

# HIV/AIDS - Draft

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Also called Acquired Immunodeficiency Syndrome, Human Immunodeficiency Virus, HIV Positive

## *Description of the Disability*

AIDS (Acquired Immunodeficiency Syndrome) is a long-term, progressive, currently-incurable infection that weakens a person's immune system allowing other "opportunistic" infections and cancers to run unchecked. Many of these infections and cancers are rare in the general population because most people's immune system can kill them off without any trouble, but the "opportunity" of a person with a weakened immune system allows them to take root. In addition to the basic symptoms of AIDS (see below), these opportunistic infections often cause significant disability or death.

AIDS is caused by the Human Immunodeficiency Virus (HIV). The HIV virus destroys one of the body's main infection fighters (CD4-positive T cells, also called CD4+ Leucocytes, T-helper cells, or just T-cells) found in the blood). Without these cells in its immune system, the body has difficulty fighting off various diseases. However it takes a while for the HIV virus to do this damage and a person can have a low-level infection of the HIV virus (be "HIV positive" or HIV+) without having AIDS or any significant problem with their immune system. Thanks to newer and more effective drugs for fighting the HIV virus, more and more people are living HIV+ for years without developing AIDS, or living for years with AIDS while still being able to work and live independently.

Although people talk about HIV as if it were one thing, there are actually many strains of the HIV virus. It is possible for a person who is already HIV+ to become further infected with additional strains.

Physicians diagnose AIDS based on the number of T-cells a person has in their blood and the types of infections they are getting. A healthy person typically has 1000 T-cells per cubic millimeter of blood. AIDS is diagnosed when a person has fewer than 200 of these cells per cubic millimeter of blood or when they are experiencing some of the AIDS Defining Illnesses listed below.

As a counselor, you may not always be aware of a client's HIV status. The person may have other conditions that qualify them for services and may not disclose their status to you. In addition, a diagnosis of HIV might not be enough to qualify someone for services if they are not experiencing any functional limitations due to the infection. The HIV/AIDS diagnosis is legally considered a disability and meets the first criterion for eligibility for vocational rehabilitation services but, like any potentially chronic disability, there must also be significant functional issues that interfere with employment. In the case of HIV/AIDS, these functional issues are likely to involve symptoms of the secondary illnesses described below rather than direct symptoms of the HIV infection itself.

People with HIV or AIDS often experience a lot of social stigma from others. Historically, the general public in the US has associated HIV with homosexuality, the use of illegal intravenous

drug, and sexual promiscuity. In fact, there are a variety of ways to contract HIV/AIDS that do not directly involve any of these activities. However, people with HIV/AIDS may be afraid (with reason) that others will judge them or discriminate against them if they publicize their diagnosis. Because of this, there are significant confidentiality issues related to the disease.

As a counselor, you should not assume a client with HIV or AIDS will experience rapid development of symptoms after a diagnosis. Some people do not develop serious symptoms for up to ten years after getting the diagnosis. Others experience a much faster progression. In addition, many people with HIV/AIDS experience the most significant functional issues from the opportunistic infections rather than the HIV infection itself. Women with HIV who act as caregivers for their children or immediate family may have unique challenges because they may give less attention to their own health and not seek medical attention until their symptoms are already significant.

**AIDS Dementia Complex** - (ADC, also called AIDS-related Dementia and HIV-associated Dementia). Unlike most other conditions associated with HIV/AIDS, this is caused directly by the HIV virus itself, not by a secondary infection taking advantage of the person's impaired immune system. The HIV virus enters a person's brain soon after they are infected. However, for some reason the virus does not directly infect nerve cells, only the various support cells, blood vessel cells, etc. in the brain. Something about this infection of the support cells also damages the nerve cells and leads to Dementia. The symptoms of ADC include memory difficulty, changes in behavior, speech problems, vision problems, balance problems, difficulty walking, loss of bladder control, and, in advanced cases, mania or psychosis. The speed at which the dementia progresses varies widely from person to person. (See entry on Alzheimer's Disease for more information on functional issues of dementia syndromes)

### **AIDS Defining Illnesses (ADIs)**

The Center for Disease Control (CDC) has compiled a list of 25 illnesses that occur more commonly in people with AIDS than in the general population. These illnesses are so distinctively associated with AIDS that the CDC uses them as an alternative way to diagnose a person's transition from simply being HIV positive to having a diagnosis of AIDS, even without a low T-cell count in their blood. These AIDS Defining Illnesses (ADIs) include opportunistic infections, some neurological diseases, certain kinds of cancer, and HIV Wasting Syndrome.

- **Opportunistic Infections.** Many of the Opportunistic Infections in the ADI list are treatable and curable. However, the weakened immune system of people with HIV/AIDS and complicates treatment and makes re-infection common. These Opportunistic Infections include:
  - **Cytomegalovirus (CMV)** - this is a herpes-type virus that attacks the internal organ, but it usually affects the eyes, colon, and throat. It can cause vision problems including AIDS-related blindness (see entry on Blindness & Low Vision). When the colon is involved, the person may experience cramps, diarrhea, and weight loss. When the throat is involved, the person may have difficulty swallowing or have chest pains. When the colon is involved, the person may experience cramps, diarrhea, and weight loss.

- **Mycobacterium Avium Complex (MAC)** - This is a complex of two related bacteria from the same family (mycobacterium) as Tuberculosis. In people without HIV, MAC usually causes respiratory problems, but in HIV-related cases it usually targets other internal organs, including the lymph nodes, the liver, spleen, and bone marrow. Symptoms include night sweats, fevers, diarrhea, and weight loss.
- **Pneumocystis Carinii Pneumonia (PCP)** - This lung infection is caused by a germ that is related to - but distinctly different from - the one that causes typical pneumonia. In people with HIV/AIDS, PCP is a potentially fatal illness and must be treated immediately. There are specific drugs people with HIV/AIDS can take to help prevent PCP. These drugs have reduced the frequency of PCP in people with HIV/AIDS, but it is still the most common serious infection they experience. Symptoms include fever, dry cough, tightness in the chest and difficulty breathing.
- **Toxoplasmosis of the Brain** - This infection is caused by eating unwashed fruits and vegetables or undercooked meat, or contact with cat feces. It is actually very common in the general population but most people's immune system fights it without any problem. In individuals with HIV/AIDS it may affect the lungs, liver, heart, skin, muscle, brain, and spinal cord membranes. To be an AIDS Defining Illness, it must infect the brain. Initial symptoms usually include headache, fever, and confusion.
- **Tuberculosis (TB)** - Tuberculosis typically infects the lungs, but in people with HIV/AIDS it can affect other areas of the body as well. Symptoms include coughing, fever, night sweats, weight loss, and fatigue. A person can have an "inactive" TB infection for many years without any significant symptoms, but a weakened immune system will allow it to become active. Fortunately, there are drugs to effectively treat and prevent TB infection. TB spreads through coughing and sneezing.
- **Cancers.** In addition to opportunistic infections, there are also certain kinds of cancer that are more likely to develop in someone who has AIDS and are considered ADIs. These include:
  - **Kaposi's Sarcoma** - This is the most common AIDS-related cancer, but it is not exclusively associated with HIV/AIDS. Among others, transplant recipients and some gay men who are not HIV positive can also get Kaposi's sarcoma. There is some evidence that it may be a herpes-like virus. Initially it causes reddish purple lesions - usually on the skin, but sometimes in the mouth or anus. As it progresses, the cancer spreads to the lymph nodes, intestinal tract, internal organs, and ultimately the heart and lungs. Over time, the frequency of Kaposi's sarcoma among people with HIV/AIDS has been decreasing but it is still common.
  - **Primary CNS Lymphoma** (Cancer of the Lymphatic System that has moved into the brain) - this **Systemic Non-Hodgkin's Lymphoma** is a cancer of the lymph nodes that can spread to other parts of the body, including the liver, bone marrow, and other organs. (Hodgkin's Lymphoma is a very similar but rare type of cancer that progresses in a more orderly, predictable way than Non-Hodgkin's Lymphomas). Symptoms can include fever, fatigue, weight loss, cardiac arrhythmia, and gastrointestinal bleeding. In advanced stages it can move into the brain or central

nervous system, when it is called CNS Lymphoma. People with CNS Lymphoma may experience confusion and memory loss, partial paralysis, and seizures.

- **Invasive Cervical Cancer** - As its name implies, this is cancer in the cervix of a woman. It can cause bleeding and pelvic pain. If not treated, it can spread to involve the bladder, pelvis, digestive tract, liver, lungs, or other organs.
- **HIV Wasting Syndrome** - The final item in the CDC's list of AIDS Defining Illnesses is HIV Wasting Syndrome. Wasting is the loss of 10% or more of body weight, especially muscle mass, without dieting or exercise. When this happens to someone with HIV, it is usually because of poor nutrition (often from loss of appetite or from frequent diarrhea and vomiting), metabolic problems from the HIV infection, opportunistic infections, or side effects of medication.

### ***Incidence Statistics***

- More than 816,000 cases of AIDS have been reported in the US since 1981
- An estimated 950,000 people in the US may be infected with HIV
- 25% of people in the US infected with HIV may not know they are infected
- HIV is the leading killer of African American men ages 25-44
- The annual AIDS-related death rate decreased from 51,670 in 1995 to 15,603 in 2001
- The proportion of women (adult and adolescent) in the US with AIDS increased from 7 to 25% from 1985-2001
- Of new infections in women in 2001, 75% were infected through heterosexual contact and 25% through injected drug use. 64% were black, 18% white, and 18% Hispanic. Percentages of other ethnicities were very small.
- Of new infections in men in 2001, 60% were from homosexual contact, 25% by injected drug use, and 15% heterosexual contact. 50% were black, 30% white, and 20% Hispanic.
- Of people with HIV/AIDS, those who are less likely to be currently employed include people with AIDS (as opposed to HIV), people with more opportunistic infections, people with significant mental health issues, and people who are actively abusing alcohol or drugs.

### **Transmission Facts**

- The most common means of spreading HIV is through unprotected sex with a person who has HIV. The virus enters through the lining of the vagina, vulva, penis, rectum or mouth.
- It is possible to contract the virus through contact with infected blood, but blood transfusions are an unlikely source. Since 1985, health professionals have screened and heat-treated blood products, so the chances of contracting HIV from a transfusion today are very small.
- HIV is not spread through saliva, sweat, tears, urine, or feces.
- HIV is not spread through casual contact or through biting insects such as mosquitoes.
- People who actively abuse substances are at higher risk of HIV/AIDS. Individuals injecting illegal drugs may contract the virus by sharing needles and syringes used by a person with

the virus. Once a person has HIV, continued substance abuse can prematurely weaken their immune system and bring on symptoms more quickly.

- People who have a sexually transmitted disease such as syphilis, genital herpes, or Chlamydia are at higher risk of contracting HIV.

### ***Common Treatments, Medications, and Side Effects***

When a person is diagnosed as HIV+, their physician will begin monitoring the person for signs the infection is advancing to full AIDS. Every three or four months the person will go for a series of blood tests, including a Complete Blood Count (measuring the amount of the various types of blood cells), a Chem Screen (measuring various chemicals in the blood), a T-cell count, and a "viral burden" or "viral load count" test (measuring the amount of HIV virus moving freely in the blood). These regular blood tests will continue even after the person has advanced to AIDS. Although the physician usually won't diagnose AIDS until the blood T-cell count goes below 200, if any of these tests show the infection is advancing significantly, the physician will start the person on antiviral medications to help slow down the progress of the infection.

There are five different categories of antiviral medications used to treat HIV/AIDS. All of them work to prevent HIV from multiplying. There are no drugs that actually kill the virus in the body.

- **Protease Inhibitors (PIs)** - As the name implies, PIs inhibit an enzyme called protease. All body cells use protease in the final stages of making proteins (to maintain the cell's functions) or making copies of genetic material (to reproduce). Viruses reproduce by forcing the body's cells to make copies of the virus' genetic material instead of the cells' own genes. By stopping the process of genetic copying, PIs stop the replication / reproduction of the virus. PIs work on cells in the process of being infected and on cells that are already infected. They are powerful drugs, but they can have powerful side effects and many people have trouble tolerating them.
- **Nucleoside Reverse Transcriptase Inhibitors and Nucleotide Reverse Transcriptase Inhibitors (NRTIs)** - (also called "Nucleoside Analogues" or "Nukes") although the HIV virus works by taking over a cell's DNA, the HIV virus uses a different kind of genetic material called RNA instead of DNA. To put its own DNA codes into the cell's DNA, the virus uses a translation enzyme called Reverse Transcriptase, which makes DNA versions of the RNA using building blocks called nucleotides and nucleosides. NRTIs introduce fake building blocks into the process, which ruins the DNA translations and stops the infection of the cell. Note that this only works for cells that are in the process of being infected, not those already infected.
- **Non-nucleoside Reverse Transcriptase Inhibitors (NNRTIs)** - (also called "Non-Nucleoside Analogues" or "Non-Nukes") Instead of giving the Reverse Transcriptase enzyme faulty building blocks like NRTIs (above), these drugs bind directly to the enzyme and plug it up so it cannot assemble new DNA strands. This achieves the same result, stopping the infection of the cell.
- **Entry Inhibitors** - (including Fusion Inhibitors) these drugs block the "hooks" that the HIV virus uses to latch on to the cell walls of T-cells before entering them and infecting them.

Some Entry Inhibitors block the hooks directly and some block the places to which they bind on the cell walls. Physicians often use these drugs for people whose HIV strain has become resistant to other anti-viral drugs.

Both NNRTs and PIs have a lot of cross-resistance, meaning that once a person becomes resistant to one drug, they are also resistant to other similar medications.

### **HAART**

In the late 1990s, physicians began mixing these drugs into a treatment "cocktail" called **Highly Active Antiretroviral Therapy (HAART)**. HAART usually includes at least three of the drugs described above. This combination therapy has been very effective in slowing down the progress of the HIV infection in individuals and reducing the rate at which an individual's strain of HIV becomes resistant to the drugs. The therapy has revolutionized the field of HIV/AIDS treatment by tremendously extending the life expectancy of people with the disease.

However, these drugs are very powerful and they can have serious side effects. Side effects vary from specific medication to medication, but the more common symptoms include:

- Rash
- Diarrhea
- Headaches
- Nausea
- Peripheral neuropathy (tingling, numbness, or pain in limbs)
- Anemia
- Pancreatitis (inflammation of the pancreas) (severe pain, nausea, weakness, fever, rapid heartbeat, can be life threatening)
- Liver damage
- Muscle inflammation
- Changes in body fat (sometimes called **Lipodystrophy**) (either emaciation from loss of fat or swelling from additional fat in usual areas, including a fattening of the chest and upper extremities, a dramatic swelling of the abdomen, and a swelling of the neck)
- Hypersensitivity reactions (fever, rash, fatigue, vomiting, joint pains)
- Confusion, problems with Concentration
- Dizziness

It is important to note that the drugs and symptoms described above only include direct treatment of the HIV infection. Most individuals will also be taking medications and treatments for various opportunistic infections and other secondary diseases.

People sometimes have problems staying on their treatment regimen because, with so many drugs involved, there can be many contradictory requirements. For example, some of the drugs require that the person take them with food in order to be absorbed in the blood while others require an empty stomach to work properly. Interactions with other medications can either reduce or enhance the effect of other medications, leading to possibilities for either ineffective dosages or overdosing. The regular chem screens (blood analysis) mentioned above help the person's physician monitor the various medications and look for interaction effects or dosage problems.

### **Structured Treatment Interruptions**

Researchers are studying a treatment approach called Structured Treatment Interruptions (STI) or "Drug Holidays," which involves taking a person with HIV/AIDS off antiviral medications for a brief period of time, usually 30 days, even though the medications are controlling the virus well and the viral count in the person's blood is essentially 0. There are several reasons for trying this, but the main reason is a theory that when the concentration of the virus in the person's blood climb back up, the body's immune system may reset itself to fight the virus again. There are anecdotal reports that some people have been able to stop taking antiviral drugs after a drug holiday, at least for a while, and that others have been able to significantly lower the amount of antiviral drugs they need to control the infection. On the negative side, there is a risk that a drug holiday may give the virus a chance to build up resistance to the drugs or that the person may lose their tolerance for the drugs' side effects and have to re-acclimate when the drugs resume. At this point there is very little research on this approach.

### ***Possible Functional Issues***

Functional issues for every disability varies from person to person, but this is especially true for HIV & AIDS because functional issues are a complex interaction of the HIV infection, secondary illnesses, and a wide variety of possible drugs for both.

Common functional issues include:

- Low energy, fatigue
- Depression
- Difficulty with short-term memory and confusion
- Difficulty concentrating
- Light sensitivity
- Severe and persistent diarrhea, nausea, vomiting
- Personality changes
- Problems with motivation
- Peripheral neuropathy (tingling, numbness, or pain in limbs)
- Reduced coordination and fine motor skills

- Vision Impairment
- Difficulty breathing, especially during strenuous or long activity
- Headaches
- Nausea
- Hypersensitivity reactions (fever, rash, fatigue, vomiting, joint pains)
- Dizziness
- Social skills are usually not affected
- Communication skills are usually not affected
- Long term memory and previous cognitive skills are usually not affected (except in late stage dementia)

### ***Initial Interview Considerations***

#### Initial Questions

- When is the person at their best? Do they feel better during the day or evenings?
- What has the person done to help them cope with HIV?
- What is the person's daily routine like? Weekly routine?
- What, if any, side effects do they experience from their medications?
- What other symptoms does the person experience, either from HIV or from secondary illnesses?
- How do their drugs, other treatment regimes, and symptoms functionally impact their life? What things do they have trouble doing?
- What do they do to maintain their health?
- What is their history of symptoms? How long have they had those symptoms? Are the symptoms stable or changing?
- How often does the person see their doctor? How often do they have therapy appointments?
- When was the last time the person was hospitalized? What were the circumstances?
- Do they have any problems with concentration or memory?
- How has the person's family or other support systems reacted to their diagnosis?
- What hobbies does the person have?
- What social groups (churches, clubs, sport's teams) does the person belong to?
- Do they have a problem abusing drugs or alcohol? Has anyone ever told them that they do?
- How often, on average, do they use recreational drugs or alcohol?
- How does the person feel about disclosing their diagnosis?

- How does the person feel about being in public? Would they feel comfortable with a job that involves meeting the public?

### Initial Observations

- Does the person appear to easily follow the conversation? Do they seem to get confused, off-topic, or forget what is being discussed?
- Do they appear to be tired?
- How was their fine motor coordination? How well could they write, for example?

### Interview Accommodations (if any)

- Offer to provide large print documents if needed
- Ask in advance if the person has light sensitivity or any other environmental sensitivities so you can make adjustments
- If you become sick before the appointment, let the person know and give them the option to reschedule

## ***Possible Accommodations and Assistive Technology***

- **General Accommodations**
  - Flexible schedule to allow for doctor's visits, therapy appointments, or unexpected illness
  - Confidentiality options to allow the person to disclose or not as they choose
  - Child care or dependent care supports
  - Benefits planning support, especially around health insurance issues
- **Concentration and Memory Accommodations**
  - Written directions in writing
  - Repeated directions if needed
  - A quiet work space (minimize distractions)
  - Help to prioritize tasks
  - A calendar or planner
  - Increased job structure
- **Diarrhea Accommodations**
  - Workstation located close to a restroom
  - Flexibility to use the restroom when needed
- **Fatigue Accommodations**
  - A parking spot close to the entrance
  - A workstation close to other facilities the person might use (copier, mailroom, restroom)
  - Frequent breaks
  - Job sharing
  - Ability to sit or change positions when tired or weak
  - Flexible work schedule
  - A place to rest or lay down during breaks

- **Light Sensitivity Accommodations**
  - Lower wattage lighting
  - Flicker-free lighting (no fluorescent lights)
  - Appropriate window treatments
  - Workstation placement away from uncomfortable lighting
- **Neurological Accommodations** (seizures, dizziness, numbness) (See seizure disorder for additional accommodations)
  - Modify jobs needing finger dexterity
  - Protective gear (such as gloves)
- **Respiratory Problems Accommodations**
  - Good workplace ventilation
  - Few temperature extremes
  - A work environment free of odors, chemicals, dust
  - A scent-free work environment (ask coworkers not to wear heavy perfumes or other body products or burn candles or potpourri)
- **Visual Impairment Accommodations** (See entry on Low Vision for additional accommodations)
  - Screen reading software
  - Screen magnifiers
  - Large print materials
  - Anti-glare screen
  - Frequent breaks to rest eyes
  - Large button telephone
  - Strong lighting
- **Weight Loss Accommodations**
  - Provide a place to store food or supplements
  - Comfortable/padded office furnishings

### ***Career Planning Issues***

- If the person is experiencing significant mental disorders or is actively abusing drugs or alcohol, consider getting them some treatment or support.
- Always plan long-term. It is important to remember that the progression of the HIV infection is unpredictable. Some people with HIV never develop AIDS. Others live symptom-free with HIV for many years. On the other hand, some individuals develop AIDS soon after testing positive for HIV. Even for individuals with the AIDS diagnosis, it is possible they will be able to work and live independently for many years. With the recent improvements in antiviral drugs, people with HIV/AIDS are surviving longer and with a higher quality of life.
- Keep long-term career plans flexible. It is best to plan for both extremes of the time spectrum - that a client with HIV/AIDS will develop significant functional issues within a year or so or that they will live decades without significant functional issues. Consider ways their career could be scaled back to part-time or transitioned to be partly home-based when needed and what additional supports the person will need at that time. Laying out these options improves the likelihood of a successful career path and helps the person deal with common anxiety over the unpredictability of the illness.

- Consider consulting a Benefits Specialist. Health care and insurance options are especially important to people with HIV/AIDS. If they get insurance, they may be charged 2 to 3 times the usual rate because of their diagnosis, which financially impacts all other areas of their work and life. If the person qualifies for Medicaid, they may be very concerned about losing those benefits if they go back to work. Alternatively, they may be concerned about the long reapplication process if they later quit working again and need to return to Medicaid.
- Confidentiality is often a significant concern for people with HIV/AIDS. You should explore various approaches to the issue and the implications of each, allowing the individual to choose the best solution for different situations.

### ***Emerging Issues***

- New treatments, including preventive vaccines, chemical barriers to transmission, and immune-boosting therapies
- People from ethnic or social minorities with HIV/AIDS

### ***Additional Information Resources***

- The Body - health, workplace, treatment, policy issues and activism: [www.thebody.com](http://www.thebody.com)
- Phoenix Rising Reentry - support materials for decisions about returning to work or school: [www.phoenixrisingreentry.org](http://www.phoenixrisingreentry.org)
- Positive Resource Center - benefits counseling and employment services for people with HIV/AIDS: [www.positiveresource.org](http://www.positiveresource.org)
- AIDSinfo - Information about clinical trials, treatment and prevention, and experimental drugs. <http://aidsinfo.nih.gov>
- AIDSMEDS - health, treatment, living issues plus discussion forums: [www.aidsmeds.com](http://www.aidsmeds.com)