healthcare BILLOFRIGHTS HealthcareBillOfRights.org

Your personal life and relationships affect your health more than you realize, so your doctor and other providers need to know your story.

We should **all** feel safe talking about our sexual partners, sex lives, sexual orientation, HIV status, and gender identity.

LEARN MORE AT HEALTHCAREBILLOFRIGHTS.ORG

- Learn how to file a complaint if you've faced discrimination.
- See how you can find a medical provider who will respect your rights and identity.
- Read how you can plan for your future care with a healthcare power of attorney.



RIGHT TO BE TREATED WITH EQUALITY AND RESPECT

• You deserve to be treated with respect and made to feel welcome no matter who you are.

Currently, there is no federal law that directly says a healthcare provider cannot discriminate against someone because they are LGBT. However, the Affordable Care Act (or Obamacare) <u>bans</u> <u>discrimination on the basis of sex</u>, which courts and government agencies are increasingly coming to see <u>as including</u> gender identity and sexual orientation. You can even <u>submit a complaint</u> to the Department of Health and Human Services if you feel you've been discriminated against in this way.

Some states and local jurisdictions have even stronger protections for LGBT people seeking healthcare. Many states have an Office of Civil Rights or Office of Human Rights that can take on discriminatory healthcare providers. Connecting to a <u>local LGBT community center</u> or a lawyer can help you learn about all the options where you live.

Additionally, the Joint Commission – which accredits healthcare providers – requires them to have a nondiscrimination policy that includes LGBT discrimination. If the provider does not, you can <u>file a</u> <u>complaint</u> with the Commission.

• You have a right to not be denied service or given inferior service.

You deserve to receive the best possible care, and your healthcare providers have a duty to provide it, especially in an emergency. Although a doctor does not have to accept new patients in a non-emergency, and every individual you encounter may not always be perfectly polite, there are many laws and regulations that might prevent a provider from being able to turn you away for being LGBT. If you have been given poor care or denied care, and you think it is because you are LGBT, you should visit our <u>get help page</u> to try to find a new, LGBT-friendly provider, and to learn how to file a complaint against a discriminatory provider.

RIGHT TO AFFIRMATION OF YOUR TRUE GENDER IDENTITY

• You deserve to be called by your chosen name and gender pronoun and to include these preferences in your advance directive (see below).

For individuals who are transgender or gender-nonconforming, it is important for a doctor or nurse to know about your specific medical needs, since they may not always be obvious. For example, a transman may need different cancer screenings than a cisman would. Because gender identity makes a difference in the kind of care a person needs, it is especially important that you feel safe talking with your doctor, nurse, and other providers about this – and that they show you respect in turn.

If a provider refuses to treat you with respect based on your gender identity, it could amount to discrimination on the basis of sex, and thus be illegal under the Affordable Care Act (or Obamacare). You can <u>learn about filing a complaint</u> with the Department of Health and Human Services, which enforces this antidiscrimination part of the law.

You also have a right to include instructions about your gender identity and expression in your advance directive, a document that gives orders to your doctors in the event of an emergency, and tells doctors who gets to make emergency decisions for you. Scroll down to learn more about your right to have an advance directive. You can also learn all about how to tailor an advance directive to include trans-specific protections.

• You deserve to be able to use the gender-based facilities of your choice.

If a provider refuses to let you use the gender-based facilities of your choice based on your gender identity, it could amount to discrimination on the basis of sex, and thus be illegal under the Affordable Care Act. You can <u>learn about filing a complaint</u> with the Department of Health and Human Services, which enforces this antidiscrimination part of the law. Also keep in mind that you may have additional

protections under state or local law; for example, in Washington DC, the Human Rights Commission helps ensure that transgender individuals have appropriate access to restrooms. Connecting with your <u>local LGBT center</u> or a lawyer can help you to understand what rights (and ways of enforcement) are available in your area.

RIGHT TO HELP DESIGNATING WHO WILL MAKE DECISIONS FOR YOU

 As soon as you are admitted, you have a right to be told how to create an advanced directive – and you have the right to pick whoever you want to be your decisionmaker.

You can learn all about healthcare planning and advance directives for LGBT people here.

An "advance directive," also known as a healthcare power of attorney, is a legal document that names who can make medical decisions for you in case of an emergency. For example, if you need to undertake surgery and will be unconscious during and after, the advance directive will say who gets to talk to your doctors and make choices that arise while you are incapacitated.

Advance directives are <u>especially important for LGBT people</u> because otherwise healthcare providers might be reluctant to recognize our partners, spouses, children, families of choice, or friends as the "right" decision-maker. Additionally, many LGBT people do not want their legal next-of-kin (usually a parent, sibling, or adult child) to be their decision-maker because that person may be estranged from them or may not respect their orientation or gender identity.

Federal regulations require hospitals, nursing homes, and home health aides to give you information about how to create an advance directive under state law (this regulation is cited as 42 CFR § 489.102). You can also learn more about creating an advance directive online, but because they vary by state law, it is best to have a healthcare provider or better yet an attorney assist you. If you are transgender or gender-nonconforming, <u>this guide</u> explains how you can tailor an advance directive to include gender identity-related protections.

You can name *anyone you want* to be your healthcare power of attorney (meaning the one who makes decisions for you). You do not have to be married or "biological" family. You should name someone who you trust to be a good advocate and who knows you well.

Often, an advance directive also includes a "living will" – a document that says what kind of care you would like to receive if you were ever in a terminal condition. For example, you can state whether you would want to be kept alive using a feeding tube and assistive devices, or would prefer to be kept comfortable and allowed to pass away naturally. These documents are especially important for LGBT people because providers may second-guess what our decision-maker has to say (for example, a provider might not trust a same-sex spouse to make this choice because of an anti-gay bias). You can <u>learn more about living wills</u> and should make sure this information is either included in your advance directive or completed in an additional, legally-valid document – meaning talk to a lawyer if possible.

RIGHT TO VISITATION BY ANYONE YOU CHOOSE

• You have the right to be visited by anyone you choose (regardless of your legal or biological relationship) at any reasonable time.

Following action by the Obama administration, federal law (specifically a regulation cited as 42 CFR § 482.13) requires hospitals to allow visits from anyone a person chooses; the rule specifically states that all spouses and domestic partners, including of the same sex, are included in this policy. Additionally, this rule forbids hospitals from discriminating against visitors on the basis of gender identity, sexual orientation, or disability (which includes HIV status).

If you are in a nursing home, your right to have visitors – whoever you want and whenever you want to see them – is even stronger than in a hospital because for some people that facility becomes their long-term home. Residents are given a broad right under the Nursing Home Reform Act to have any reasonable request for a visitor to be granted. The facility cannot limit visitors to certain hours and not permit exceptions.

• If denied a visitor, you can ask the facility to show you the rule that prohibits that visitor.

The same regulation noted above (42 CFR § 482.13) also requires hospitals to have written visitation policies and to notify each patient about their rights. Even if you are not sure that the hospital is "discriminating" against you, you can prove that they are in the wrong if their own rules say they should be admitting visitors in that situation.

Hospitals also have to apply the rules equally to everyone, so if opposite-sex partners are allowed to visit at a certain hour, they cannot then deny a same-sex partner the same privilege.

RIGHT TO YOUR PRIVACY

- You have a right to the privacy of your medical records and care under a law known as HIPAA the Healthcare Insurance Portability and Accountability Act.
- Your doctors and nurses can only share your medical information if it is necessary to provide you with care, or if you give them permission to share it with others.

HIPAA is a law that protects the privacy of healthcare information. The law is very strong in what it includes – even gossip between one healthcare worker and another could be considered a violation if sharing that information was not necessary in providing you with care. If a nurse or doctor decided to share information about you with someone who was not a healthcare worker at all – for example, telling another patient – that would almost certainly be a violation. And the law even allows you to tell a doctor, nurse, or other healthcare worker that you do not want information shared with a certain individual or group of people, just to be absolutely clear that you want your privacy respected.

Privacy can be an especially big issue for transgender individuals, as healthcare employees sometimes think that they can get away with gossiping about private information. For example, cases exist of a nurse waiting for a trans individual to leave a room, and then exclaiming personal information about that person's gender identity or sex assigned at birth. Not only is this disrespectful and unprofessional – it's illegal.

It is possible to file a complaint against a provider that you think has violated your healthcare rights. Visit our <u>get help page</u> or <u>click here</u> to go to the Department of Health and Human Service's HIPAA complaints website.

And maybe the best part of HIPAA is that even saying it out loud (it's pronounced "HIP-uh") can get you results. For example, if you think a provider is saying more than they should to others about your personal information, saying you want to talk to someone at the facility about HIPAA compliance is likely to get any employee to rethink their actions quickly.

RIGHT TO PROTECTIONS IF YOU ARE DISCHARGED DUE TO DISCRIMINATION

• You have a right to protest being discharged or transferred from a hospital, rehabilitation facility, assisted living facility, or nursing home.

Discrimination is not always obvious or easy to prove. Sometimes a facility might find an excuse to discharge you (meaning, kick you out) or transfer you (meaning, move you to a different facility). You may not be able to prove that it was done with a discriminatory intent, but you still might be able to

challenge the discharge or transfer because treatment facilities have very particular rules they have to follow when they end care.

If you are in a hospital, federal regulations (cited at 42 CFR § 482.13(a)(1)) require that the hospital inform the patient or their representative of the patient's rights before discontinuing care "whenever possible," which includes all but emergency situations. If you are in a nursing home, the Nursing Home Reform Act (cited at 42 U.S.C. § 1396r(c)(2)(A)) gives facilities only a few acceptable reasons to discharge a patient.

If you feel you're being discharged or transferred improperly – due to discrimination, or for any other reason – tell the facility you want to appeal the decision. See the subsection immediately below for more on filing an appeal.

• You have the right to get information on how you can appeal the decision, and to have time to figure out where you will go when you are discharged.

As the subsection immediately above explains, facilities have to give you your rights when they attempt to discharge or transfer you. At that time, you will be able to request an appeal of their decision to make you leave.

The exact process will vary greatly depending on what type of a facility you are at (such as a hospital versus a nursing home), what type of insurance you have (because some, like Medicare, have their own process), and the laws of your state. But the facility has the duty to provide you with information on how to do it. It is likely that the first level of appeal will be speaking to a designated person within the facility, and if that office refuses to stop the discharge or transfer, the process would move to an external entity.

If you think that you are being discharged or transferred because of someone's anti-LGBT bias, you should say so during this process. Also be ready to say why you are not medically ready to be discharged or transferred.

At the very least, appealing the decision will likely buy you a few days more at the facility while the appeal is being considered. Use this time to come up with a back-up plan. If you are being transferred, try to determine if the potential new facility is LGBT-friendly; our <u>get help page</u> has some resources that may help you find a provider that serves LGBT people well.

No facility is allowed to discharge or transfer you without giving you notice and creating a plan for what will happen after you leave, and if they have not done so, that alone is enough to appeal the decision. For example, discharge from a nursing home is supposed to happen over the course of a few days so that the facility can create a plan for you to get the care you need when you leave the facility and go home; they are not permitted to simply tell you to get out.

If all the appeals processes fail, you can visit our <u>get help page</u> to learn about other ways to have an advocate work on your behalf – either to get you to stay, or to at least hold the facility accountable after the fact.