

HIV

After Diagnosis

A Detailed Guide for Patients



DAP Health Center



Dear Client:

We know it is not easy receiving the news about your HIV diagnosis. It's normal to feel a wide range of emotions and be concerned about achieving and maintaining good health. By coming to Desert AIDS Project (DAP), you have already taken the first step in managing your HIV. You have also made the right choice—we have been helping people from all walks of life thrive with HIV since 1984.

Over these nearly 40 years, we have learned that medication alone is not enough to treat HIV. You will need good nutrition, regular sleep, and emotional support. We have a dedicated team to help you make sure these and other important elements of your care are in place so that you can focus on living a healthy, purposeful life with dignity.

Our team can also help link you to resources for housing, employment, and insurance coverage. Resources such as food and transportation assistance are also available based on your need and income.

We hope this guide answers your initial questions about living with HIV, but your clinician is the best resource to help you build a sense of safety around being HIV-positive. You can also find more information and resources at www.desertaidsproject.org.

Today, HIV can be a manageable health condition like diabetes, as long as you receive competent healthcare. The whole team at DAP wants you to know that we are here for you every step of the way!

Sincerely,

David Brinkman, MBA
Chief Executive Officer
Desert AIDS Project



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Newly Diagnosed With HIV: What You Should Know

What is HIV?

HIV stands for Human Immunodeficiency Virus. The virus can lead to Acquired Immunodeficiency Syndrome (AIDS) if not treated. HIV attacks the body's immune system, specifically your CD4 cells (T cells). CD4 cells help the immune system fight off infections. Untreated, HIV reduces the number of CD4 cells in your body making you more likely to get other infections or infection-related cancers. AIDS is diagnosed when a person's CD4 count is less than 200. Over time, and without treatment, HIV can destroy so many of these cells that the body can no longer fight off infections and diseases. These opportunistic infections or cancers take advantage of a very weak immune system and signal that a person has AIDS, which is the last stage of HIV infection.

What does an HIV diagnosis mean?

If you have been diagnosed with HIV it means that you were exposed to the virus and a test has shown that you are now living with HIV in your body. You will not be able to get rid of HIV completely, even with treatment. Once you have HIV, you will live with it for the rest of your life. However, there is a lot of hope.

The medication we have today, and the combination of drugs called antiretroviral therapy (ART), allows millions of people living with HIV (PLWH) to lead full lives, as if they only had a health condition like diabetes. If you get on ART quickly, and work with your clinician on a plan for your overall health, you will be taking a major first step towards thriving with HIV.

What does viral load mean?

The amount of virus present in your blood is called viral load. The less virus present in your body, the less damage HIV can do. Taking HIV medication as prescribed can make your viral load very low. This is called viral suppression. While you will still have the virus in your body, treatment can reduce the viral load to a level that is so low testing cannot detect it in your body fluids. This is called an undetectable viral load, and this is the goal you want to reach.

Is there a cure for HIV?

No cure currently exists, but if your viral load stays undetectable, you can live a long, healthy life and have effectively no risk of transmitting HIV to an HIV-negative partner. Before the introduction of ART in the mid-1990s, people with HIV could progress to AIDS in just a few years. Today, someone diagnosed with HIV and treated before the disease is far advanced—and who takes their medication every day—can potentially live as long as those not living with HIV.

How do I find HIV care and treatment?

Our Early Intervention Specialists (EIS) are experts in helping you access healthcare and support services. You will be given the choice of getting your HIV healthcare at DAP or from a different organization based on your preference. If you choose DAP, an EIS expert will provide education and help you overcome any barriers to getting care, like transportation issues. If you already have a clinician you wish to stay with, DAP is happy to work with them to ensure your HIV healthcare needs are fully addressed.

Where can I find an HIV clinician?

DAP has been helping people in the Coachella Valley live with HIV for almost 40 years. We would love to be your clinician so that we can share our expertise with you in the effective management of your HIV. You can also locate trusted HIV-care clinicians throughout California and across the U.S. by visiting:

- www.hiv.gov
- www.findhivcare.hrsa.gov

When choosing a clinician make sure to confirm they accept your health insurance plan.

Is HIV different for transgender and non-binary people?

If you are transgender or non-binary, you may have already experienced difficulty in your medical care. It can be difficult to find a clinician who has the experience and mindset to provide competent transgender healthcare. Now that you are living with HIV, it is very important that you find a clinician who has the knowledge and attitude to embrace transgender and non-binary clients who also have HIV. You will need a clinician who can support you wherever you are in your gender journey, while also setting you up to thrive with HIV. Living with HIV does not have to alter your surgical or hormone treatment plans. However, because certain cancers and cardiovascular problems are more common with HIV, your clinician will help protect you by monitoring your blood work regularly.

Isolation and depression are also very common—and dangerous—if you are transgender or non-binary and living with HIV. Your clinician might include a behavioral health component of your overall care plan to make sure you are getting all the support you need. The information in this guide is useful for anyone newly diagnosed with HIV, including transgender, intersex, and gender diverse individuals.

HIV Treatment

When should I start treatment?

Treatment guidelines from the U.S. Department of Health and Human Services recommend that a person living with HIV begin antiretroviral therapy (ART) as soon as possible after diagnosis. Starting ART slows the progression of HIV and can keep you healthy for many years.

If you delay treatment, the virus will continue to harm your immune system and put you at higher risk for developing AIDS, which can be life threatening. Many healthcare clinicians will recommend you start HIV treatment the day you are diagnosed or within a few days. The sooner you start treatment the sooner you can stop HIV from damaging your immune system.

Follow your treatment plan exactly as your clinician has prescribed. Medication should be taken at specific times of the day, with or without certain kinds of food. If you have questions about when and how to take your medication, talk to your clinician or pharmacist.

Why is treatment so important?

Although a cure for HIV does not yet exist, ART can keep you healthy for many years by reducing the amount of virus (or viral load) in your blood and body fluids. ART is recommended for all people with HIV, regardless of how long they have had the virus or how healthy they are. If taken as prescribed, ART also reduces your chance of transmitting HIV to others. There have been many advances in HIV medications which are very effective, have fewer side effects, offer many medication options (including one pill/ day options), and result in a longer life expectancy and quality of life.

What are the benefits of taking my HIV medication every day as prescribed?

Sticking to your HIV treatment provides many benefits:

- Allows HIV medication to reduce the amount of HIV in your body
- Helps keep your immune system stronger and better able to fight infections
- Reduces the risk of passing HIV to others
- Helps prevent drug resistance

What should I do if I miss a dose of my HIV medicine?

Taking your HIV medicines exactly the way your clinician tells you to will help keep your viral load low and your CD4 cell count high.

Talk to your clinician if you miss a dose. In most cases, take the medicines as soon as you can, then take the next dose at your usual scheduled time (unless your pharmacist or clinician has told you otherwise).

If you miss many doses, talk to your clinician or pharmacist about ways to help you remember to take your medication. You and your clinician may even decide to change your treatment regimen to fit your healthcare needs and life situation, which may change over time.

Do I need to keep taking my HIV medication if my viral load is undetectable?

Yes. If your viral load goes down after starting ART, then the treatment is working and you should continue to take your medication as prescribed.

What if my medications do not work well or if I have side effects?

If the HIV medicines you are taking are not working as well as they should, your clinician may change your prescription. A change in medication is not unusual because the same treatment does not affect everyone in the same way.

Let your clinician and pharmacist know about any medical conditions you have and any other medicines you are taking. Additionally, if you or your partner is pregnant or considering getting pregnant, talk to your clinician to determine the right type of ART, which can greatly reduce the risk of transmitting HIV to your baby.

What are some possible side effects of HIV medicine?

Like most medicines, antiretroviral therapy (ART) can cause side effects. However, today's medications are tolerated much better on average than earlier treatments were. Contact your clinician if you experience any of the following symptoms:

- Nausea and vomiting
- Diarrhea
- Difficulty sleeping
- Dry mouth
- Headache
- Rash
- Dizziness
- Fatigue

Your clinician may prescribe medicines to help manage any side effects, or they may decide to change your treatment plan. It is important to understand some of the challenges you may face and to think about how you might address them before they occur.

Tell your clinician right away if you are having difficulty sticking to your plan. Together, the two of you can identify the reasons why and plan to address those barriers. Joining a support group, or enlisting the support of family and friends, can also help you stick to your treatment plan.

What if I lose my insurance?

Because it is so important that you always take your HIV medication, it is also important that you know how to keep receiving it if you lose access to insurance coverage for any reason. There are also programs that will help you get back into coverage if you have lost it. You should be aware of the following resources:

- AIDS Drug Assistance Program (ADAP) is a federal program that will cover the cost of your HIV medications, as well as help with premiums in some situations.
- Medi-Cal is a free, or low-cost, program for health coverage based on your income.
- Covered California is a marketplace offering for-cost health plans with financial assistance available if you qualify.
- The Ryan White HIV/AIDS Program works with cities, states, and local community-based organizations to support caring for low-income patients.

Your eligibility specialist can tell you more about these programs.

Understanding Care

Who will be on my healthcare team?

Your primary HIV healthcare clinician leads your team. They will work with you to determine which HIV medicine is best for you and they will monitor your progress in treatment. In addition, a team of physician assistants, nurses, lab techs, and pharmacists will work with your healthcare clinician to make sure your care is complete. This also includes general health checkups and the management of other health concerns not necessarily connected to HIV.

Using MyChart

When you are not seeing your care team in person at DAP, we keep you connected to them with the MyChart patient portal. You can download the app on your smartphone, tablet, and computer. This confidential and secure website enables you and your clinician to have conversations about your healthcare without you having to be in their office and it cuts down on telephone time as well.

You can also use MyChart to access your lab results, make appointments, and fill/refill your prescriptions. Your clinician will get you set up with your own MyChart account and will guide you through using it for your healthcare at DAP.

What is treatment adherence and how can I make the most of my medical care?

HIV care and treatment is most successful when you take your medications as prescribed, keep every medical appointment, and get your lab work done every time your clinician requests it. It is important that you feel comfortable speaking honestly with your clinician. They will need to have the most accurate information to take the very best care of you.

Here are some additional suggestions, based on our experience:

- Make sure to give DAP your new phone number and/or home address if either should change so that we can call to remind you of upcoming appointments several days beforehand.
- Let your assigned EIS (Early Intervention Specialist) know in advance of any transportation barriers that may prevent you from making your appointments. They can help you with transportation assistance.
- Share any concerns regarding insurance and medication coverage with your EIS expert. DAP will not turn you away for lack of funds and we will help you get your information current.
- Before your appointment, consider writing down any questions or concerns that you would like to discuss with your clinician and be prepared to write down the answers.
- Use MyChart to keep track of your lab results, medical visits, appointment schedule, medicines and medicine schedules, and care and treatment plans.



If you find yourself struggling to remember your appointments, here are some suggestions:

- Use a calendar to mark your appointment days
- Set reminders on your phone
- Keep your appointment card in a place where you will see it
- Ask a family member or friend to help you remember your appointment

What can I expect during a medical visit?

During a medical visit, your clinician may:

- Ask you questions about your health history
- Conduct medical exams to see how HIV is affecting your body
- Take a blood sample to check your viral load and CD4 count
- Look for other kinds of infections or health problems that may weaken your body, make your HIV worse, or prevent your treatment from working as well as possible
- Give you immunizations, if you need them
- Discuss, prescribe, and monitor your HIV medicines
- Discuss ways to help you follow your HIV treatment plan
- Help identify additional support you may need
- Ask you about your sex partners and discuss ways to protect them from getting HIV

What are the different tests that help monitor my health?

In addition to other general health tests, your clinician will order blood tests to monitor your HIV infection. These test results will also help your clinician decide whether he or she should make changes to your treatment and address any other health needs.

These tests include:


CD4 Count

CD4 cells, also called T-cells, are a type of white blood cell that plays an important role in your body's ability to fight infections. Your CD4 count is the number of CD4 cells you have in your blood. When you are living with HIV, the virus attacks and lowers the number of CD4 cells. This makes it difficult for your body to fight infections. Typically, your clinician will check your CD4 count every three-to-six months.

Viral Load Test

Your viral load is the amount of HIV in your blood. When your viral load is high, you have more HIV in your body, which will cause increased damage to your immune system. Your clinician will use a test to determine your viral load.

You should have a viral load tested every three-to-six months, before you start taking a new HIV medication, and two-to-eight weeks after starting or changing medication. Your clinician will let you know how often you will need to have a viral load test. This will likely become more frequent unless your viral load maintains undetectable status.



Telling Others

Am I legally required to share my HIV status with others?

California does not require this. Even though disclosing your HIV status may be uncomfortable and is not required by law, doing so allows others to make choices to protect themselves. In some states, there are laws that require you to share your HIV status with your sex and injection drug-use partners.

- Medical clinicians and other HIV-related service clinicians need to know your HIV status
- Telling new partners that you have HIV before you have sex or inject drugs together allows them to make decisions that can protect their health
- You do not have to tell your employer

The following resources can provide more information on sharing your HIV status with others:

- The Center for HIV Law and Policy identifies which states have HIV-specific criminal laws and provides additional resources about disclosure, confidentiality, and the law.
- Your state health department can also provide information on your state's laws and how they apply to disclosure.

How do I let my partners know they may have been exposed to HIV?

If you have been diagnosed with HIV or other STIs, it is very important to let your current and former sex or injection drug- use partners know that they may have been exposed. Informing partners that you have HIV lets them know that they should be tested. These conversations can be challenging because you may have become infected by one of these individuals, or they may have been exposed to HIV by someone else.

There are a few ways to let your partners know:

- You tell your partner
- The health department tells your partners. This is sometimes called "Partner Services"
- You and the health department staff work together to tell your partners

Through Partner Services, health department staff notify your current and former sex and/or injection drug-use partners (without disclosing who you are) that they may have been exposed to HIV and/or other STIs and provide them with testing, counseling, and referrals for other services.

Partner Services programs are available at DAP or through health departments and some medical offices or clinics. Your clinician, social worker, case manager, EIS, or HIV testing center can help put you in touch with a Partner Services program.

Should I share my HIV status with my friends and family?

Sharing your HIV status with trusted family and friends has emotional and practical benefits. Having trusted people to talk to can help you cope better with an HIV diagnosis. They can also support you with the longer-term issues of treatment and disclosing your status to others. Trusting people with this knowledge will allow them to speak for you in case of an emergency and help you navigate the medical system. Do not overlook the expertise of people you know. Many of them have had these difficult conversations and they can help you work through what you should say. Whom you tell is completely up to you and only you.

If you don't have someone in your life whom you feel ready to talk to about your HIV status, let a member of your healthcare team know that you're interested in support. DAP has groups of survivors who prevent anyone facing HIV alone, plus therapists who are experts at helping you continue living a full life with your HIV diagnosis.

Some conversation starters to help you begin talking about your status with others include:

- "There's something I want to tell you. I'm living with HIV. Have you ever known someone with HIV?"
- "About a year ago, I found out that I'm HIV-positive. Since then, I've been taking medication and I feel good."

Protecting Others

Can I transmit HIV if I have an undetectable viral load?

HIV medicine lowers the amount of virus (viral load) in your body and taking it as prescribed can make your viral load undetectable. If your viral load stays undetectable, you effectively have no risk of transmitting HIV to an HIV-negative partner through sex.

Needle Sharing Partners

We do not know whether getting and keeping an undetectable viral load prevents HIV transmission through sharing needles or other injection drug equipment. It very likely reduces the risk, but we do not know by how much. For this reason, never share needles or other equipment to inject drugs.

Mother-to-Child

Mothers with an undetectable viral load at all stages of pregnancy, labor and delivery have much better chances for a healthy baby. Unfortunately, breastfeeding is not proven safe, even with viral suppression. Each mother and child have unique needs, which is why it is so important to be in continuous care with a supportive HIV specialty doctor.

Preventing Sexual Transmission of HIV

Treatment is a powerful tool for preventing sexual transmission of HIV, however, it only works as long as you have an undetectable viral load.

Consider taking other actions to prevent HIV, like using condoms or having your partner(s) use the medication pre-exposure prophylaxis (PrEP) for added peace of mind.

Taking these actions can be useful, especially if you:

- Have trouble regularly taking your HIV medicine
- Have an increased viral load, or a load of 200 copies/ml of blood or greater
- Have not had a recent lab test (in the last 3 to 4 months) that shows the viral load is undetectable
- Missed some doses since your last viral load test
- Have stopped taking HIV medicine in the past and may choose to do so again in the future

What is Pre-Exposure Prophylaxis (PrEP) and why should it matter to me?

PrEP is an HIV-prevention method that was approved by the U.S. Food and Drug Administration in 2012 to prevent HIV infections.

Truvada and Descovy are medications approved for PrEP. When taken every day by HIV-negative individuals, either one can prevent HIV infection. These medications are also used to manage viral loads in people living with HIV. DAP follows the Centers for Disease Control and Prevention (CDC) PrEP guidelines which recommend that a person on PrEP be tested every 3 months for HIV and STIs.

If you are in a relationship, or have a sex partner who is HIV- negative, it is important for them to consider PrEP as an option that can help prevent them from becoming HIV-positive. The same is true if they are having sex or sharing needles with someone living with HIV, or if their HIV status is unknown.

What is Post Exposure Prophylaxis or PEP?

PEP is a 30-day treatment for individuals who are not living with HIV, not on PrEP, and who have had a risky sexual or needle-sharing encounter. If a person thinks they may have come in contact with HIV, PEP may decrease the risk of getting it. PEP can only work if it is started within 72 hours of the risky encounter.

Where can someone get PrEP or PEP?

If you know someone who might benefit from PrEP, or who might have had a risky sexual encounter, they can access PrEP or PEP in multiple ways:

- Visit The DOCK Sexual Health Clinic at DAP, which has specially trained expert PrEP Navigators who can help someone through the process of getting PrEP and PEP. In addition, the PrEP navigator will help remove any insurance coverage barriers.
- By seeing their primary care clinician.
- Accessing or switching their primary care to DAP.

How do I talk to my HIV-negative partner about safer sex?

Here are some conversation starters to help you begin talking about safer sex options:

- "I really like you and like where this is going, but before we go any further there's something I want to tell you. I'm HIV-positive. Have you heard of the term Undetectable = Untransmittable? Let me explain it."
- "Let's start talking about ways to keep each other healthy and safe. When was the last time you were tested for HIV?"
- "Did you know that there are medicines that you can take that can further reduce the chance of you getting HIV? Have you heard of PrEP (pre-exposure prophylaxis)? Maybe we should talk to our doctors to see if it's right for us."
- "Can we talk about sex? Safe sex is really important to me."
- "So we haven't really talked about it, but can we agree that when the time comes we'll use condoms to keep each other safe?"
- "I know we just met, and we don't know everything about each other, but you should know that practicing safe sex is really important to me. When was the last time you were tested for HIV and other STIs?"

For partners who are both HIV positive:

- "If we're going to have sex, let's get tested for other STIs together before we take that step."
- "Getting a STI could really compromise our health. Let's stay healthy and get tested for STIs regularly."
- "Let's talk about how we can practice safer sex so that we don't increase our chances of getting an STI or a new strain of HIV."

Living with HIV

Thanks to medical and pharmaceutical advancements, HIV is considered a chronic medical condition that can be well managed, and a person living with HIV can have an excellent quality of life. You are a partner with your clinician and all the other members of your healthcare team. Your care team will help you through the entire process and support you in living with HIV.

If you do not feel like you are able to discuss any of your health-related issues with your clinician or care team members honestly, you may not have the right care team and may want to switch medical clinicians. It is very important that you trust your medical clinician and feel you can talk honestly with them and that they really hear you.

Mental Health

How can HIV impact my mental health?

Almost every person faces mental health challenges at some point. Major stresses—such as the death of a loved one, divorce, loss of a job, injury or health crisis, or moving—can have a major impact on mental health. Similarly, having HIV can be a source of major stress. You may find that living with HIV challenges your sense of well-being or complicates existing mental health conditions.

HIV can also affect your nervous system and can lead to changes in your mood and/or behavior. Good mental health will help improve your quality of life and is essential to successfully treating HIV. To help manage your mental health, it is important to know when, how, and where to get help.

What is HIV depression and where can I find treatment?

One of the most common mental health conditions that people with HIV face is depression, which can range from mild to severe and have symptoms that can affect your day-to-day life, including:

- Persistent sadness
- Anxiety
- Feeling “empty”
- Feelings of helplessness
- Negativity
- Loss of appetite
- Disinterest in engaging with others

The good news is that in most cases depression is treatable. Ask your clinician, social worker, EIS, or case manager to refer you to a mental health clinician who can provide you with the care you need.

Looking Forward: Healthy Living with HIV

Can my HIV or my HIV treatment affect my diet and nutrition?

Yes, people with HIV and those on HIV treatment sometimes face issues that can affect their nutrition, such as:

- Changes in your body's metabolism
- Loss of absorption of needed nutrients resulting in a decrease of those nutrients in the body
- Medications that can upset your stomach
- Opportunistic infections that can cause issues with eating and swallowing

Healthy eating is important for everyone's overall health. In addition, if you are living with HIV, following a healthy diet offers several benefits:

- Provides the energy and nutrients your body needs to fight HIV and other infections
- Maintains a healthy bodyweight
- Manages HIV symptoms and complications
- Improves absorption of medications and helps manage potential side effects

Talk to your clinician about your diet and ask specific questions about what steps you should take to maintain good nutrition. He or she may refer you to a nutritionist or dietitian who can talk with you about your nutrition needs.

Why is exercise important?

Exercise offers benefits that can help you maintain good physical and mental health. Exercise can also increase your strength, endurance, and fitness, and help your immune system work better to fight infections.

People living with HIV can do the same types of exercise as people who do not have HIV. Take time to find a fitness routine that you enjoy. Make exercise fun and commit to exercising regularly.

What does smoking do to a person with HIV?

Smoking has many negative health effects on people living with HIV. For example, they are more likely than non-smokers with HIV to:

- Develop lung cancer, head and neck cancers, and cervical and anal cancers
- Develop bacterial pneumonia, pneumocystis jiroveci pneumonia, COPD (Chronic Obstructive Pulmonary Disease), and heart disease
- Develop conditions that affect the mouth, such as oral candidiasis (thrush) and oral hairy leukoplakia
- Have a poorer response to antiretroviral therapy (ART)

In addition, people living with HIV who also smoke have a greater chance of developing a life-threatening illness that leads to an AIDS diagnosis. People who smoke and live with HIV also have a shorter lifespan than people with HIV who do not smoke.

Research Resources

Research at DAP

At DAP, we are committed to improving the lives of everyone living with HIV. Our research program is part of several prestigious studies that make living with HIV easier by studying a range of topics influencing the lives of our clients who live with HIV.

Study participants can benefit in several ways. Learning about emerging HIV health trends, and early access to cutting-edge HIV treatments are just a few examples. For many of our clients, knowing that they are helping the next generation of people living with HIV is a great feeling.

We often need volunteers to take part in our research studies. If you are interested in finding out more information, please call (760) 323-2118 and ask to be connected to our research coordinator.



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Se Habla Español