The Cost of Being Chronic in 2023: A Special Report

For Americans with health conditions, it can feel like there's a bill for just getting out of bed in the morning. We unpack what's behind rising fees—and what to do.

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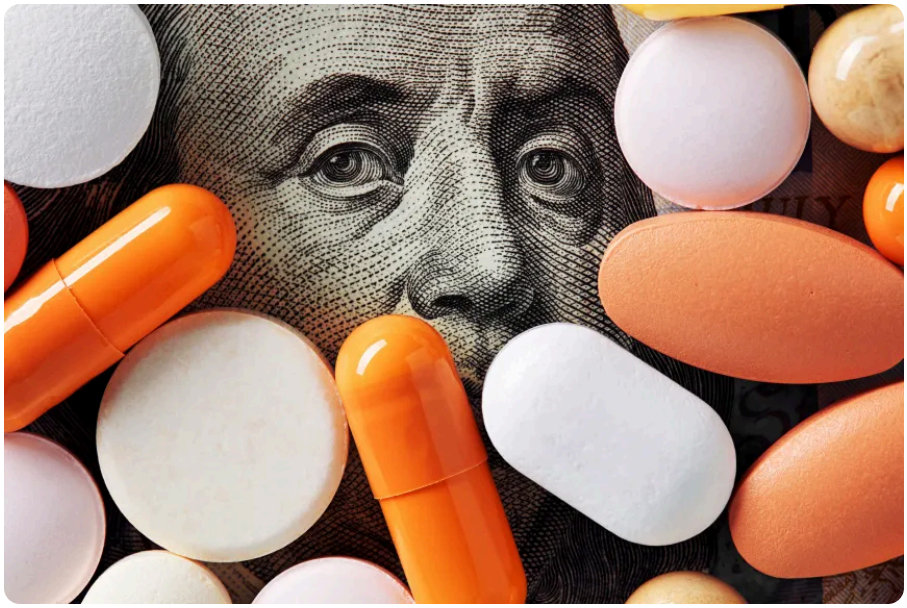
By: Erin L. Boyle



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You're not imagining it—things are getting more expensive. With inflation running high in the U.S., the cost of everything from eggs to fuel oil has increased dramatically. But it's not just pricey goods and gas: The cost of health care is way up, too. (As if we need to tell you.)

In fact, for employer-sponsored family health care coverage, health care premiums have risen by 87% since 2000, according to the Partnership to Fight Chronic Disease (PFCD), an organization of patients, providers, business and labor groups, and health policy experts that examines the issues associated with chronic illness, including medical costs. In 2023 alone, the average cost of health insurance without subsidies rose 4% from the previous year.

Meanwhile, health care spending—which includes health care goods and services, public health activities, government administration, the net cost of health insurance, and health care investments—grew 2.7% in 2021 (the most recent data on record) from 2020, reaching $4.3 trillion. Health-*related* spending, too, was up for Americans in many areas of medicine, reports the Centers for Medicare & Medicaid Services (CMS). This encompasses spending for hospital care services, which saw a 4.4% annual increase in 2021 to reach $1.3 trillion, per the CMS, with retail prescription drug spending increasing 7.8% to $378 billion during the same timeframe. Meanwhile, nondurable medical products—including over-the-counter medicines, medical instruments, and surgical dressings—soared in spending by 14.1% to $97.4 billion in 2021, compared to 2020's annual increase of 5.1%.

Drill down to specific chronic conditions, and you'll find hefty upticks in costs there, too. The cost per person with diabetes jumped by 24.8%; hypertension, by 24.9%; stomach and intestinal disorders, by 29.9%; and other endocrine, nutritional, and immune disorders, by 19.1%, all between 2020 and 2021, per the PFCD.

If you live with a chronic health condition, you're likely thinking: Well, this isn't news to me. That's because in 2023 your health care coverage on average costs $6,032 annually—five times higher than for people without a chronic condition. You're faced with the tough choices about what—and where—to spend your money. Treat your disease or pay your rent? Pay the electric bill and face unmanaged symptoms, or have the lights switched off and feel better in the dark? Or simply set aside that astronomical medical invoice and risk a debt collector's call. (One in five Americans have medical debt, according to the U.S. Census Bureau; that number jumps to nearly one in three for people living with health issues.)

These are unfathomable decisions members of the chronic community feel forced to make. Whether it's a young adult with ulcerative colitis (UC) trying to avoid bankruptcy or a 63-year-old with stage 3 chronic kidney disease balancing family needs with co-pays for expensive meds, the basic costs of care keep going up. And up, and up. What's being done to stop it? Can you bring your costs down? Here's where things stand right now—and what you can do about it.

The Cost of Survival

If you have a chronic condition in the U.S. in 2023, you're not alone. Six in 10 adults in the U.S. have at least one chronic disease, according to the Centers for Disease Control and Prevention (CDC). Four in 10 adults have two or more.

Bridget Edwards, 27, of Brewer, ME, is one of those people. She has afibrinogenemia, a rare, inherited blood disorder that prevents her blood from clotting normally. Her chronic condition requires her to receive prophylactic infusions to prevent bleeds, and the medication runs between $25,000 and $30,000 annually. Even with health insurance, her out-of-pocket/deductible costs are roughly $7,500 a year. Add to that $300 co-pays for every emergency room visit—she typically has 10 to 15 ER visits each year—and her chronic condition is a real financial burden. "It's devastating how much I have to pay just to survive," she says.

"I've maxed out credit cards before to pay medical bills, so they won't go to collections. I've paid medical bills over household utilities—and end up with late charges to again avoid medical bills going to collection. I've reached out for support from different organizations to help offset this struggle but because my disease is so rare, I sometimes don't get chosen to receive support and have even been told there is no support available because of how rare my condition is," Edwards explains.

Common chronic autoimmune conditions, such as rheumatoid arthritis (RA) and multiple sclerosis (MS), can also be debilitating. All told, about 50 million Americans live with an autoimmune disease, according to the journal *Science Translational Medicine*. Some 20 years ago, officials at the National Institutes of Allergy and Infectious Diseases (NIAID)

reported that autoimmune disorders cost more than $100 billion a year. Now, that cost is likely much higher, say officials at the American Autoimmune Diseases Association (AARDA) because just "seven of the 100+ known autoimmune diseases—Crohn's disease, ulcerative colitis, systemic lupus erythematosus (SLE), MS, RA, psoriasis, and scleroderma—are estimated through epidemiological studies to total from $51.8 to $70.6 billion annually." Care for people with these chronic conditions, as well as others, comprises 90% of the country's more than $4 trillion spending in annual health care costs, according to the CDC.

And the total costs of chronic disease are estimated to grow. Between 2016 and 2030, that figure is estimated to be $42 trillion in the U.S., projects the PFCD.

Why Health Care Costs Keep Rising

So, why is the rent—sorry, health care—so darn high?

There are many reasons, says Jacob Hascalovici, M.D., Ph.D., a pain specialist at Albert Einstein College of Medicine in New York City and chief medical officer of Clearing, a telehealth platform for chronic pain patients. A major one is health care insurance with all its financial ins and outs.

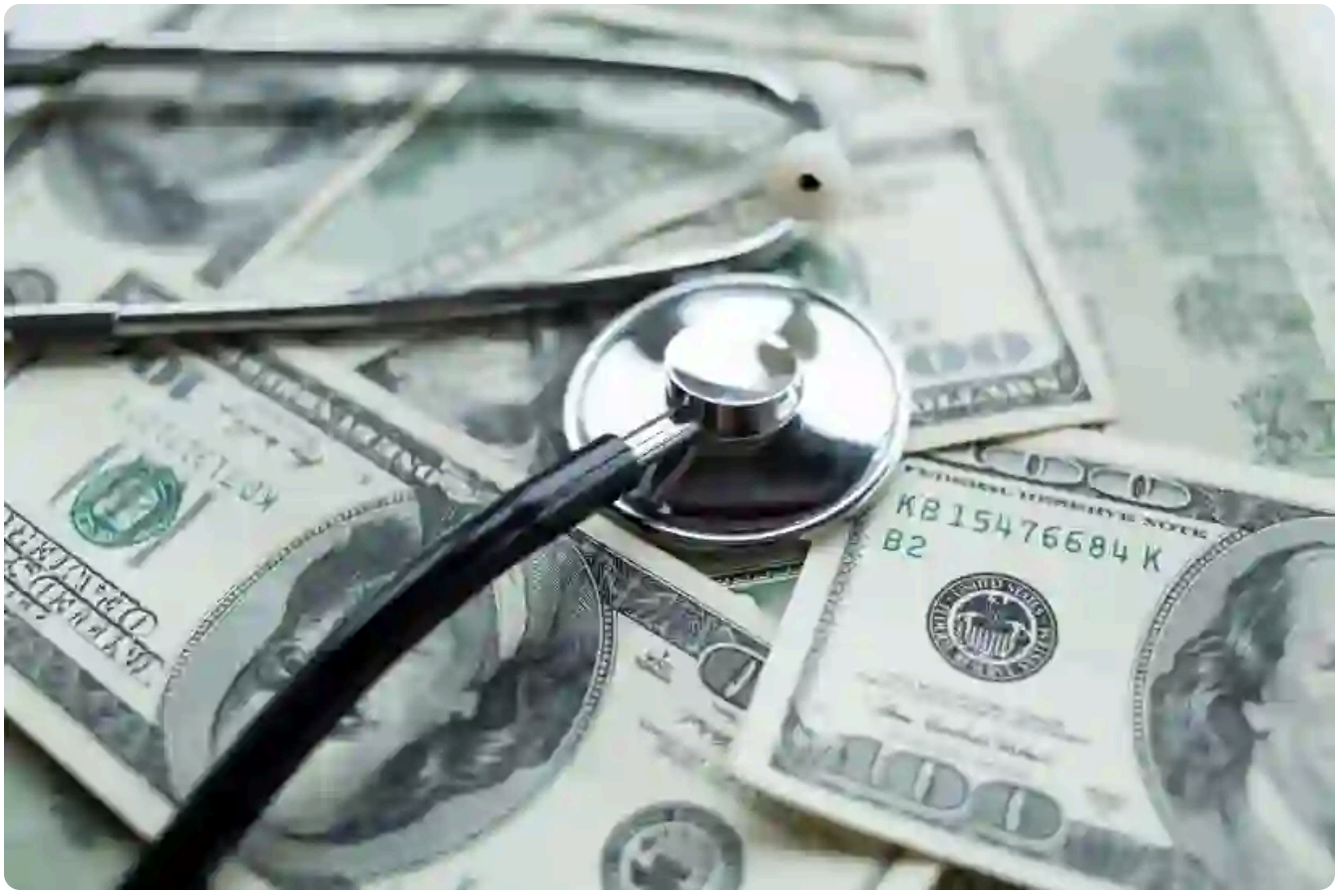
Private insurance in the U.S. typically has a deductible, Dr. Hascalovici explains, which is a set price point you must meet before your health care is fully covered. There's also the premium, the amount you pay for your health insurance per month. In addition, plans also have a set amount you pay for certain services, called a co-pay. How much you pay in co-pays can be impacted by things like your plan type, including your deductible and whether you pay more for in-network vs. out-of-network services, doctor visits, medication, and imaging/testing. Specialist appointments that are needed to manage chronic conditions can have more expensive co-pays than primary care doctor visits. And you might need to drive a longer distance to see those specialists, too.

Curtis Warfield, 63, of Indianapolis, IN, knows all about the cost of co-pays with a chronic condition. Diagnosed with stage 3 chronic kidney disease following a routine doctor's visit, he had a kidney transplant in 2016. Post-transplant, Medicare covered his meds for the first three years before he switched back to private insurance in 2019. He now pays

about $250 to $300 per month in co-pays, mainly for immunosuppressant and side effect medications. He says he's fortunate that he has insurance, but it's not always enough.

"I still have to cut other corners ... especially if there are other family or household issues that come up," he says. "It sucks. While I understand the need, I don't like the cost. Some meds I can't substitute for the generic types, and there is little assistance from some of the pharmaceutical companies."

Out-of-pocket costs are pricey, too. They can include the cost of medical care equipment that insurance doesn't cover. Molly Tinnin, 35, from Baton Rouge, LA, has ulcerative colitis, or UC, a form of inflammatory bowel disease (IBD). She's had to navigate her new ostomy while struggling to pay for durable medical equipment costs and student loans—all to prevent bankruptcy.



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"Coping with the cost of managing my ulcerative colitis has taken a greater toll on my mental health at times than coping with my actual illness has," she says.

The price tag on health care has increased steadily since Lauren Beach, 30, of South Boston, MA, was diagnosed with Crohn's disease at age 12. Out-of-pocket essentials for ostomy supplies following her eight IBD surgeries have added up. "Those are not covered by my insurance, as they are considered a 'disposable item,'" she explains. "I have to pay around $350 per month for those. That means even at 30 years old, I still [have to] get a little help from my parents."

What's more, a chronic condition may cause complications or lead to a *new* chronic condition, like when constant pain leads to cardiovascular risk factors associated with metabolic syndrome, for example. Or how eye problems can stem from diabetes. And you might need more expensive treatment and complementary therapies that aren't covered at all by insurance, such as acupuncture or massage for pain.

"Despite health insurers' best efforts to cover patients' needs, there may not be sufficient funds to offer what a patient with a complex, chronic condition would actually require to adequately manage, much less recover from, their condition," Dr. Hascalovici says.

Reality Check: Research and Development Is Pricey

Let's return to Crohn's disease. One 2019 article in the journal *Inflammatory Bowel Diseases*, part of the Crohn's & Colitis Foundation's Cost of Inflammatory Bowel Disease (IBD) Care Initiative, found that in the first year after diagnosis of an IBD (including both Crohn's and UC), those who are diagnosed can spend a mean of $26,555—and then, going forward, are saddled with more than twice the annual out-of-pocket costs ($2,213 vs. $979) than folks without IBD. Those funds went toward things like treatment with specific (and expensive) therapeutics such as biologics, opioids, or steroids; emergency department use; and health care services needed for relapsing disease, anemia, or a mental health comorbidity.

In particular, medication prices have skyrocketed in the last decade as more expensive—but also more effective—therapeutics have been developed that help achieve clinical remission. Take biologics. One, Humira (adalimumab), can treat Crohn's, UC, RA, and other chronic inflammatory conditions. Prices vary depending on a variety of factors, but the drug can retail for more than $9,000. And it's an every-other-week drug. Which adds up. Fast.

“Medications are becoming more complex and involved as researchers aim to solve high unmet needs,” explains Cathy Kuhn, Pharm.D., vice president of clinical offerings at Custom Health, a technology platform in Mountain View, CA, that uses remote monitoring to help patients remember to take their medications.

“Pharma is playing a greater role in ensuring medications are effective by targeting treatments to individuals. But the fact is, this research and development cost is high. Drug discovery and development is complex and costly,” Kuhn says.

Biologics, for example, can take up to 18 months to manufacture, according to pharma company Genentech. To be developed, biologics must be:

- **Programmed.** Through genetic engineering, something called a “cell line” is created to develop the biologic from sequenced DNA.
- **Grown.** A small vial of the cell line is thawed and grown in a specific environment for several days to expand the cell population into trillions of cells. These are working together, “acting as tiny factories to produce a biologic,” per Genentech. When they’re developed to just the right amount, the cells are placed in large-scale production tanks and continue to grow for another two weeks.
- **Purified and harvested.** Next, the biologic is separated from cells, proteins that aren’t needed, and other impurities created during the growing process. This is called harvesting. It coincides with the purification process, which is key to making the final biologic.

In other words, development is far from free. And because biologics are so complicated to produce, they’re more expensive than chemically synthesized drugs, including conventional disease-modifying anti-rheumatic drugs (DMARDs)—like methotrexate, which costs about $43 for a supply of 20 tablets, out-of-pocket, to treat RA.

Creating medicine in general can be a costly endeavor. But when it comes to using the genetic modification technology to develop new biologics, those costs can easily run into the millions—for one biologic agent alone. This process can be so expensive that it’s also prohibitive: There is often little competition within the industry to make more, alternative brands, which can help reduce costs.

Big Pharma R&D Can't Fully Explain Price Increases

Some R&D costs, though, are paid through public support (i.e., tax dollars), especially for biomedical research done through the U.S. National Institutes of Health (the NIH, the world's largest government funder of such research). In fact, publicly funded drug R&D has "played at least some role in virtually all of the 26 most clinically and commercially significant drugs and drug classes approved over the past several decades," according to a 2020 article in the journal *F1000 Research*.

Yet, while our tax dollars have helped discover important pathological processes and find potential drug targets, it's the private sector that's been the main investor for many new therapies, researchers report, with an estimated $120-plus billion per year invested in biomedical research, compared to the government's $40 billion.

Meaning, big pharma R&D is not the only reason behind some drugs' hefty price tags. And remember, biologics are just one type of expensive drug in the U.S. Costs have been rising for other meds, too.

For example, from 2008 to 2016, the list prices of brand-name oral medications increased about 9% each year, while list prices of injectable agents increased an average of 15% each year, according to a 2019 research article in *Health Affairs*.

And a 2022 study looking at 60 drugs approved by the Food and Drug Administration (FDA) from 2009 to 2018 found that R&D did not explain the variation in drug list prices. "This study offers empirical evidence that, in the U.S., drug companies charge what the market will bear," the study's authors write.

Out-of-Control Costs Can Bring Unhealthy Dividends

Due to soaring costs of medication, patients will do many things that are not great for their overall health. HealthCentral's survey of more than 200 people with chronic conditions found that:

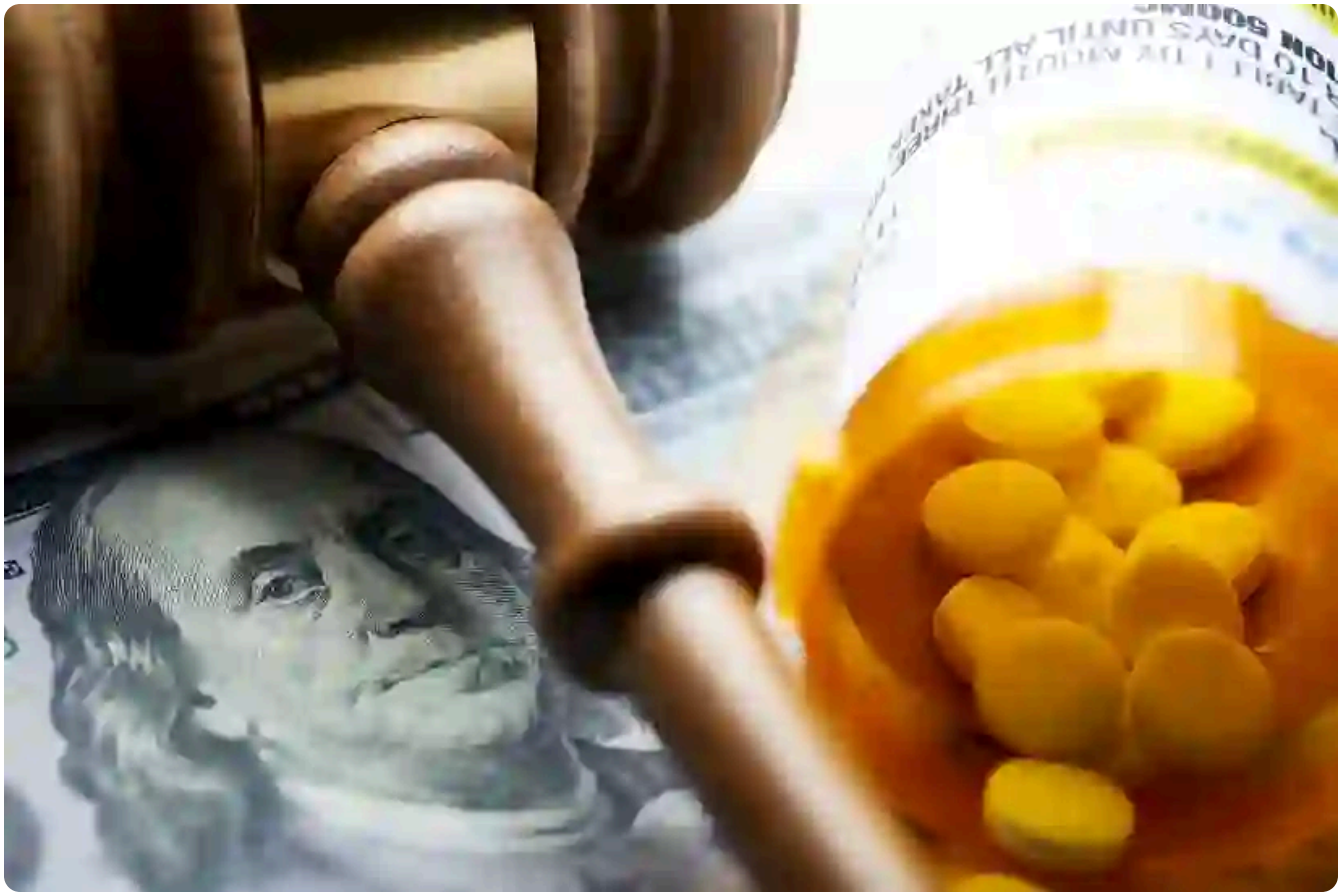
- **44%** switched to another drug due to cost.
- **15%** skipped a dose to make it last longer.

- **11%** cut meds in half to stretch out a prescription.
- **7%** stopped taking their meds altogether.

Beach says she's lucky—without her parents' assistance, she'd be "seriously struggling." She's on meds for Crohn's disease, so she needs to take care in selecting her health care coverage: "I have to choose the most expensive health insurance plan my company offers [in order] to ensure the most ideal coverage when things come up."

Proactive Care Keeps Costs Down—With Better Outcomes

If you can't afford a high deductible, rising co-pays, and pricey out-of-pocket expenses, you might be tempted to skip health care altogether. But if you leave your chronic condition untreated, you may lose wages and experience worsened symptoms—costing you more in the end.



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That's according to public health expert Kenneth E. Thorpe, Ph.D., a Robert W. Woodruff professor and chair of the department of health policy and management in the Rollins School of Public Health of Emory University in Atlanta, GA. He's also the chairman of Partnership to Fight Chronic Disease.

The problem, Thorpe believes, is that raising the cost of a chronic person's care by even a single dollar ultimately costs both patient and insurers multiples more. "If you charge a patient $1 more out-of-pocket for a medication for these conditions, it increases total spending by $1.80," he explains, "because hospitalizations go up. Ambulatory care visits go up. If you're not maintaining the right medication regimen, your blood pressure could spike, your blood sugar could spike. You could have an asthmatic event. Just go down through the list."

Brooke Epps experienced a 180 in her health when she was finally able to address her lifelong symptoms with the right level of care. The 47-year-old from Denver, CO, first learned she had juvenile myoclonic epilepsy, a chronic condition that often starts during the teen years and continues into adulthood, when she was 17. Until the Affordable Care Act (ACA) was passed in 2010, she had sporadic access to health care due to high insurance costs—and limited-to-no access to related costs, like necessary imaging. Not coincidentally, her care (and overall health) improved after the ACA became law.

"I found out that a person with epilepsy can be labeled disabled from the state and pay for Medicaid based on how much they make. Since I have started doing this, I have had the best insurance of my adult life. I am able to get blood drawn, which helps to see if meds are working effectively; go see general doctors; get mammograms; get vaccinations; and still be able to afford my medications and see a specialist for my epilepsy."

The vital importance of sticking to your meds and seeing your doctor when you have a chronic condition can't be emphasized enough, says Daniel Chandler, M.D., a primary care physician at Tufts Medical Center in Boston, MA. He knows the high cost of care, and the burden that expensive medications present. But he's adamant that the old cliché, an ounce of prevention equals a pound of cure, applies here.

"Once people have been diagnosed, they can have that sense that their disease has already reached its peak," he says. "But with chronic illness, it's really much more of a marathon than a sprint. And keeping on top of things helps prevent future complications."

Federal Fixes May Deliver Some Financial Relief

There are things on the horizon that might help. One development in this arena is the Inflation Reduction Act. This federal legislation, signed into law by President Joe Biden in August 2022, gives Medicare officials newfound ability to negotiate lower prescription drug prices. That will start in 2026. It's set to help reduce health care and prescription drug costs for the millions of Americans 65 and older.

In addition, right now, bipartisan legislation called the Pharmacy Benefit Manager Transparency Act is heading to the U.S. Senate after passing the Senate Committee on Commerce, Science, and Transportation. It's looking to do just what it says—increase the transparency in prescription drug pricing by "[holding] pharmacy benefit managers (PBMs) accountable for deceptive and unfair practices that drive up prescription drug costs," according to a press release.

So just what is a PBM? These groups were created to help process claims and negotiate lower drug prices with drugmakers. But now, just three PBMs control 80% of the prescription drug market, "operating out of the view of regulators," says Sen. Maria Cantwell (D-Wash.). This legislation could help control the process.

Currently, the high cost of many meds is still absorbed by patients of all ages, including those with chronic conditions—often determined by how well a PBM negotiates rates for insurance coverage. And how does that play out for our drug example, biologics? While less than 20% of the half a million Americans with Crohn's disease use biologics, reports a 2019 *Inflammatory Bowel Diseases* article, this group is charged two to three times the total cost of care per year, compared with people who are not on them.

Maybe you've also heard about the recent cap on insulin prices. The three drug companies that make up 90% of the insulin market for type 1 and 2 diabetes treatment, Eli Lilly, Novo Nordisk, and Sanofi, have all announced that they've capped pricing of the drug as of March 2023.

The cost of insulin has certainly been at the front of Mindy Bartleson's mind: "I've had diabetes for almost 23 years, and over the past 20-plus years, the price of insulin has increased by about 600%," estimates the 30-year-old from Boston, MA. A single vial of

the essential drug retails for up to $250 (and possibly more). And remember, some people with diabetes need up to six vials per month.

This price capping follows the successful passage of the Inflation Reduction Act, which restricted out-of-pocket insulin costs for more than 3 million people on Medicare to $35 per month. Still, it applies only to people 65 and above and doesn't offer a price cap for younger people like Bartleson.

Some states, too, have passed laws capping a range of Rx drug costs—often insulin—says Louise Norris, a health policy analyst for healthinsurance.org in St. Louis Park, MN. But state rules don't apply to self-insured health plans. And the majority of people with employer-sponsored health insurance rely on self-insured plans.

"The federal government has stepped in with rules, such as the ACA's requirement that essential health benefits be covered, but that only applies to individual/family and small-group health plans," she notes. "Various consumer protections apply to some folks' coverage but not others, which makes it especially important for each person to understand the specifics of the coverage options that are available to them."

What You Can Do About the Cost of Care

If you have a chronic condition (or conditions) and the cost of your care is causing you financial hardship, there are ways you can protect yourself, our experts say.

- **Evaluate your insurance.** "Benefit design matters," says Thorpe, who advises looking for lower deductible plans. "What's really important is, what does that out-of-pocket component look like, in terms of what you pay for a physician visit, what you pay for prescription drugs, and so on." Norris agrees. "There are lots of plans available with lower caps on out-of-pocket costs, and some folks with chronic conditions find that they're better off with one of those options," she says. "There's no one-size-fits-all, though. Some people with chronic conditions find that their total costs are lower if they pick a plan with lower premiums and higher out-of-pocket costs." The provider network and the covered drug list (formulary) matter, too. Resources like HealthCare.gov and Healthinsurance.org can help you learn about your options that best fit your needs.

- **Use drug assistance programs.** These programs are run by pharmaceutical companies (particularly for more expensive drugs) and can be a great help in lowering medication cost, Thorpe says. Asking your pharmacist for ways to cut down on medication costs is also a good idea.
- **Negotiate medical costs.** Negotiating your medical bills with providers and others is a good idea too, Dr. Hascalovici suggests. "Remember that you can often discuss pricing ahead of time, can look into discounts [adjustments] and can see if you can negotiate alternate charges," he adds.
- **Seek out your primary care doctor.** Sticking to often-cheaper co-pay visits with your primary care doctor—and having them be the team leader on your care—can help lower prices and build continuity of care, Dr. Chandler says.

Ultimately, the cost of chronic care in 2023 and into the future is steep, and while there are ways to help reduce it, the burden remains.

"Having a chronic illness is challenging mentally, physically, and unfortunately, financially," Beach points out. "I didn't ask or sign-up to have this condition, and I know others dealing with a chronic illness would likely say the same thing. It feels unfair that we are forced to live a more expensive life in order to *have* a life at all."

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SOURCES

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