Getting HIV Drugs in the US [1]

Submitted on Feb 3, 2023

Table of Contents

- Health Insurance in the United States
- Changes Due to the Affordable Care Act (ACA)
- Health Insurance Marketplaces
- AIDS Drug Assistance Program
- Medicaid
- Medicare
- Drug Company Programs
- Clinical Trials
- Buyers’ Clubs
- Seeking Help

Health Insurance in the United States

Health insurance covers some of the cost of prescription drugs, including HIV drugs. The most common way to get health insurance is to work for an employer who provides it. Some employers, especially small businesses, do not offer health insurance. If this is the case, you may be able to buy an individual insurance plan from an insurance carrier, whether directly or through a health insurance marketplace (see Health Insurance Marketplaces below).
Mail-order pharmacies can have benefits like lower co-pays and home delivery of medications.

If you do not work, or your employer does not offer health coverage, you can also check to see if you qualify for any public health insurance programs (see Medicaid and Medicare below). People living with HIV who need help paying for HIV drugs may qualify for medication coverage through their state drug assistance programs (see AIDS Drug Assistance Program below). Some clinics now have patient navigators, social workers, case managers, or insurance specialists; any of these professionals can help you get the coverage you need.

Most insurance plans include some drug coverage. However, co-pays add up. Some people choose to get their medicines from mail-order pharmacies. Mail-order pharmacies can have benefits like lower co-pays and home delivery of medications. However, it is important to realize that mail-order pharmacies – like local pharmacies – can make mistakes. When they do, it can take a few days for the correction to be made. You may want to speak to your insurance carrier and your health care provider about using a mail-order pharmacy to see if it is a good option for you.

Note: During the COVID-19 pandemic, which began in 2020, short-term relief legislation had expanded eligibility and added health insurance options. However, many of these changes are not permanent and are ending.

Changes Due to the Affordable Care Act (ACA)

The Affordable Care Act (ACA) was signed into law by then-president Barack Obama in 2010. The ACA provides for several changes that can dramatically improve the health of people living with HIV by increasing their access to health care. For example, it stops insurers from denying coverage to those with pre-existing conditions (such as HIV or pregnancy) and stops insurers from putting lifetime or annual spending limits on insurance benefits, which often affect those living with long-term conditions like HIV. The ACA has also increased women's coverage for reproductive health care (e.g., birth control, cervical cancer screenings).

The ACA creates health insurance marketplaces for people to buy affordable health insurance if they do not have access to insurance through their employer. It also provides for changes to many programs that already help people living with HIV get their HIV drugs, like Medicaid and Medicare.

It is important to note that, as of this writing, the ACA is still in effect. At the end of 2017, Republican lawmakers eliminated the ACA's requirement that nearly all individuals have health insurance or else pay a fine, commonly known as the individual mandate. The ACA itself is still very much alive, but specific provisions may change.

For more information, read about each of the specific programs below and see our fact sheet on The Affordable Care Act and Women in the US [2].

Health Insurance Marketplaces

If you do not have access to insurance offered by an employer and do not qualify for Medicaid, you can look for affordable health insurance through the health insurance marketplaces. These marketplaces for individuals and families are available either through your state, if it chose to set up a marketplace, or through the federal government, if your state chose not to participate. Click here [3] to learn more about enrolling in the federal marketplace.

For those who have trouble paying, there are federal tax credits and subsidies (money the government gives you) for people with low and middle incomes to help make the insurance premiums more affordable.
AIDS Drug Assistance Program

The Ryan White HIV/AIDS Program (RWHAP) includes the AIDS Drug Assistance Program (ADAP [4]), which is funded by the federal government to help pay for HIV drugs for people who might not be able to afford them otherwise. This fund may even be used to pay for health insurance premiums for eligible clients in some cases.

Each US state provides its own coverage, and your local ADAP office can let you know which drugs it pays for and what the income limits are for your state. If you become part of the ADAP program, you will need to recertify (show that you are still eligible for the program) every six months. Your local ADAP office can support you in this process as well.

In the past, some states have had a waiting list for ADAP. In other states, the ADAP program is big enough to cover not only HIV drugs, but also laboratory work, some medical care, and non-HIV medications, like those used to manage side effects and other chronic diseases.

The Ryan White program can also pay for doctor visits and support services for people living with HIV. In some instances, family members who are not living with HIV can receive support through a Ryan White program for women and/or children living with HIV. To find out more about the Ryan White program in your state, call your state’s HIV/AIDS hotline [5].

Medicaid

Medicaid is a government-sponsored insurance program that covers healthcare and medications. If you are disabled, not working, or earning little money, you may qualify for Medicaid. Like ADAP, each state has its own program so you will need to talk to a local Medicaid worker in order to apply. The ACA allows states to provide access to Medicaid for people living below 133 percent of the federal poverty level, though this guideline varies depending on the state. In addition, Medicaid eligibility is now determined based on income alone; disability status is no longer required.

Many of the states that have decided not to expand Medicaid are also the states with the highest numbers of people living with HIV.

It is important to note that only some states have chosen to expand their Medicaid coverage and change their eligibility requirements through the ACA. Many of the states that have decided not to expand Medicaid are also the states with the highest numbers of people living with HIV. To see a list of which states have chosen/not chosen to expand Medicaid coverage (updated regularly), go here [6].

If you are pregnant [7] and living with HIV, check to see if you qualify for Medicaid. In order to provide HIV treatment and prenatal care, income limits are increased for pregnant women. Medicaid may pay for your prenatal care, including counseling and medicines to prevent you from transmitting HIV [8] to your baby. You may be able to stay on Medicaid for some time after you deliver your baby – how long depends on the rules in your state.

Medicare

Medicare is a government-sponsored insurance program for people over 65 and those who are disabled or blind. Part D of Medicare pays for medications. The ACA will gradually close the gap in Medicare's prescription drug benefit (Part D), known as the "doughnut hole." The doughnut hole refers to the amount between total drug costs (what you and your plan spend on medications) and a person's total out-of-pocket spending maximum for the year (this includes any co-pays, co-insurance, and deductibles). In addition, ADAP payments for prescription drugs are now considered contributions toward the True Out of Pocket Spending Limit (TrOOP) for Part D, which means that people can move through the doughnut hole more quickly.

Facebook
For more information on ADAPs, Medicaid, and Medicare, see the Health Benefits section of our fact sheet on [Public Benefits and HIV in the US](https://www.thewellproject.org) [9].

**Drug Company Programs**

Drug companies run Patient Assistance, Expanded Access, and Compassionate Use Programs. Each company has its own rules for deciding how the program works. Your health care provider will need to complete forms in order for you to apply.

Patient Assistance Programs help people get medications that are already approved by the US Food and Drug Administration (FDA). If you qualify for the program, you will be able to get your HIV drugs without cost. Patient Assistance Programs are usually a short-term solution until another way of paying for the drug is arranged. However, this can be helpful if you are waiting for insurance or government benefits to begin.

Expanded Access and Compassionate Use programs provide drugs that are not yet FDA-approved to people who are at serious risk of illness or who have no other way to construct a good treatment regimen. The drugs are provided free of charge by the companies developing them through participating health care providers.

A company will often create an Expanded Access Program just before the drug is about to be accepted by the FDA. The rules are the same for everyone using the program, while with Compassionate Use Programs, each case is looked at individually.

**Clinical Trials**

In some cases, you can get HIV drugs free of charge through a clinical trial [10]. However, drugs being tested in clinical trials may not be FDA-approved, so there is some risk involved in taking an experimental treatment. You will also need to meet the entry requirements of a trial in order to be allowed to participate and you may not have control over which drugs you receive.

Clinical trials are important because they determine if a drug is safe and effective. Some HIV drugs affect women’s bodies differently than men’s. If you take part in a clinical trial, you will help people know more about how HIV and HIV drugs affect women.

Being in a trial can mean answering extra questions and taking more time at your provider’s office or clinic. Before joining a trial, make sure that it is the right decision for you. If you are joining primarily to have access to HIV drugs, speak to your health care provider and get all the facts before relying on this method to get your medications.

**Buyers' Clubs**

Buyers’ clubs sell complementary treatments [11] and supplements [12] at prices generally lower than retail. Many of them are nonprofit and some offer financial assistance if necessary. If you use supplements, buyers’ clubs can help cut costs.

**Seeking Help**

It is important that you not take a friend's drugs even if they are the same as yours.

Some community organizations have money to help people in an emergency get the drugs they need on a short-term or one-time-only basis. Your local ASO may have a program that can assist you while you are waiting for insurance or government benefits. Click here [13] to find an ASO in the US.

Facebook
It is important that you not take a friend's drugs even if they are the same as yours. Your friend will run out early and may not be able to get the prescription refilled. In addition, it is best to take only drugs that were meant for you.

If you are having trouble getting your HIV drugs, talk to your health care provider before you run out. He or she may have samples of drugs that will last you until a prescription program starts.

It can be awkward or embarrassing to ask for help. However, taking your HIV drugs is the key to living a long, healthy, and productive life with HIV. If you cannot afford your HIV medications, it is important that you ask your provider, treatment advocate, case manager, or representative from a local AIDS service organization to help you find short- and long-term options for getting the HIV drugs you need to stay healthy.

Tags:

Getting HIV drugs [14]
ACA HIV [15]
Affordable Care Act HIV [16]
HIV insurance [17]
HIV Buyers clubs [18]
HIV clinical trials [19]
ADAP [20]
AIDS Drug Assistance Program [21]
Ryan White [22]
Medicare HIV [23]
Medicaid HIV [24]
Health Insurance Marketplaces HIV [25]
HIV drugs [26]
HIV treatment [27]
HIV patient assistance programs [28]
HIV compassionate use [29]
HIV Expanded access [30]
HIV drug company programs [31]

Additional Resources

Select the links below for additional material related to getting HIV drugs.

HIV Drug Assistance Programs (POZ) [32]
Needy Meds [33]
Available Care & Services (US Health Resources & Services Administration) [34]
About ADAP (ADAP Advocacy Association) [35]
Plan Finder (HealthCare.gov) [36]
Summary of the Affordable Care Act (Kaiser Family Foundation) [37]
Pennies from Above (Positively Aware) [38]
The Cost of HIV Treatment (Healthline) [39]
Paying for HIV Care and Treatment (HIV.gov) [40]
List of Drug Co-Pay and Assistance Programs (VeryWell Health) [41]
HIV Medication Assistance Programs (AIDS Education & Training Center Program) [42]
Continuing HIV Treatment When You Change Jobs or Lose Insurance (GoodRx Health) [43]
How to Navigate HIV Care If You Don't Have Insurance (healthline) [44]