

# What does medical care look like when you're transgender?

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There are an estimated 1.4 million people in the United States who are transgender. It's a relatively big number—and yet, many of these individuals have difficulty finding doctors who are right for them and



their needs. Many have heartbreaking stories about their experiences with health care providers, even during a routine physical. Some providers make dehumanizing comments or won't acknowledge their gender identity. Others ask inappropriate questions or even refuse to treat them.

But those who care for <u>transgender patients</u> have a message: Don't give up on getting <u>medical care</u>.

"The doctor's office should be one place where everybody feels safe and cared for," says Christy Olezeski, Ph.D., a psychologist and director of the Yale Medicine Pediatric Gender Program, which serves children, teenagers, and <u>young adults</u> up to age 25.

But she says that patients have raised legitimate questions about how to continue medical care as they transition out of the program. "They've said, 'I don't even know if it makes sense for me to transition—even though this is who I am—because I'm afraid of what's going to happen in the doctor's office for the rest of my life,'" Olezeski says. "Will they have providers that are understanding and supportive of their identities, who will not ask intrusive questions?"

She says a concern is that some people choose to not seek medical care, even when they need to go to the Emergency Department, because they're afraid of what's going to happen.

## Why do transgender patients face roadblocks when seeking care?

One big issue is that many people, including <u>health care providers</u>, don't understand what the term "<u>transgender</u>" means, Olezeski says. Some think it is related to <u>sexual orientation</u> (whether they are sexually



attracted to men, women, neither, or both), which it is not. Rather, transgender people have a <u>gender identity</u> and/or expression that is different than the male or female gender they were assigned at birth.

Every transgender person approaches that differently. "Everybody's gender journey is unique to that individual," Olezeski says. "Not everyone chooses the same interventions to align their body and their presentation to be more consistent with their gender identity."

Transgender individuals' concerns about having their choices respected are not unfounded. About a third of transgender people report having had negative interactions with medical providers. These range from the need for them to educate the provider about transgender health to a provider's refusal to treat them, all the way up to verbal harassment, and even physical or sexual assault, as reported in a survey by the National Center for Transgender Equality. Fear of mistreatment kept 23% of people who responded to the survey from seeking care.

Another challenge they face is being left out of "traditional" medicine categories. Clair Kronk, Ph.D., a postdoctoral fellow in medical informatics at Yale—herself a transgender woman—recalls signing up for a COVID-19 vaccine clinical trial only to be turned away because there was no category for her. "I have complicated feelings about it, because these were some of the most important clinical trials in the history of the United States," she says. "There were lives on the line, and I was trying to do my part."

#### There can be mistreatment in the doctor's office

On one occasion, Kronk consulted an optometrist about her astigmatism, a common condition that affects the curvature of the eye. The doctor told her the problem was "probably associated with taking hormones," a theory her endocrinologist later told her didn't make sense, in part, says



Kronk, because the astigmatism was diagnosed two decades prior to her starting hormones.

Some young adults who Olezeski has worked with are concerned about something many of us have never had to think twice about, which is how they feel while sitting in medical office waiting rooms. Transgender men may still need gynecological care, but might be wary of waiting in a room full of cisgender women. (Cisgender is a term to describe those who identify with the gender they were assigned at birth.) Visiting a urologist raises similar concerns. There is a common misconception that urologists are men treating men, even though people across the gender spectrum seek care for urologic issues, says Jaime Cavallo, MD, MPHS, a Yale Medicine urologist.

Some transgender patients are fearful of physical examinations, especially when the doctor is a gynecologist or urologist performing genital exams, Dr. Cavallo says. Individuals may have experienced a complicated life journey. "Some transgender patients have depression, anxiety, or post-traumatic stress disorder [PTSD], and an examination can elicit their depression, anxiety, or fear," Dr. Cavallo says.

There also have been reports about doctors who aren't familiar with transgender care not knowing how to properly care for patients who have had non-genital gender-affirming (sometimes casually referred to as "top") surgery, or genital gender-affirming (or colloquially known as "bottom") surgery, which can feel alienating to the patient, she adds. "Sometimes, patients feel more comfortable if they bring a loved one to be present during their exam," says Dr. Cavallo.

## Regular medical care is especially important to the transgender community



Some transgender people do not pursue health care at all after hearing these kinds of stories, Olezeski says, and this may be one reason why they face disturbing health risks: Their risk of death, from a variety of causes, is twice as high as in those who are not transgender, according to a Dutch study published in 2021, based on five decades of data around adult transgender people receiving hormone treatment.

Olezeski also blames the elevated risks for health problems on the cumulative stress related to discrimination, including such things as attempts on their lives, physical and sexual assault, and threats from family members, saying that transgender people are more likely to be rejected and even homeless. "The effects of harassment, rejection, and microaggressions can add up. The impact on the stress response and the cascade effect on mental and physical health can be devastating," she says. "And small health issues can definitely increase if you're not getting preventive care, and if you're not getting things treated at an earlier stage."

That's why a transgender person absolutely should have a primary care doctor, says Olezeski. Just like anyone else, they also should expect to have respectful care from medical specialists in their adult lives.

A short list might include the following:

## 1. Ongoing care with a urologist after a medical or surgical transition

"The urologic history and examination should be uniquely tailored to the patient, depending on the types and duration of hormone therapy they have received, the patient age at initiation of hormone therapy, and what surgeries they've undergone," Dr. Cavallo says. She recommends that anyone who has had genital gender-affirming surgery visit with a



urologist at least once a year; they should be monitored for strictures and fistulas that can cause problems with urination and any issues with sexual function.

Transgender women who have kept their penis or testicles need to be monitored for benign and malignant diseases of these organs. Similarly, transgender women who have kept their prostate need to be monitored for benign prostatic issues and prostate cancer, she adds.

Hormone therapy and genital surgeries can make the diagnosis and treatment of cancers of the reproductive organs more nuanced for transgender individuals. "Insufficient and poor-quality data in the medical literature on urologic cancer incidence, stage at diagnosis, and outcomes for transgender individuals prevents us from being able to accurately assess their risks at this time," says Dr. Cavallo. "Well-designed studies inclusive of transgender patients are needed."

#### 2. Annual visits with a gynecologist

The American College of Gynecologists provides clear guidelines on transgender care, including this description of the doctor's role: "To guide preventive medical care, any anatomical structure present that warrants screening should be screened, regardless of gender identity."

That includes cervical cancer screenings for individuals assigned female at birth, and breast cancer screenings for those assigned female at birth and transgender women, as well as screenings for HIV and other sexually transmitted diseases for all transgender people. "Screening for HIV as a component of routine medical care is part of our message," says Michael Virata, MD, a Yale Medicine infectious diseases specialist. The U.S. Transgender Survey reported that the number of transgender people living with HIV (1.4%) is nearly five times the rate than in the U.S. population (0.3%) overall and high among transgender women of color.



Kronk points out that the numbers may even be higher than reported. "Providers rarely know about HIV/AIDS treatments such as PReP [pre-exposure prophylaxis], and if you don't have insurance, PReP can be expensive," she says. "It's often free if you do have it, but many trans people can't get insurance."

It's also worth noting that a number of trans people are also forced into sex work just as a way to survive and get by, she adds. "The numbers, when presented without context, may imply that trans people are hypersexual as part of being trans, which is not necessarily the case," she says.

Transgender men or nonbinary individuals (those whose gender identity falls outside of the traditional gender binary structure of girl/woman and boy/man) who still have their reproductive organs may still be able to get pregnant, so a gynecologist should still provide counseling on birth control. Most will stop menstrual bleeding with testosterone supplements; those who continue to have menstruation may be managed with hormonal therapies or surgery, says Amanda Kallen, MD, a Yale Medicine gynecologist and reproductive specialist.

## 3. A reproductive specialist if you are planning for children

Anyone who wants to have a child should have the choice of using their own eggs or sperm, regardless of their gender identity, says Dr. Kallen.

Although it can be expensive (and may not be covered by insurance), the Yale Fertility Center provides services for freezing sperm for later use by a female partner or surrogate, and for freezing eggs and embryos. "The good news is that fertility clinics are now promoting themselves as being friendly to transgender people," Dr. Kallen says. "At the Yale Fertility Center, the number of patients we saw in consultation for



transgender fertility preservation has gone up by 900% in five years," she adds.

### Should you let your doctor know your transgender status?

"It can be a tough question," says Susan Boulware, MD, a pediatric endocrinologist who works with patients in the Pediatric Gender Program. "Unfortunately, it does fall on the patient's shoulders to be as educated as possible," Dr. Boulware says. "We talk with patients about what kinds of things are important for a new doctor to know—and how forthcoming to be in certain cases."

One young transgender patient needed to visit a college urgent care clinic with a sprained ankle, for example; they wanted to know if they had to tell the doctor they were taking testosterone, adds Dr. Boulware. "We discussed that the patient needed to answer questions regarding medications honestly; if asked about it, they could say that testosterone is being used for 'hormone replacement therapy.'" Explaining that they are a transgender individual may not be necessary in that situation, she explains.

In other cases, though, it's important to be upfront, she says, especially regarding hormone therapy. Transgender people should always let their primary or specialty care doctors know if they are on estrogen therapy, so they can be monitored for potential side effects. Dr. Boulware says "puberty blocker" medications can impact bone density, and estrogen elevates the risk for blood clots. Similarly, transgender men or nonbinary individuals who take testosterone-based treatments may have a higher risk of cardiovascular issues.

David Mulligan MD, chief of transplant surgery for Yale Medicine, says



both doctors and surgeons need a complete medical history so that they can administer treatments properly. "We always have to be careful to monitor the impact of hormonal therapy and the development of other hormonal diseases, like diabetes," he says.

Still, the decision to disclose can be a difficult one for patients. A complete medical history can be very important—or even life-saving—but that isn't always the case, adds Kronk. "Patient privacy is important, and given that many jurisdictions can refuse care to LGBTQ+folks, it's understandable why people would not disclose that information," she says. "Providers have a duty to create a safe and trustworthy environment for their patients. It is not the patient's responsibility to assume that every environment is safe and trustworthy."

## There are efforts underway to improve transgender care

It's hard to know exactly how many transgender people there are, despite the best efforts of demographers to make accurate estimates. At Yale, Kronk led researchers in an effort that could contribute to achieving some clarity, while paving the way to more research around the transgender population. She worked with other transgender researchers in the U.S. and Canada on recommendations for updating the way transgender patient information is recorded.

Until 2015, most electronic medical records (EMRs) limited their gender fields to categories for "male," and "female." Many didn't even allow "other" as an option. It would just be left blank and recorded as "unknown," says Kronk.

In 2021, Kronk and her fellow researchers published a paper in the *Journal of the American Medical Informatics Association* that



recommends a two-step self-identification approach. It would allow people to specify both their gender identity—"female," "male," "non-binary," "questioning," "not listed," "prefer not to disclose"—and their assigned gender at birth or the gender that appears on their birth certificate.

Implementing recommendations like this "will take advocacy on different levels," Kronk says. "For it to work, you need to have base-level providers—not just gender clinics—opting into this."

But EMRs matter, Kronk adds. They provide alerts to providers when a drug may be less effective or may impact negatively on certain interventions, and raise other flags. But as far as gender, they are based on whatever the patient tells the doctor—or sometimes what the doctor assumes, based on the patient's appearance, which can cause issues. "If you choose to make all decisions based on 'gender identity' or 'assigned gender at birth' alone, you can miss information that could lead to severe outcomes," she says.

## Transgender patients need to seek out supportive doctors

Experts hope that as more doctors are trained in transgender care, it will get better. For now, <u>transgender people</u> will have to be persistent about seeking supportive doctors who are sensitive to their issues. "This is often uncharted territory for many providers," Dr. Boulware says, adding that most doctors won't have specialized training. "So, it often falls on patients' shoulders to educate themselves."

Dr. Kallen adds that, "This is a hard part. But at the end of the day, preventive screening is a critical part of overall health care."



For transgender individuals, a local organization that is sensitive to LGBTQIA+ issues may be able to recommend a provider, Dr. Kallen says. "It also can end up being a lot of word of mouth, asking around about providers who might be welcoming," she says.

Meanwhile, there are simple, common-sense changes any provider can make, says Olezeski. "You can think about what the medical questions are that you would ask anybody about—or anyone with these particular organs," she says. "Or you can tell a patient why you need to do a particular test or exam and offer the option to opt out, as there might be previous trauma."

And, if a doctor still doesn't feel knowledgeable enough, they can refer the patient to another doctor who has more experience in transgender care.

"But it's important to consider that pushing this to specialist care may make wait times longer; the solution here is more training and education across the board," says Kronk.

Olezeski agrees. "It's really important to be aware. Even a negative meeting at the receptionist's desk can stick with people. We need to be kind and respectful to all of our patients," she says.

**More information:** Clair Kronk et al, Transgender Data Collection in the Electronic Health Record (EHR): Current Concepts and Issues, *Journal of the American Medical Informatics Association* (2021). DOI: 10.31235/osf.io/qnc2g

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