



*and*

# Confidentiality

**YOUR LEGAL RIGHTS**

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*published by:*



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This is one in a series of booklets published by the AIDS LEGAL COUNCIL OF CHICAGO. All are designed to help you understand YOUR LEGAL RIGHTS in Illinois. The booklets in this series are:

*HIV and Confidentiality*

*HIV and Discrimination*

*HIV and Insurance*

*HIV and Public Benefits*

*HIV and Undocumented Immigrants*

*HIV in the Workplace*

*HIV: Issues for Families with Children*

*HIV: Issues for Youth and Young Adults*

*HIV: Returning to Work*

*HIV: Wills and Powers of Attorney*

All of these booklets are free and available at:

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This guide is intended as an overview of HIV-

# HIV AND CONFIDENTIALITY

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## INTRODUCTION

When you tested HIV positive, people may have told you that you were required to tell your boss, your dentist, or your family. If you have a child who is HIV positive, you might have heard that you have to tell the principal of your child's school. None of these statements is true. With very few exceptions, **your HIV status is nobody's business but yours.** In addition, your HIV status is confidential according to Illinois law, which means that almost no one can disclose your HIV status without permission from you.

This booklet is designed to answer your questions about confidentiality. If you have more questions after you're done reading, you can call the AIDS LEGAL COUNCIL OF CHICAGO at **(312) 427.8990**. Someone there will be happy to speak with you.

## Chapter One

### GETTING AN HIV TEST

#### **1) Under Illinois law, am I required to take an HIV test?**

Generally, no. HIV testing is not mandatory for the general public in the state of Illinois. In fact, it is not mandatory in any state.

However, there are a few situations in which people are required to be HIV tested. For example, anyone entering the military must be tested for HIV. Anyone convicted of certain sexual crimes must be tested for HIV. But for private citizens not involved in the military or the criminal legal system, no law requires an HIV test.

#### **2) If I apply for life or health insurance, can the insurance company require me to get an HIV test?**

If you apply for life insurance, the company can require you to get an HIV test before they sell you the policy. But if you are applying for health insurance, your HIV status doesn't make any difference and the company can't test you (or even ask you) your HIV status before selling you the policy.

#### **3) Do I have to get an HIV test to apply for a marriage license?**

No. There was a law in Illinois in 1986 which required people applying for marriage licenses to submit to HIV tests. But that law was repealed a year

later when it became clear that testing all marriage applicants was an enormous waste of time and money.

#### **4) Do I have to get an HIV test if I'm pregnant?**

The law says your doctor must *counsel* you about HIV, and the doctor must test you for HIV *unless you refuse*. Once your baby is born, the law says that your doctor is supposed to test your baby for HIV within 48 hours *only if your HIV status is unknown*. So if you refuse to get an HIV test yourself, then your baby will be tested.

#### **5) Can I get an anonymous test?**

Yes. You have a right to get an HIV test without giving your name. You can get an anonymous HIV test at most public health clinics.

#### **6) What's the difference between an anonymous HIV test and a confidential HIV test?**

An **anonymous** HIV test is one that does not have your name attached to it. Sometimes you will give the person taking the test a code to identify yourself, like a string of numbers. But when you test anonymously, your name should not appear on the test result. No one could use that test result to prove your HIV status.

A **confidential** HIV test **does** have your name on it. But the test result must be kept confidential, in accordance with Illinois law. In other words, the test result with your name on it will end up in your medical records, but no one can see your records without legal authorization.

## 7) I'm 15 years old. Can I get an HIV test without telling my parents?

Yes. In Illinois, anyone **12 or over** can get an HIV test **without** having to tell their parents or guardians. You don't need anyone's permission to get an HIV test, or a test for any sexually transmitted disease. For more information, see the Council's booklet *HIV: Issues For Youth and Young Adults*.

## 8) Can a doctor test me for HIV without telling me?

Generally, no. The Illinois AIDS Confidentiality Act says that no physician may order an HIV test without first obtaining the **documented, informed consent** of the test subject. In other words, the laws say that the person testing you for HIV must first ask for your consent, and document the fact that you agreed to have any HIV test. Without that consent, the doctor is not supposed to test you for HIV.

However, there is a big exception to this law. The exception says that if a doctor believes it is necessary to test you for HIV in order to diagnose and treat your symptoms, then he can test you without your consent. The AIDS Legal Council believes this exception is bad public policy. The Council believes that a doctor should **always** get consent from a patient before testing for HIV, so long as the patient is able to consent. Unfortunately, the exception to the law gives physicians permission to test a lot of people for HIV without telling them.

So if you go to the doctor and you do not want an HIV test, make sure to tell your doctor so. It would be a good idea to tell your doctor **in writing** that you don't want an HIV test.

**9) Can anyone ever legally test me for HIV against my will?**

Yes, but only in a few certain circumstances:

- ◆ If you have been involved in a blood accident with a health care worker, police officer or paramedic.
- ◆ If you are convicted of a sex crime
- ◆ If you are entering the military

## Chapter Two

### DISCLOSING HIV TEST RESULTS

#### 1) If I test positive for HIV, who will know the results?

The answer depends on whether you test **anonymously** or **confidentially**.

If you test **anonymously**, that means your name is not written on the test result. So the only person who knows your test result is the health care worker who informs you. There is no other record of your HIV test. No one else will be informed. It is the same as taking an HIV test you bought at the drugstore in the privacy of your own home.

If you test **confidentially**, then your name and certain other information will be reported to the department of public health. Public health departments have very strict rules about the confidentiality of information reported to them.

#### 2) If I test positive, does my doctor have to give my name to the Department of Health?

Yes. Illinois law requires that doctors report the names of their patients who test HIV-positive to the Department of Health.

#### 3) If I am a high school student and I test HIV positive, is my school informed?

No. That used to be the law, but the law was changed in 2013. No one at your school will have to know your HIV status unless you or your parents (if you are under 18) decide to tell them.

**4) If I test HIV positive, does my doctor have to tell my spouse, civil union partner, or sexual partner?**

No. The only sexual partner your doctor is allowed to tell is your legal husband, wife, or civil union partner. Even then, the doctor must first give you a chance to tell your spouse or civil union partner yourself. If you don't tell your spouse or civil union partner, then your doctor can tell them. But even then, he is **not required** to tell them. If you are afraid you will be hurt or homeless if your spouse or civil union partner finds out you are HIV+, be sure to tell your doctor.

The law does **not** allow your doctor to inform any sexual partner except your legal spouse.

**5) If I test HIV positive, does my doctor have to tell my family or my roommate?**

No. In fact, your doctor would be in violation of the law if he told your family or your roommate that you were HIV positive without getting permission from you first. It is **your** decision whether or not to tell your family or roommate about your HIV status.

**6) If I test HIV positive, does my doctor have to tell my employer?**

Absolutely not. Most people who test HIV positive do not want their

employer to know, because they are worried that their employer might discriminate against them. **Your doctor has no right to disclose your HIV status to your employer without your permission.** For more information on your rights as an employee, see the Council's booklet *HIV in the Workplace*.

**7) If I test HIV positive, do I have to tell anyone when I have sex or share needles?**

Sometimes. Illinois law says you have to disclose your status if you are having anal or vaginal sex without a condom ("barebacking"). If you have anal or vaginal sex without a condom and do not tell your partner you have HIV, you can be convicted of criminal transmission of HIV, even if your partner does not get infected. You can also be convicted of criminal transmission of HIV if you share needles without disclosing your status. Again, it doesn't make any difference if the person you shared needles with actually gets HIV or not.

The good news, though, is that you don't have to share your HIV status if you are practicing safer sex. For example if you are having intercourse but using a condom, or if you are having oral sex, you do not have to disclose your HIV status to your partner.

**8) I don't think I can bring myself to tell my sexual partners that I'm HIV positive. But I'd feel better if someone told them to get tested. Is there any way this can happen without using my name?**

Yes. Your local department of health can notify your sexual and needle-sharing partners that they may be at risk for HIV, but they won't disclose

your name. If you want the department of health to do this for you, you should call your local office and tell them you want to cooperate with their **voluntary partner notification program**. You will go down to the health department office and meet with a worker who will talk to you about your sexual and needle-sharing history. That worker will determine which of those people should be notified about the risk of HIV infection, and will contact those people. **But the worker will not disclose your name.**

## Chapter Three

### CONFIDENTIALITY AND YOUR HIV STATUS

- 1) My boyfriend and I had a big fight. Now he is threatening to tell my family and neighbors that I'm HIV positive. Can he do that?**

Legally, he cannot. The **Illinois AIDS Confidentiality Act** states that **no person** can disclose your HIV result without permission from you. So if your boyfriend starts telling people that you are HIV positive, and you have not given him permission to do so, he is breaking the law.

- 2) What can I do to stop someone from telling other people I'm HIV positive?**

One thing you can do is make it very clear to that person that any unauthorized disclosure of your HIV status is a violation of the law. The Illinois AIDS Confidentiality Act says that each time someone intentionally discloses your HIV status, that person can be fined \$10,000 by the courts. If this person is threatening to tell five people about your HIV status, he might be liable for \$50,000 in damages!

**3) I have insurance through work. If I file an HIV-related claim, can the insurance company tell my employer I'm HIV positive?**

Your employer should not find out about your HIV status. A federal law called the **Health Insurance Portability and Accountability Act (HIPAA)** generally prohibits an insurance company from disclosing confidential information to your employer. However, the insurance company will probably disclose the claims history to your employer. This means your employer will be told what types of health conditions people have who are insured under the group policy – without being told who those specific people are. So if you work for a small company, and your employer finds out that one person on the group health insurance plan has HIV, your employer may guess who that person is.

**4) I tested HIV positive in my doctor's office, and I don't want my insurance company to know. Is there a way I can hide my HIV status from my insurance company?**

The only way to prevent an insurance company from knowing your HIV status is to test anonymously. That way your name is never associated with the test result.

But if you don't test anonymously, and your HIV result ends up in your medical records, then you cannot hide your positive status from your insurance company. If your insurance company reviews your medical records at some point, your HIV status will be disclosed. But remember, since January 1, 2014, it has been illegal for insurance companies to discriminate against you because you have HIV.

## **5) I have to fill out an insurance form for my employer that asks me questions about my health. What do I say?**

These questions should go away soon, since it doesn't make any difference whether or not you have HIV, but if you are asked one, here are your answers.

If you work for a smaller company, then your employer is probably giving you a standard form called the "Illinois Standard Health Employee Application for Small Employers." If you look at Section F of that form, it tells you to talk to your employer if you prefer to submit the application directly to the insurance company or insurance broker. You can just say "I'd rather submit this directly like it says in Section F. Can you tell me how to do that?"

If you work for a very large company (say over 1000 employees), you should be okay, because they probably have other employees with serious health problems and their Human Relations Department probably knows the rules about keeping medical information confidential. But if you have any doubts, or you work for a smaller company, here are three ways that you might handle this.

- ♦ Put a big circle around the whole section that lists all the health conditions and write "various pre-existing conditions – full details available from my doctor" and give the doctor's name and phone number. Sign a form at your doctor's office that it's okay to tell the insurance company about your HIV, but not your employer.
- ♦ Tell your employer, "I know I'll be in trouble if I leave anything out on this form so I'm just going to take it to my doctor's office and have them fill it in. My doctor is a nut about privacy, though, and he'll want to fax it directly to the insurance company. Could you give me their fax number?" Then, whether or not you give it to your doctor,

fax the completed form to the insurance company yourself with a note that they must not share the information with your employer (which they already should know).

- ♦ Call the insurance company yourself and tell them your situation. Tell them you are going to fill out two forms – one for them with all the truthful answers, and one for your employer that leaves out your HIV and anything else you might be worried about disclosing (for example, mental illness). Get their fax number. Then tell your employer you need an extra form because you messed up on the first one. Fax the form with the true information to the insurance company. Turn the other one in to your employer.

## Chapter Four

### OTHER QUESTIONS

- 1) I'm worried that my partner may be HIV positive, but she refuses to get an HIV test. How can I make her get tested?**

You can't. Legally, she is not required to take an HIV test simply because she is in an intimate relationship. If she does not want to take an HIV test, she does not have to.

- 2) I know someone who is HIV positive, and he is having a lot of unsafe sex. Can I**

