

Living with HIV AIDS

Overview

We have been treating people living with HIV (human immunodeficiency virus) and AIDS (acquired immune deficiency syndrome) for over 30 years. HIV and AIDS are manageable complex chronic conditions.

If you are diagnosed with HIV or AIDS, we will typically refer you to an HIV specialist. The HIV specialist works with you and a multidisciplinary team of other practitioners who are available to help you manage your HIV/AIDS care. This team may include:

- Medical doctor
- Nurse practitioner
- Nurse
- Social worker
- Pharmacist
- Nutritionist
- Medical assistant
- Health educator
- Counselor

This team will provide you with ongoing specialized care. This includes discussing with you:

- Recommendations to successfully manage your HIV to avoid the least disruption to your lifestyle.

- The importance for regular routine laboratory tests, including the type of test and expected values.

- Why and when to start antiretroviral medications and the benefits and risks involved.

- When to call us with concerns regarding your health.

- How to manage health complications related to HIV/AIDS.

- How to prevent giving HIV to others.

- How to disclose your HIV status to others.

HIV positive women and pregnancy

The risk of mother to baby transmission is possible during pregnancy, childbirth, and breastfeeding. If you are HIV positive and pregnant or considering pregnancy, we will discuss the risks of pregnancy and how to decrease the risk of passing the virus to your child.

We will also discuss with you:

- The benefits and risks of delivery options (cesarean versus vaginal delivery).

- Additional treatment to both you and your baby during delivery to minimize HIV exposure to your baby.

- Treating your baby with a short course of antiretroviral medications after delivery to reduce the chance of HIV infection in your baby.

- The use of formula instead of breastfeeding since the HIV virus can be passed to your baby through breast milk.

Along with the considerations above, the risk of mother-to-child transmission of HIV is as low as 1 to 2 percent for pregnant women who are on HIV treatment with a fully suppressed virus.

Symptoms and Diagnosis

Symptoms of HIV infection are difficult to identify early on and many people have no symptoms. Within 2 to 12 weeks after you are first infected with HIV, you may develop flu-like symptoms. These symptoms usually go away, and you probably would not associate them with an HIV infection.

Common flu-like symptoms that may indicate HIV include:

- Fever
- Swollen lymph nodes

- Headache
- Sore throat
- Rash
- Fatigue

More advanced symptoms of HIV infection

After exposure to HIV, it can take months or years before experiencing symptoms related to the infection. Overtime, HIV weakens your immune system to where you can no longer fight infections and diseases. Additionally HIV can result in damage to certain organs like the brain or kidneys resulting from inflammation directed at the virus. Although everyone is different, it takes an average of 10 years for HIV to weaken your body's immune system to this point. Symptoms may include more serious health concerns such as:

- Shortness of breath
- Weight loss
- Night sweats
- Fever over 100 degrees Fahrenheit
- Persistent severe fatigue
- Persistent swollen lymph nodes
- Daily headaches
- Long-term (chronic) diarrhea
- Sores or rashes on your body

AIDS diagnosis

If HIV infection is untreated, it can significantly damage your immune system. A diagnosis of AIDS is made when a test of your immune system (CD4 count) shows it has weakened to a particular point (a CD4 count at or below 200 mm³) or you have one or more complications because of a weakened immune system. Examples of some AIDS defining conditions include:

- Pneumonia (pneumocystis or "PCP")
- Parasites (cryptosporidiosis, microsporidiosis, toxoplasmosis)
- Respiratory infections (mycobacterium tuberculosis, recurrent pneumonias)
- Cancers (lymphoma, Kaposi's Sarcoma)
- Brain-related problems (dementia, progressive multifocal leukoencephalopathy)

Everyone's immune system and experience living with AIDS is unique. It is not uncommon for someone with AIDS to have AIDS-related problem, recover with treatment, and then be healthy again for many years.

Screening and Testing

After receiving a positive HIV antibody test, we will test your blood to determine your viral load (VL) and CD4 cell count. These tests will be rechecked every 3 to 6 months to see if HIV medications are needed, or to check how you are responding to your treatment. There are other laboratory tests that we may order, depending on your symptoms and other medical conditions.

Viral load. This test measures how much HIV RNA (Ribonucleic Acid; the virus' genetic material) is in your blood. A high viral load indicates a higher risk to your immune system and a greater likelihood of transmitting the virus to others. An "undetectable" viral load (< 75 copies/mL) tells us that the HIV medications are working to control your HIV infection. This does not mean you are cured. The HIV is still present in your blood and it is still possible to pass the virus to others. An undetectable viral load is important to keep your immune system healthy and to reduce your risk of becoming ill from AIDS related conditions.

CD4 cell count. CD4 cells are a type of white blood cell that help the immune system respond to any infection. HIV attaches to the surface of the CD4 cells, enters the cells, and can either destroy them or remain in the cell until the cell becomes active. As HIV progresses, the number of CD4 cells gradually decline:

A healthy CD4 cell count is usually between 500 to 1200mm³(cubic millimeters). Use of antiretroviral medications becomes more critical when you have a lower CD4 count.

A CD4 count of 200 mm³ or lower is considered an AIDS diagnosis.

A drug resistance test (**genotype**) will be done to check if your virus is resistant to any of the available HIV medications. This will help us to prescribe the most effective drug regimen for you.

Treatments and Medications

One of the most effective ways of treating people who have HIV or AIDS is with antiretroviral medications.

When to start antiretrovirals

After you are diagnosed with HIV, we will usually discuss starting you on HIV anti-retroviral medications (ARVs).

The decision to begin or change treatment is different for everyone, and is based on:

- Your CD4 count and viral load without treatment
- A diagnosis of AIDS
- HIV-related symptoms or conditions
- Pregnancy
- The existence of other diseases like HIV-related kidney disease, or co-infection with hepatitis B (HBV) or C (HCV) virus
- Your response to your HIV medications
- Development of resistance to your HIV treatment
- Side effects from HIV antiretrovirals
- Your readiness to start treatment

Treatment response is also different for everyone. It may take several attempts before we find the medication combination that works best for you.

Antiretroviral medications

Antiretroviral medications play a significant role in managing your HIV. There are six classes of antiretroviral medications. Each works differently on how they attack the HIV. The standard treatment is to use a combination of three drugs from at least two different drug classes. This is sometimes called **HAART** (highly active antiretroviral therapy).

The drug classes are:

NRTIs (nucleoside reverse transcriptase inhibitors). These drugs stop HIV infection by blocking the reverse transcriptase enzyme that the HIV needs to make more copies of itself. This is the most common class and is often the basis of an HIV regimen. Examples from this class include zidovudine (AZT, Retrovir) and tenofovir (Viread).

NNRTIs (nonnucleosidereverse transcriptase inhibitors). This class works in a different way to also block the same reverse transcriptase enzyme. An example from this class include efavirenz (Sustiva).

PIs (protease inhibitors).These drugs block the HIV protease enzyme. This enzyme is needed by the HIV to split the new genetic material into many pieces in order to make more viruses. Examples include darunavir (Prezista) and atazanavir (Reyataz). A small dose of ritonavir (Norvir) will also be prescribed along with some PIs to help ""boost"" the blood levels.

Fusion inhibitor. This drug blocks HIV from attaching to CD4 cells. The only available agent in this class is an injectable drug called enfuvirtide (Fuzeon).

CCR5 antagonists. This class blocks a protein called CCR5 that is found on CD4 cells. A special test must be performed first to determine if you will respond to this type of drug. An example of this class is maraviroc (Selzentry).

Integrase inhibitors. This class blocks the HIV integrase enzyme that is needed by the HIV to combine its own genetic code into the CD4. The first agent in this class is raltegravir (Isentress).

Once you start treatment, you will need to take these medications daily for the rest of your life. It is very important not to miss doses in order to prevent resistance from developing.

Please alert us if you are taking any other medications, vitamins, or supplements so that we can review these for any potential drug interactions with your HIV regimen.

Medication Management

Medication adherence is very important. You may find yourself taking multiple medications, sometimes with different food requirements or instructions and at different times of the day or night. This can sometimes be challenging, but we can help you set up a system to manage your medications. It is also important that you let us know if you are not taking your medications as prescribed, as it may influence the effectiveness of your treatment.

All medications have potential side effects. Some of the common problems include nausea, vomiting, diarrhea, or skin rash. These side effects are often short-term and manageable. Please call us right away if you experience any adverse effects from your treatment.

Some tips for keeping track of your treatment include:

Know your medications. Ask your physician, case manager or pharmacist to explain each of your medications: what they are for, how they work, what to expect, common potential side effects and how to manage them should they occur.

Keep a list of all your medicines, and have us review and update it if needed at each visit.

Know when to take your medication. Know how often you should take each medication and any special requirements (e.g., with food). Take your medications around the same time every day to avoid low blood levels, which can impact the effectiveness of the regimen. If you miss a dose, take it when you remember. If it is too close to the next dose, just wait until then. The fewer doses you miss, the longer we can keep you on your regimen.

Use a pillbox with compartments to arrange your medications. Using a pillbox lets you know when you have taken each dose so that you do not miss one.

Manage side effects. Some medications have unpleasant side effects. Ask your physician or pharmacist what side effects to expect and how you can successfully manage these side effects. If you develop any severe symptoms, let us know right away. Do not stop taking your medicines or change the dose on your own unless you have been instructed to do so. We can often suggest an alternative regimen that you may better tolerate if any of the symptoms do not resolve.

Continued monitoring

As part of your treatment we will continue to monitor your viral load and CD4 count. If your viral load does not drop as expected, or your CD4 cell counts starts to fall, we will work with you to determine why treatment was not effective. **The two most common reasons why HIV treatment fails:**

The regimen was not potent enough or the HIV has become resistant to any or all of the medications you are taking.

You are not taking your medications as prescribed and the virus has mutated and become resistant.

Lifestyle Management

Living with HIV/AIDS requires special care and attention to all areas of your life. Staying healthy will help you maintain a high quality of life for many years. Some things to consider when you are living with a chronic condition like HIV/AIDS include:

Medications and treatment

One of the most important things in managing HIV/AIDS is maintaining your antiretroviral medications. Stick to your treatment plan. Keep up with your regular clinical visits and get immunizations and medicine you need to prevent infections.

Healthy diet

Eating healthy helps the body stay healthy as well as repair itself when you are ill. If you have a weakened immune system, we may recommend that you avoid uncooked foods like sushi, or raw oysters, eggs, and meats, which may contain bacteria or parasites causing you to become ill.

Alcohol, tobacco and other drugs

Drinking alcohol or using other drugs can compromise your immune system and may interact with your antiretroviral drugs. Drink in moderation or consider not drinking. Avoid the use of drugs that are not prescribed by your doctor. If you smoke, quit. Smoking increases the risk of heart attack and lung cancer. Let us know if you need help with discontinuing your use of alcohol, tobacco or other drugs.

Regular exercise

Exercise boosts your immune system and mood and supports cardiovascular and muscular health.

Emotional support

Living with a chronic health condition can be stressful. Seek counseling or talk with a family member or friend. We offer support groups for people living with HIV/AIDS. A support group can be a good place to share information, experiences, problem-solving tips, and your feelings.

Alternative and complimentary therapy

Stress-reduction techniques and massage can benefit the mind and body. Be sure to talk with us first if you want to try additional methods to boost your immune system. This is especially important for vitamins or herbal supplements. Check with your physician or pharmacist to be sure which vitamins can be safely combined with your medications.

Advance directives

If you have not already done so, prepare a list of advance directives. These are instructions to your healthcare team about the kind of care you want if you cannot speak for yourself.

Travel

Prepare for your trip by talking with your doctor. Make sure you have enough medication to last your trip and an extra supply just in case. Find out before you travel where you can seek medical treatment if needed.

Pets

Animals can rarely carry parasites and other diseases. Let us know if you have any animals or are considering a new pet.

Please talk to us about any lifestyle choices that you believe could impact your health and medical care. We will also share with you resources at Kaiser Permanente to help you live well with your HIV/AIDS.

Prevention

There are effective ways to prevent the spread of HIV. Follow these guidelines to prevent the spread of HIV to others. These steps will also protect you from becoming infected with a new strain of HIV or from other sexually transmitted diseases

The most common ways HIV is transmitted is through anal or vaginal sex or by sharing needles or injection devices with a person infected with HIV. Steps to reduce these risks include:

Practice safer sex. Latex condoms (or polyurethane condoms for those allergic to latex) can help to protect you and your partner against HIV and STDs (Sexually Transmitted Diseases). Use only water based lubricants with condom. Oil or lotion based lubricants cause condoms to weaken and break more

easily.

Don't share needles. If you use IV drugs, use clean needles whenever possible. If you do share needles, clean them first with bleach and water. If you get a tattoo or any body piercing, make sure the person providing the service is using new needles.

Talk with your partner. Talk openly and honestly with your partner about safer sex. Be clear about what you will and will not do sexually. Also, respect what your partner will and will not do. Decide together what is right for both of you.

If you think you have exposed your HIV negative partner or another person to HIV within the last 72 hours, have them call us immediately. We can provide them with medications or refer them to help to decrease the likelihood that they will become HIV positive. These medications are most effective when started as soon as possible after a risk exposure. For immediate assistance, call to speak with an advice nurse who can arrange to get them care as quickly as possible. Advice is available 24 hours a day, 7 days a week.

Ask others to wear protective gloves if they need to care for you and may have contact with your blood or other body fluids, or if they have a cut on their hand.

Use your own personal items. Do not share toothbrushes, razors, sex toys, or other items that may have blood, semen, or vaginal fluids on them.

Do not donate your blood, plasma, or organs. These contain HIV which would be passed on to the recipient.

Women with HIV who are pregnant or are considering pregnancy should discuss with us the risks of passing HIV to their babies. HIV can be transmitted to a baby in the womb, during childbirth, or by breastfeeding. There are medications available to pregnant women that greatly decrease this risk to as low as 1 to 2 percent.

If you have any questions about preventing the spread of HIV, please ask us.

For Caregivers

Most people living with HIV live full, healthy lives and do not require caregivers as a result of their HIV diagnosis. When needed, the support of a caregiver can greatly improve the quality of life. Below are some tips for caregivers:

Provide emotional support, listen, and offer encouragement.

Take care of yourself by sharing your experiences with others in a similar situation and getting help when you need it.

Learn about the medications they are taking, how to give the medicine, and know where to get help in an emergency.

Protect yourself against HIV. Take necessary precautions so you are not in direct contact with blood, semen, or vaginal secretions.

Wear rubber gloves when handling the HIV-positive person's needles, blood, or anything that contains the person's blood, such as used tissue or toilets. Cover any of your own sores, especially if they are open wounds. If you are intimate with the person living with HIV/AIDS, make sure to use condoms and discuss safe sex.

Limit exposure to others. Sometimes exposure to other infections and germs, even with a common cold, can be life threatening for people living with HIV/AIDS. Use your best judgment on when you and others visit, and wear protective gear like masks.

Keep the home environment clean and free of germs. When someone is at a stage of more critical care, it is important to keep the house clean and free of germs. Clean toilets often and replace plastic bedpans or urinals at least once a month. Be careful not to splash any liquids that contain blood,

including toilet bowl water.

Stay current with annual influenza and pneumonia vaccination. Do not take vaccinations that contain live viruses. Let your health care provider know that you are a caregiver for someone with a compromised immune system.

Take good care of pets. Make sure other animals in the house do not have parasites that can be transferred to the person with HIV and become life threatening.

Prepare for long-term home care. If the person's HIV infection has progressed to AIDS, additional care may be needed, such as preventing or caring for bedsores and providing other supportive care. Additional care depends on the specific health problem that may develop.

Your Care with Me

Typically your personal physician will facilitate the process of referral to an HIV specialist. We have a multidisciplinary team available to assist you with your care in our HIV Specialty Clinic. If appropriate, she or he might call me or one of my colleagues while you are in the office so we can all discuss your care together. If we decide you need an appointment with me after that discussion, we can often schedule it the same day or soon thereafter.

During your office visit, we will discuss your medical and family history and I will perform a physical exam. I will explain the findings of your exam and answer any questions or concerns you may have. We will discuss treatment options and develop a treatment plan that is right for you.

Your Care with Me Local

If you need to talk with me after your visit or procedure, please call my office. You can also e-mail me with nonurgent issues from this website whenever it is convenient for you.

For general medical advice, our Appointment and Advice line is available 24 hours per day, 7 days per week.

If you have urgent concerns or issues while my office is closed, or need general medical advice, you can call the Appointment and Advice line. You will be connected with a nurse who can give you immediate advice.

If you are experiencing a serious problem or an emergency, call 911 or go to the nearest Emergency Room when the clinic is not open.

Additional References:

[The Body The complete HIV AIDS Resource](#)
[Project Inform](#)
[WORLD - Women Organized to Respond to Life threatening Disease](#)
[The Well Project](#)

[The Body The complete HIV AIDS Resource](#)
[AIDS Info - NIH](#)
[HIVInsite Dosing Toolkit](#)

[HIV Medication Schedule](#)
[HIVInsite Dosing Toolkit](#)

[We Care HIV AIDS Support Network, Inc](#)
[Project Inform](#)
[WORLD - Women Organized to Respond to Life threatening Disease](#)
[The Well Project](#)

[The Body The complete HIV AIDS Resource](#)
[Project Inform](#)
[WORLD - Women Organized to Respond to Life threatening Disease](#)
[The Well Project](#)

Caring for Someone with AIDS at Home - CDC

If you have an emergency medical condition, call 911 or go to the nearest hospital. An emergency medical condition is any of the following: (1) a medical condition that manifests itself by acute symptoms of sufficient severity (including severe pain) such that you could reasonably expect the absence of immediate medical attention to result in serious jeopardy to your health or body functions or organs; (2) active labor when there isn't enough time for safe transfer to a Plan hospital (or designated hospital) before delivery, or if transfer poses a threat to your (or your unborn child's) health and safety, or (3) a mental disorder that manifests itself by acute symptoms of sufficient severity such that either you are an immediate danger to yourself or others, or you are not immediately able to provide for, or use, food, shelter, or clothing, due to the mental disorder.

This information is not intended to diagnose health problems or to take the place of specific medical advice or care you receive from your physician or other health care professional. If you have persistent health problems, or if you have additional questions, please consult with your doctor. If you have questions or need more information about your medication, please speak to your pharmacist. Kaiser Permanente does not endorse the medications or products mentioned. Any trade names listed are for easy identification only.