many people with type 2 diabetes like James lower their blood sugar.

Emily: Drugs like Ozempic, Wegovy, Mounjaro. They've been in super high demand. And there's been a ton of hype about their various potential health benefits. For weight loss, for heart health. Scientists are even interested in whether it can help people with substance use disorders. Meanwhile, for Eli Lilly and Novo Nordisk, the returns on these drugs dwarf anything else they're selling. Novo Nordisk even became the biggest company in Europe – for like a minute... but still.

Dan: OK, this is interesting, but what does it have to do with the price of insulin?

Emily: I'd wondered... maybe these companies can just better afford to buy some political peace by lowering insulin prices, because they are making so much bank on these new drugs, ? Ed Silverman had a take on that.

Ed Silverman: It makes perfect sense that these cash cows, these medicines that are used for diabetes and, weight loss are going to become increasingly important to their bottom line more than other medicines

Emily: More than insulin. And they're selling so much so fast, they can hardly keep up with demand. Which could end up affecting people who need insulin.

Dan: Wait, how?

Emily: Look, for example, in November, Novo Nordisk said they were investing 3 and half billion dollars into ramping up production of injection pens for Wegovy, one of their top drugs in this category. Less than a week later, Novo announced they would be phasing out one of their insulin products from the US market – an insulin called Levemir. It's one of the insulins whose prices they just dropped. And... coincidence... Levemir also comes in a pen.

Dan: So Novo Nordisk is phasing out an insulin pen so they can make more Wegovy pens?

Emily: Well, we don't know that for sure. But Novo Nordisk did tell me that “manufacturing constraints” were part of why they're dumping Levimir. They said it was one of several reasons and also wrote: “*We made this decision after careful consideration and are confident that given the advanced notice, U.S. patients will have access to alternative treatments and can transition to other options.*”

Dan: Huh. OK.

Emily: But even if pulling this insulin Levemir off the market had nothing to do with their trouble meeting the demand for their big blockbuster drug... it brings to mind an important question about all the changes we talked about today -- whether it's the copay savings or the lowered list prices. Here's Ed Silverman.

Ed Silverman there's no guarantee that the companies will keep these in place. Maybe after time, some of the attention on insulin is diverted and maybe eighteen months from now, one company might quietly roll back some of the Benefits, if you want to use that word, there's nothing requiring them to maintain the steps they've taken.

Emily: I asked all three insulin makers about this. None of them promised there would never be any backsies. Lilly wrote back "Lilly is committed to ensuring all patients can access any Lilly medicine they need" -- and touted their efforts to date. Similarly, Sanofi wrote "We continually review our affordability offerings to support our aim that no one should struggle to pay for their insulin. Novo Nordisk's response was "Novo Nordisk increases the price of some of our medicines each year, in response to changes in the healthcare system, market conditions, and the impact of inflation."

Dan: Yeah, that especially does not sound like a pinky-swear, no-backsies kind of response.

Emily: AND that's not much comfort for insulin activists. Folks like Shaina Kasper, who works for T1International. They're a group that's been at the forefront of this fight for years. I Asked her...

Emily-on-tape: So is this issue of high insulin prices just resolved now?

Shaina Kasper: No, it hasn't been. It's been really frustrating...

Emily Shaina and others are worried that the announcements from the manufacturers about savings cards and voluntary list price reductions will take the pressure off the government to do something more sweeping. Because for now...

Shaina: the manufacturers really hold all of the power here And if patients are counting on these programs to literally be able to survive, that has life and death consequences

Dan: This question about who holds the power, it reminds me of a story we did a few months ago... the one about how the writer John Green led a kind of online crusade targeting the drug-maker Johnson & Johnson. And how, even though the pressure campaign worked — J & J ended up allowing lower-priced versions of an important tuberculosis drug — activists who worked on the issue were like: It's a problem that Johnson & Johnson has the power to say yes or no here..

Emily: Exactly. That which pharma giveth, pharma can taketh. At least the way things are set up now. Now I should say, all three companies told me they plan to continue their affordability offerings. But if insulin continues to be the poster child for high drug prices, prices virtually everyone in America agrees are too high...it does raise the question: are voluntary programs from pharmaceutical companies the

solution we want? To Zoe from Mutual Aid Diabetes, the answer is no. They find these manufacturer savings cards kind of a bitter pill... no pun intended.

Zoe Witt: there's certainly no justice in these programs,

Emily: And zoe for one would say that justice is overdue.

Zoe Witt: These companies have price gouged us. for years, making obscene amounts of money. Then, presumably, as, we're often told is the justification for these ridiculous prices, they did research and development for more diabetes drugs, which are Ozempic, Monjoro, etc. And now, these companies, for, the next 15 years, are set to make, billions and billions of dollars, on these drugs,

Emily: I asked the big three insulin manufacturers about what Zoe said - about how angry folks like them are over the cost of insulin. Novo Nordisk said *"we continually review and revise our offerings as well as work with diverse stakeholders to create solutions for differing patient needs."* And Sanofi and Lilly both said something very similar.

Emily: So... in the end-- or at least for now-- here's the answer to our listener's question.... There are more avenues than ever to get a month's supply of insulin for \$35. Great. It may be a lot easier to avoid rationing your insulin now than it was a couple years ago. That's also really great. But people with diabetes do not think this fight is over.

Dan: So what DO they want?

Emily: Some people still want the federal government to just put a cap on what people pay for insulin, like by law.. Others are working to build alternatives to the existing pharmaceutical industry, like California's CalRx program.

Dan: Cal Rx... now you're calling back our story from the last time we talked about insulin.

Emily: Yep, Cal Rx is the state of California's attempt to enter the insulin market, to introduce some low priced generics and sell them essentially at cost. Other states are joining in. Even if some of these specific plans fall apart -- even if California somehow can't get its government-sponsored insulin to market, even if Pharma rolls back some of the discounts...the past few years have been enormous for people with diabetes. Mostly because they've found each other.

Zoe Witt: I was rationing insulin in 2018, I didn't even know that there was a term for it. I didn't know other people were doing it. I know a lot of people died that year. And there were multiple occasions where I, in retrospect, definitely almost died. And the one good thing that has, that has happened between now and then is that people have been talking about it and People are now more comfortable telling others that they're struggling, that they can't get their insulin.

Emily: Connecting with Mutual Aid Diabetes or other networks to get or give help.

ZOE: we're all keeping each other alive, like to me, that's the number one thing that has changed.

Emily: I think that's a huge lesson here, and a takeaway that's not new on this show. Keeping each other alive -- or even just keeping each other from getting bankrupted by the medical system -- is up to us. And while a mutual aid group modeled exactly like Mutual Aid Diabetes may not work for every disease or every drug, Zoe says they're more than willing to talk to anyone who might be interested in trying.

Zoe Witt: I mean, we've even had people ask, like, is there like a mutual aid asthma or something like for inhalers?

Emily: their advice?

Zoe Witt: I think that, you know, to start, you would want, like, probably at least, like, five to ten "ride-or dies," like, people that are really willing to, like, go the extra mile,

Dan: Five to ten-- that just does not sound like that many! (I mean, I think.) One thing I'm taking away is: This is a lot of activism over a long time, that eventually had a big effect. Another thing I'm taking away here? Sneaky policy changes -- like lifting the Medicaid rebate cap -- can make a huge difference. God bless whatever nerds are writing the next little bit of law to sneak into a giant bill, like a hacker with a virus.

Emily: Totally. OK. I gotta take a shot, and eat my lunch.

Dan: Go for it. We'll be back with a new episode in a few weeks. Till then, take care of yourself.

This episode of an arm and a leg was produced by Emily Pisacreta and me, Dan Weissman and edited by Ellen Weiss.

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