



KNOW YOUR RIGHTS: HIV AND PREGNANCY

Women who are HIV-positive and pregnant or considering becoming pregnant often face judgment and discrimination from the very medical care providers they rely upon to keep them healthy. This resource provides a brief review of the rights of pregnant women living with HIV to access non-discriminatory health care and to make informed decisions based on medically sound, understandable, and accurate information. **This resource does not constitute legal advice, and an individual with a question about the law or their particular circumstances should speak with an attorney.***

- **You have the right to informed consent before you undergo any specific medical treatment or procedure, and to choose or refuse treatment based on what you think is right for you.** Pregnant women living with HIV often face choices about treatment to reduce the possibility of transmitting HIV to their children while pregnant or during childbirth. Such treatment choices include anti-retroviral drugs during pregnancy and birth, and a Cesarean surgery (or “C-section”) birth. Your health care provider must obtain your informed consent before providing you with any treatment.
 - Informed consent is a process of communication between the health care provider and the patient, in which the health care provider must disclose:
 - Your diagnosis, if the health care provider knows it;
 - The nature and purpose of a proposed treatment or procedure;
 - The risks and benefits of a proposed treatment or procedure;
 - Your alternatives, regardless of their cost or whether they are covered by health insurance;
 - The risks and benefits of alternative treatments or procedures; and
 - The risks and benefits of not receiving or undergoing a treatment or procedure.
 - You should have an opportunity to ask questions to get a better understanding of the treatment or procedure, so that you can make an informed decision to accept or to refuse a particular type of medical treatment.
 - Although there are some emergency exceptions to the informed consent rule, being in labor is not automatically this kind of an exception—you have the right to informed consent in labor and delivery.
 - Informed consent is a legal requirement spelled out in the law in all 50 states. It is also an ethical duty that health care providers have when they provide you care.

- **You have the right to be told you are receiving an HIV test before you are tested, and, except in very rare circumstances, to refuse an HIV test.** HIV testing is recommended for all individuals who have engaged in any activity—sex or sharing needles—that puts them at risk. It also is recommended for pregnant women in particular because, if you know you have HIV, you can make decisions about treatment to reduce the risk of mother-to-child HIV transmission during pregnancy and birth. However, whether and when to get an HIV test should be your individual choice.

* For help in locating a lawyer who can advise you on your rights and your situation, go to <http://www.hivlawandpolicy.org/resources/view/4>, for an online directory of HIV legal services offices, or go to <http://www.abanet.org/legalservices/findlegalhelp/home.cfm> to search the ABA’s online directory of free legal services programs across the country. You also can contact your local HIV/AIDS service organization for assistance in getting a referral to a legal services provider.

- Depending on your state law, your state may require the health care provider to get your specific consent before testing (“opt-in” testing), or the state law may only require the health care provider to let you know you will be tested and give you the option to “opt-out” of having an HIV test.
 - Unfortunately, a small number of states—Arkansas, Alabama, and North Carolina—allow (or even require) health care providers to test pregnant women without their consent, and a few states (e.g., New York) also require that your newborn baby be tested for HIV immediately after birth.
 - Websites such as <http://www.nccc.ucsf.edu/StateLaws/Index.html> outline each state’s testing laws, including prenatal testing, so you can know your rights and insist that your health care provider follow the law. Health care providers sometimes misunderstand or ignore their state law requirements to get your consent or provide you with counseling about your HIV risk and how HIV is transmitted. It might even help to bring a copy with you when you see your health care provider.
- **You have a right to have your HIV status remain confidential.** Your health care provider cannot tell your HIV status to anyone else (including your spouse, significant other, family, or employer) without your consent. They cannot, for example, mention your status when others are in the room. Most states do allow a health care provider to notify your known sexual partners (including a spouse) that they have been exposed to HIV, but typically they are not allowed to reveal your name.
- **You have the right not to be denied medical treatment because of your HIV status, or to be discriminated against in your medical treatment because of your HIV status.**
 - Your health care provider cannot turn you away because of your HIV status, tell you it is “too dangerous” to treat you, or give you worse care than other patients because you are living with HIV.
 - Your health care provider cannot refer you to another provider just because you are HIV-positive. One court has ruled that a physician can refer an HIV-positive pregnant patient to another hospital or physician with more experience, but this is only under rare circumstances, and must be based on your individual medical situation, not just your HIV status. For example, if your health care provider never treats individuals living with HIV, this is evidence of discrimination, which is illegal.
- **If you are pregnant, you have the right to make the choice to continue your pregnancy or have an abortion without being pressured or coerced by anyone.** You are in the best position to determine the right choice for you.
 - HIV does not mean that women should avoid having children. In fact, a recent study found that HIV-positive women who become pregnant stay healthier than those who do not. Also, being HIV-positive does not mean your child will necessarily develop HIV. Even without any medical interventions, the mother-to-child transmission rate is about 25%, and appropriate medical interventions can reduce this to less than 2%. The risk that you will transmit HIV to your baby depends on your individual health circumstances, such as your HIV viral load (if it is very low, then the risk of transmission to your baby also is very low).
 - Abortion is also safe for HIV-positive women, and it is your right to determine whether or not you want to continue the pregnancy.
 - No one—especially a health care provider—should try to use coercion, guilt, shame, or your HIV status to persuade you to have an abortion or to continue your pregnancy.

For more information about HIV and pregnancy, go to The Center for HIV Law and Policy’s Women’s Advocacy Resource Connection, at www.hivlawandpolicy.org/resourceCategories/view/35, where you can find more detailed articles about the rights of women with HIV, and links to other organizations that have materials on pregnancy and HIV.