

OUT HEALTH AND WELLNESS

## Barriers to transgender health care lead some to embrace a do-it-yourself approach

Despite the health and legal risks to this approach, some experts predict it will become more common due to the current political environment.



— While not all trans people opt for hormone therapy, a recent study estimated that 9% of those who did had obtained hormones from unlicensed sources, including friends and unregulated online pharmacies. NBC News / Getty Images



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**By Nicole Rosenthal**

Max Adomat considers himself fortunate. Adomat, 26, who is nonbinary and uses they/them

pronouns, has been on a steady regimen of feminizing hormones for the last six years. They also began their gender transition in New Jersey, a progressive state where clinics offering transition-related medical care are commonplace, and name changes are confidential, they said.

But Adomat still found themselves obtaining and self-administering gender-affirming hormones from unregulated, and oftentimes illegal, overseas online pharmacies instead of licensed medical offices. The reason, Adomat said, was a lack of both health insurance and money: When they began transitioning, their low-paying job in the food service industry did not provide insurance, and they were unable to afford the steep cost of transition-related care – including hormone therapy and routine doctors appointments – without it.

Though they knew the risks – which, without supervised care, can include higher chances of blood clots, heart attacks and some cancers – Adomat felt their window for a successful transition was closing, they said.

“I just sort of decided, ‘I’m going to do it, and if and when I can see a doctor somewhere down the road, sure, but I would rather do it now and face those consequences,’” they recalled, adding that their alternative at the time was to continue to “live miserably.”





— Max Adomat, 26, has been on a steady regimen of feminizing hormones for the last six years.

Max Adomat

There are approximately 1.6 million transgender teens and adults living in the United States, according to a [report published last year by UCLA's Williams Institute](#). While not all trans people opt for hormone therapy, a [2020 study published in the Annals of Family Medicine](#) estimated that 9% of those who did had obtained hormones from unlicensed sources, including friends and unregulated online pharmacies.

Interviews with health care providers and lawyers, as well as transgender individuals who use or have used a do-it-yourself approach to transitioning, suggest the reasons people opt for the nonprescription and self-administration route vary and include cost savings, health care accessibility, medical discrimination, and the desire to choose which hormones and dosages are involved in the process.

A DIY approach, however, is not without its health and legal risks. Despite the risks, some experts predict this approach will become even more common given the current political climate: Nearly 20 states have already passed laws blocking access to gender-affirming care for minors, and other states have proposed measures that would [restrict this type of care for some adults](#).

## Out of pocket costs

A monthly supply of common feminizing hormones – including estrogen and anti-androgens – can cost patients up to \$115, according to GoodRx, which tracks U.S. drug prices. Masculinizing hormones, including injectable testosterone, are typically cheaper, costing about \$40 to \$90 a month. Through unregulated online pharmacies, however, a monthly supply of these feminizing and masculinizing hormones can be purchased for as low as \$8, plus shipping.

While price sensitivity to health care costs is not unique to transgender people, this community faces higher rates of [economic hardship and poverty](#), with 1 in 3 trans adults reporting an annual household income under \$25,000, according to a 2021 report from the liberal think tank [Center for American Progress](#).

Samme Qandil, 28, was on a medically supervised hormone regimen for three years, but when she landed a new job and her health insurance changed, she was unable to pay her new provider's \$300 copay for a six-week supply of injectable hormones. Faced with both high copay fees and a

[nationwide shortage of injectable estrogen](#), she decided to begin purchasing her hormones from an unregulated online pharmacy recommended by her friends.

While Qandil, now a graduate student in Oregon, said she didn't have many reservations about obtaining and administering hormones by herself, since she knew others who had gone through the process, she still undergoes regular blood tests to ensure her estrogen levels are within a safe range.

The prescription route cost her nearly \$700 a year for medications and \$400 in appointment copays, Qandil said – more than twice what she now pays for a two-year supply of hormones and related expenses like estrogen blood tests.

While hormone replacement therapy using a DIY approach is “cheaper and technically more accessible,” Qandil said, orders from overseas pharmacies can be unreliable, with some packages of unregulated hormones seized at the U.S. border. However, she added, DIY is cheaper even with the sunk costs, and she even has the ability to stock up on a yearly supply to ensure the hormones don't run out during a shortage or customs confiscation.

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**"In an era when patients may have no option but to 'DIY' their transitions, just as it is happening with abortions in many states, it might be important for them to know that there are ways to do it that are overall less risky."**

DR. URI BELKIND, CALLEN-LORDE COMMUNITY HEALTH CENTER

Stephanie Coiro, a clinical social worker at Northwell Health's Center for Transgender Care in New Hyde Park, New York, estimates about 10% of her transgender patients have tried acquiring hormones without a prescription at one time or another. She said this route can cut their costs by more than 50%. Though, she emphasized, those with a prescription, even if they do not have health insurance, can get testosterone or estrogen for \$20 to \$30 a month at stores like Target and Walmart with manufacturer coupons.

For those who do not have health insurance, anything out-of-pocket, including doctors appointments, is “incredibly expensive,” Coiro acknowledged. In addition to price concerns, she said recent [shortages of hormones, like testosterone](#), could also drive patients to acquire medication through nonprescription means.

The cost of hormones is often one of many expenditures associated with a transition, according to

experts and those receiving transition-related care. And a number of transition-related services and procedures are typically not covered by health insurance, including hair removal, which can be mandatory for some gender-affirming surgeries; therapy visits for referral notes, which are typically mandatory for prescriptions and surgeries; and gender-affirming facial and chest surgeries.

Dr. Uri Belkind, the associate director of adolescent medicine at Callen-Lorde Community Health Center, an LGBTQ-focused health clinic in New York City, called the long list of transition-related expenses a “transgender tax” that can cost trans people hundreds of thousands of dollars over their lifetime.

Across the pond, in the United Kingdom, Alicia Tuplin West, 19, has turned to unregulated online pharmacies for both cost and expedience. While England offers free gender-affirming care through a publicly funded health care system, West, a university student, said she faced a waitlist of up to several years through England’s National Health Service (joining around 26,000 others, [according to The Guardian](#)). Unwilling to wait and unable to afford a private health care alternative costing 1,000 pounds a year (\$1,250), West bought hormones through an online pharmacy and cut the price by 90%, she said.

“The traditional way, it’s all socialized; it’s all paid for by my taxes,” West said. “However, I would argue that the traditional way is like a myth – the idea of getting treatment from the NHS – if you want to transition in this decade.”

## Access to care

Most U.S. states still permit minors to obtain gender-affirming care with parental consent, and, for those over 18, this type of care is still legal in all 50 states. However, recent years have seen an unprecedented wave of state laws seeking to ban or restrict transition-related care, particularly for trans youths.

Eighteen [states](#) now have laws on the books banning or restricting the prescription of puberty blockers and hormones to minors, though a federal judge struck down Arkansas’ law last month, and judges have temporarily blocked laws in Alabama, Florida, Indiana, Kentucky, Oklahoma and Tennessee. At least two dozen [other states](#) are considering such measures, and a few, like Tennessee and Oklahoma, have considered bills that would restrict this type of care for some adults.

This legislative push makes legal access to gender-affirming care nearly impossible for some people, three experts told NBC News, which could lead them to unregulated online pharmacies.

Belkind said this recent legislation “absolutely” has the potential to send more transgender people online to seek hormones. He also pointed to a recent [request by Florida Gov. Ron DeSantis](#), a Republican, that asked state universities to send information to the governor’s office about students



who sought or received treatment for gender dysphoria.

“People are not going to want to be on those lists for obvious reasons,” Belkind said. “They might not even disclose to their medical providers, if they seek medical care for other things, that they are on hormones.”

Dr. Danielle Brooks, an endocrinologist at Northwell Health’s Center for Transgender Care, said state legislation restricting transition-related care will likely drive more people, including minors, down the DIY path.

“I think more and more people are aware of the path,” Brooks said. “I do think that will be something that will increase over time, and it’s probably increasing now.”

#### **Related links:**

- [The LGBTQ population is growing, but medical schools haven't caught up](#)
- [Power couple Zooey Zephyr and Erin Reed are spreading hope to fellow trans people](#)
- [Judge strikes down Arkansas ban on transition care for minors](#)
- [Judge strikes down Florida's ban on Medicaid funding for transgender treatment](#)

Dr. Joshua Safer, director of the Center for Transgender Medicine and Surgery at Mount Sinai in New York City, said patients have historically self-medicated when they don’t have access to conventional medical care. While he doesn’t think most trans youths will be able to acquire gender-affirming hormones through the informal economy, he said parents may resort to seeking medical care in other states if they have the resources.

If these youths are unable to acquire hormones, Safer said, there are “going to be negative mental health implications.”

The data supports Safer’s assertion: Transgender and gender-nonconforming individuals are at an increased risk for mental illness and suicidality, according to a study published last year in [JAMA Network Open](#), and receipt of transition-related care is associated with 60% decreased odds of moderate or severe depression and 73% decreased odds of suicidality.

Even for adults and minors who have health insurance and live in states not affected by restrictions on transition care, insurance companies may not approve coverage for such care.

Dale Melchert, a staff attorney at the Transgender Law Center, said he has seen most insurance companies oscillate gender-affirming health care coverage based on what's required under federal regulation, such as individual presidential administrations' interpretation of the Affordable Care Act. While Obama-era policies blocking widespread coverage exclusions have historically prompted insurers to adjust their plans to cover more gender-affirming care, Trump-era rollbacks of these policies have since barred many from affordable access to transition care, Melchert said.

“Most insurance companies will do anything they can to save money, and denials are a way to save money,” he said. “Technically, we still have Trump’s rollbacks on the books.”

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OUT NEWS

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Apart from the expenses associated with transitioning, unpleasant experiences with health care providers can also dissuade individuals from seeking supervised care.

“Doctors can also ask unnecessary questions that have nothing to do with the reason they came to seek care. That feels really invasive,” Melchert said. “A lot of times doctors don’t know how to provide competent care.”

A [2018 study](#) of students at 10 medical schools found that approximately 80% of survey respondents felt “not competent” or “somewhat not competent” treating transgender patients. According to the same study, while 93% of respondents felt somewhat or very comfortable treating sexual minority patients, 68% felt comfortable treating gender minority patients.

Dr. Ricardo Correa, an associate professor at the University of Arizona College of Medicine-Phoenix, acknowledged that there’s a “high” amount of bias in the health care community against trans people, echoing a sentiment also expressed by Brooks. However, he added, even those who want to refer patients to practices where they can receive gender-affirming care may be unable to, because the patients are based in communities where there’s an absence of physicians who are able to provide adequate help.

“Instead of food deserts, there are medical deserts,” Correa said. “The patient just gets more traumatized [and] trusts the system less.” This, he said, can lead patients to pursue a DIY approach, until they are able to find the care they seek.

## A desire for control

A., a postdoctoral fellow in life science at a Canadian university who requested that her name not be published due to safety concerns, sourced gender-affirming hormones through overseas online pharmacies for roughly a year. She wasn't, however, prompted by a desire to save money or a lack of health insurance. Instead, she said, her driving factor was control over her own transition.

She said she received care from a Planned Parenthood clinic in the Midwest for nearly three years, followed by care at the LGBTQ nonprofit Howard Brown Health in Chicago for several years. Eventually, she grew dissatisfied after facing remasculinization and plateauing effects, she said. Her decision to take a DIY approach was the result of a conservative approach to hormone replacement therapy by her previous health providers and a general lack of information about trans care among doctors, she said.

“At first, everything seemed to be doing fine,” she said of her transition-related care. “You see breast growth, you see that your skin is getting smoother. ... All of a sudden, for no reason whatsoever, you stall or you start regressing. Your facial and body hair come back in force, and you feel general discomfort in your body and mind.”

Following years of remasculinization – including “\$3,000 of laser hair removal out the window” and persistent gender dysphoria – she grew desperate for a solution, she said. That's when she decided to turn to online pharmacies, which enabled her to increase her hormone dosage.

She said the DIY process made her “feel empowered.”

“You feel very lost, but you feel that there's the possibility of something moving forward,” she said. “You feel like you're taking the reins of your care.”

After a year of ordering hormones through unregulated online pharmacies and self-administering, she said, she finally found a “good, private” clinic that was willing to listen to her concerns and address her needs. While she no longer personally uses a DIY approach, she continues to serve as a resource for others starting their DIY journeys through online forums, she said.

## **Health and legal risks**

Obtaining and administering hormones without regulated pharmacies and licensed health care providers can expose individuals to serious health risks, including blood clots, stroke, liver damage and cardiovascular disease.

“We're always worried about excess dosing if someone's not being monitored, because the risks are real,” Brooks said. “There's a possibility that medical history is not being taken into account or there is something being missed.”

Brooks said several patients have come to her office with a higher-than-normal concentration of red



blood cells as a result of taking “very inappropriately” high levels of testosterone. This, she added, can cause vision problems, dizziness, fatigue, weakness, confusion and, of most concern, blood clots.



**"The vast majority of products offered through online pharmacies are, at best, non-U.S. FDA-approved medicines and, more often, at worst, dangerous fakes."**

LIBBY BANEY, ALLIANCE FOR SAFE ONLINE PHARMACIES

Belkind, of Callen-Lorde, said his colleagues have seen patients who ended up with injection-site infections after self-administering hormones using the wrong technique, as well as blood clots due to using the incorrect hormone dosage.

On the flip side, Belkind said, he has had patients who, prior to seeking his care, used self-prescribed hormones and found helpful resources online, where they “learned what medications are safer.”

“In an era when patients may have no option but to ‘DIY’ their transitions, just as it is happening with abortions in many states, it might be important for them to know that there are ways to do it that are overall less risky and that there are resources created by the community where they can learn how,” he said.

Libby Baney, a partner at the law firm Faegre Drinker and a senior adviser to the Alliance for Safe Online Pharmacies, a nonprofit that combats illegal online drug sellers, cautioned that those who buy medication from unregulated online pharmacies may not actually be getting what they ordered.

“U.S. consumers buying medications from online pharmacies rarely, if ever, receive exactly what they think they are ordering,” she said. “The vast majority of products offered through online pharmacies are, at best, non-U.S. FDA-approved medicines and, more often, at worst, dangerous fakes.”

The National Association of Boards of Pharmacy’s [2022 “Rogue Rx Activity Report,”](#) which Baney’s team shared with NBC News, cites a [2008 European Alliance for Access to Safe Medicines report](#) that found 62% of medicines purchased online are substandard or counterfeit, and a [2010 Korean study](#) that found 26% of medications tested from online pharmacies contained toxins like mercury, lead and arsenic, while 37% of samples tested didn’t have any active ingredients at all.

“Anytime that you have a product where people have either a legitimate medical need or perceived need, people will go online to find it outside the regulated supply chain,” Baney said.

Of the approximately 30,000 to 40,000 online pharmacies around the globe, 96% don’t require a valid prescription, 85% offer medicines that aren’t authorized by the FDA and more than 50% offer controlled substances, according to the 2022 National Association of Boards of Pharmacy report.

When it comes to the legal risks, enforcement efforts generally aren’t targeted at individual consumers, but rather the unregulated pharmacies selling the medication or the intermediaries helping to facilitate importation, according to Carrie Harney, vice president of government and regulatory affairs at United States Pharmacopeia, a nonprofit that annually publishes standards for prescription and over-the-counter drugs.

As for Adomat, they have recently scrapped the DIY method in favor of medically supervised care in Pennsylvania. This decision, they said, came after a career switch that included health insurance coverage. Still, Adomat said, they wouldn’t change their five-year DIY experience if given the opportunity.

“My attitude for a while was, ‘If it ain’t broke, don’t fix it,’” Adomat said. “Adding on to a general distrust of doctors, I decided to continue to put it off and shoulder the costs and risks myself.”

Now, with the right insurance and doctor, Adomat said, they “pay a fraction” of what they did using DIY methods. But, they added, those aren’t the only reasons why they’re currently content with the state of their care and their health: “I’m grateful I have a supportive family and legislature around me.”

*If you or someone you know is in crisis, call 988 to reach the Suicide and Crisis Lifeline. You can also call 800-273-8255, text HOME to 741741 or visit [SpeakingOfSuicide.com/resources](https://www.speakingofsuicide.com/resources) for additional resources.*



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Nicole Rosenthal

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