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AIDS (ACQUIRED IMMUNODEFICIENCY SYNDROME)



AIDS (ACQUIRED IMMUNODEFICIENCY SYNDROME)

Caring for a loved one with AIDS is no easy task. Not only does it require physically caring for someone you love at home, but it also means facing your own concerns about the diagnosis and eventual outcome of the disease. Most people fear an AIDS diagnosis in spite of the fact that the disease can generally be treated.

Caregivers of AIDS patients are often their partners. Hearing that your partner has AIDS may make you fear for your own health. It is also a difficult diagnosis because of its stigma. There is the stigma related to the fact that AIDS is generally transmitted sexually or through IV drug use. Many people feel judged because their loved one has AIDS. Then there is the stigma attached to having a potentially life-threatening disease. This makes people uncomfortable, and some friends and family can become distant. At a time when you need it most, you may find it hard to get support.

For more information on how to get support and take care of yourself, please see the "You Have Needs, Too" section.

Physical and emotional care can be time-consuming and exhausting. Many caregivers of people with AIDS have concerns about their loved one's illness and future health prospects. Practical concerns, such as worries about financial issues and time management, are also common. The goal of this chapter is to address some of these concerns.

Learning more about AIDS is an essential first step for caregivers because of widespread myths and fears about the disease. People are afraid of "catching" AIDS and, even today, a diagnosis of AIDS can feel like a death sentence.

It can be difficult to learn about a disease when you do not know where to start. This section provides general information about AIDS, including what caregivers can do to help their loved ones.



What Is AIDS?

Acquired Immunodeficiency Syndrome (AIDS) occurs when infection with the Human Immunodeficiency Virus (HIV) destroys the body's natural protection from illness. The immune system weakens to the point where it can be invaded by "opportunistic" infections and certain cancers. These infections would not cause problems for healthy people. For people with AIDS, they may cause serious or even life-threatening problems.

Blood is an important part of the body's immune system. White blood cells help protect people from disease. Certain white blood cells called T cells perform a crucial role. Some of the T cells are "helper" cells that signal other cells to do their jobs. HIV attacks and destroys the "helper" T cells. When enough cells are destroyed, the immune system no longer works and the patient has AIDS.

(Adapted from information provided by the American Society of Clinical Pathologists, 2001)



Who Gets AIDS?

In the United States, there have been more than 700,000 reported cases of AIDS since 1981. The Centers for Disease Control and Prevention (CDC) estimates that as many as 900,000 Americans may have HIV. AIDS is now the fifth leading cause of death among people between the ages of 25 and 44 in this country.

(Adapted from the National Institutes of Health HIV/AIDS Fact Sheet, December, 2000)

Unfortunately, there are many myths about how HIV is spread. Your loved one's family members and friends may wonder if they can "catch" HIV. The disease is contagious but it cannot be spread from person to person through the air. It is usually spread through sexual contact with an infected partner. HIV can also be spread through contact with infected blood. This can occur when drug users share needles or syringes.

Myths about how HIV is spread

- n Food utensils
- n Towels and bedding
- n Swimming pools
- n Telephones
- n Toilet seats
- n Mosquito bites

Studies have shown that HIV is not spread through these types of casual contact. Although the risks of "deep" kissing are not clear, there is no evidence that the virus is spread through modest contact with saliva, tears, or sweat, or through contact with urine or feces.

Some risk factors increase the chance of getting HIV. Reducing them can lessen the risk of HIV and AIDS:

AIDS risk factors

- n Sharing drug needles or syringes.
- n Sexual contact (including oral, anal or vaginal sex) with someone who is HIV positive or whose HIV status is unknown, without the protection of a latex male condom.
- n Having another sexually transmitted disease such as syphilis, herpes, chlamydial infection, gonorrhea or bacterial vaginosis seems to increase the risk of being infected by HIV during unprotected sexual contact with an infected partner.
- n Babies can be infected by an HIV-positive mother during pregnancy, birth and breast feeding.

Common Symptoms of HIV and AIDS

Many people have no symptoms of HIV. Some have flu-like symptoms a month or two after getting the virus. These may include fever, headache, tiredness, and enlarged lymph nodes (these are organs of the immune system in the neck and groin). These symptoms usually go away before they are identified as HIV.



As the disease progresses, your loved one may develop other symptoms. HIV infected patients may get yeast infections (oral or vaginal) that do not go away or that occur often. Frequent and severe herpes infections that cause mouth, genital, or anal sores are also common. Herpes zoster (shingles) is more likely to occur in infected patients. Other pulmonary infections (such as pneumocystis carinii pneumonia) or so-called atypical mycobacterial infections, can be serious for your loved one. Women may get pelvic inflammatory disease that does not respond to treatment. The virus may attack the nervous system (nerves, spinal cord or brain) and produce a variety of symptoms ranging from tingling in the feet and trouble walking, to memory disturbances.

AIDS-related cancers include those caused by viruses such as Kaposi's sarcoma and cervical cancer, or cancers of the immune system called lymphomas. These cancers tend to be harder to treat in AIDS patients.

Symptoms of Kaposi's Sarcoma

- s round brown, reddish, or purple spots on the skin or in the mouth
- s spots tend to be darker in dark-skinned people

HIV and AIDS symptoms

- n large lymph nodes or "swollen glands" that may be enlarged for more than three months
- n frequent fevers and sweats
- n skin rashes or flaky skin that does not go away
- n short-term memory loss
- n slow growth or frequent illness in children
- n cough and shortness of breath
- n seizures and lack of coordination
- n difficult or painful swallowing
- n confusion and forgetfulness
- n nausea, stomach cramps, diarrhea, and/or vomiting that do not go away
- n vision loss
- n unexplained weight loss
- n fatigue or unusual tiredness
- n severe headaches
- n in children: conjunctivitis (pink eye), ear infections, and tonsillitis

(Adapted from information provided by The National Institute of Allergy and Infectious Diseases, 1999)

For more information on how you can help your loved one with fatigue or other symptoms, please see the "Symptom Management at Home" section.

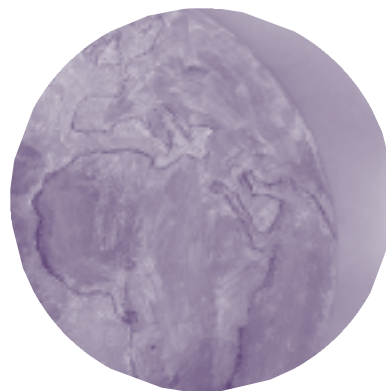
Diagnosing HIV and AIDS

If someone you love has these symptoms and you think they may have HIV, encourage them to see a health care practitioner immediately. There are various ways to make an HIV diagnosis.

Tests for HIV

- s ELISA antibody blood test
- s Western Blot antibody blood test
- s Blood test for the presence of HIV

The antibody tests look for HIV disease-fighting proteins (antibodies). These do not usually reach levels that can be detected until one, three, or even six months after infection. Early detection is important because patients are particularly infectious during the early stage of the disease and can easily pass it on to others. Detection also allows for earlier diagnosis and treatment. Anonymous testing facilities and home-based test kits are available for confidential results.



Diagnosing AIDS

- n Blood test for the presence of T cells.
According to the Centers for Disease Control, patients with less than 200 T cells per cubic millimeter of blood have AIDS (1,000 is a healthy level).
- n The diagnosis of an AIDS-related cancer.
- n The diagnosis of other clinical conditions, mostly opportunistic infections which include fungi, viruses, parasites, and bacterial infections such as pneumonia and tuberculosis.

Hearing that your loved one has AIDS marks a big change in the disease process. The potentially life-threatening nature of the disease becomes more real. You may worry about whether your loved one will get sicker or suffer. If this happens, you may want to take care of him/her but wonder if you can. There is so much for you to think about, yet you might be reluctant to talk to your loved one about your worries. It is important that you get support when you feel like this.

For more information on how to get support and take care of yourself, please see the "You Have Needs, Too" section.

Treatment for HIV and AIDS

The good news is that HIV and its complications often can be treated. With proper treatment, most infected patients can lead relatively normal lives for many years. Even with the onset of AIDS, symptoms can be greatly diminished by treatment. Treatment options include:

AIDS treatments

- s Antiviral therapy known as antiretroviral drugs
- s Treatments for infections
- s Treatments for cancers
- s Treatments for symptoms

Antiviral therapy

Antiretroviral drugs slow the progress of HIV because fewer HIV cells are formed. These are the three classes of antiretroviral drugs:

- 1 Nucleoside Reverse Transcriptase Inhibitors (NRTIs) such as zidovudine (AZT), didanosine (ddI), zalcitabine (ddC), stavudine (d4T), lamivudine (3TC), Comvivor (AZT+ 3TC) and abvacavir (Ziagen).



2 Protease Inhibitors (PIs) such as saquinavir (Invirase and Fortovase), ritonavir (Norvir), indinavir (Crixivan) and nelfinavir (Viracept).

3 Non-Nucleoside Reverse Transcriptase Inhibitors such as nevirapine (Viramune), delavirdine (Rescriptor) and efavirenz (Sustiva).

The preferred treatment is a triple drug combination called Highly Active Antiretroviral Therapy (HAART).

(Adapted from guidelines provided by the HIV/AIDS Treatment Information Service, April 1999)



There can be side effects to treatment:

Antiretroviral Therapy Side Effects

- n Fever and infection
- n Nausea, diarrhea and vomiting
- n Fatigue or tiredness
- n Headaches
- n Skin rash

Other difficulties with antiretroviral therapy include:

- s The therapy can be very expensive.
- s Patients with low viral counts may be less careful because they think the disease can no longer be spread. This is incorrect. Anyone infected with HIV, no matter how low their counts, can spread it to others.
- s Treatment using antiretroviral drugs is complicated. If patients do not take the drugs correctly, their viral counts can go up and/or their HIV can become resistant to the medication.
- s Drugs may bring on diabetes, make existing diabetes worse, or cause hyperglycemia (high blood sugar).
- s Bleeding may increase in people with hemophilia types A or B.
- s Some patients have weight gain and loss in different parts of their bodies.

(Adapted from information provided by the U.S. Food and Drug Administration, July-August 1999)

Early diagnosis of infections and disease complications

Treatment of secondary infections and disease complications is as important as treating the AIDS virus. These secondary complications can be quite serious for your loved one.

- n Radiation and chemotherapy are used to treat Kaposi's sarcoma.
- n Antimicrobial agents are used to treat many opportunistic infections such as pneumonia, tuberculosis, and herpes. Continuous treatment is sometimes required since these infections tend to recur.
- n There has been some success treating cytomegalovirus (CMV) infections with medication. These infections can cause patients to lose their eyesight.

(Adapted from Harrison's Principles of Internal Medicine, 14th Edition. Edited by Fauci, A.S., Braunwald, E., Isselbacher, K.J., et al. New York: McGraw-Hill, 1998)

Managing symptoms and side effects

Be aware of the symptoms of HIV/AIDS and the side effects of treatment. You can help reduce and prevent them. You can also help by knowing when to contact the health care team.

For more information on how and when to effectively communicate with your loved one's health care team, please see the "Navigating 'The System'" section.

Pain Management

Your loved one may experience pain related to AIDS, caused by treatment, or for other unrelated reasons. Abdominal pain, throat pain and headache are some of the most common types of pain experienced. You can help by making sure the patient gets proper treatment for pain when it occurs.

How you can help obtain treatment for pain

- s Find medical practitioners who understand your loved one's AIDS-related pain.
- s Ensure regular visits to AIDS pain specialists.
- s Ask questions of doctors and discuss your concerns.
- s Administer pain medication as prescribed.
- s Offer to massage sore or painful areas, if your physician approves.
- s Encourage the use of relaxation techniques to relieve stress and decrease pain.
- s Find ways to avoid and manage stress in the household.
- s Distract your loved one with activities he/she enjoys.
- s Watch for signs of pain or other discomfort.
- s Help the patient rate and record his/her pain in a daily pain journal.
- s Contact your medical practitioner if pain is not relieved by medication.

Please see the "Symptom Management at Home" section for other information on pain. This includes facts and myths about pain medication as well as details on a daily pain journal. For more information on relaxation techniques, see the "You Have Needs, Too" section of this directory.

Clinical trials

Clinical trials are research studies that evaluate new treatments. Those who take part in clinical trials are some of the first to receive and benefit from new approaches to HIV/AIDS therapy.

These treatments may have been tested with good results. Patients in trials are watched closely by physicians and researchers. For more information on how clinical trials and HIV/AIDS research might benefit the patient, contact the resource centers listed at the end of this section.

Complementary or alternative therapy

Complementary and alternative therapies are treatments that are not routinely used by practitioners of traditional medicine. Some (such as relaxation, visualization, and acupuncture) are so commonly tried that they are really now considered mainstream. They are used in conjunction with traditional therapies. Others are outside of usual medical practice. It is important to research and understand the risks and benefits of these therapies. In addition, it is important to let the patient's medical team know about the use of complementary techniques.

The Bastyr University AIDS Research Center (listed with the resources at the end of this section) is a good source of information on complementary and alternative therapies for HIV and AIDS.

What You Can Do to Help

- n Ask the patient's doctor for medication to help with nausea and vomiting.
- n With nausea, feed your loved one as if he/she had the flu:
 - ▼ Avoid fatty, fried, or spicy foods.
 - ▼ Prepare food for the patient when you can.
 - ▼ Serve food at room temperature or cold.
- n Encourage your loved one to eat even when his/her appetite is poor.
- n Help the patient keep his/her mouth clean; brush teeth at least twice a day.
- n Encourage the use of relaxation techniques to relieve stress and decrease symptoms.
- n Distract your loved one with activities he/she enjoys to decrease pain or other symptoms.
- n Make sure your loved one gets plenty of rest.
- n Help rate and record the patient's pain and/or fatigue in a journal.
- n Help the patient take his/her medications in the correct way.

For more information on how to treat fatigue, nausea, vomiting, or skin problems, please see the "Symptom Management at Home" section.

For more information on relaxation techniques, see the "You Have Needs, Too" section of this directory.

HELPFUL AIDS RESOURCES

Organizations

n National Institute of Allergy and Infectious Diseases

Office of Communications and Public Liaison
Building 31, Room 7A-50

31 Center Drive MSC 2520

Bethesda, MD 20892-2520

<http://www.niaid.nih.gov/daids/>

- This is the primary National Institutes of Health organization for research on AIDS. It provides understandable information presented in a format that is easy to follow, including information on treatment: <http://www.niaid.nih.gov/daids/therapeutics/>; general disease information: <http://www.niaid.nih.gov/factsheets/hiv-inf.htm>; and other HIV/AIDS information.

n The AIDS Clinical Trials Information Service

(800) TRIALS-A (800-874-2572)

(800) 243-7012 (TDD/Deaf Access)

<http://www.actis.org/>

- This service provides information about Food and Drug Administration-approved HIV-related clinical trials being conducted around the United States. It operates from 9 a.m. to 7 p.m. Eastern Time, Monday through Friday. Spanish-speaking specialists are available.

n HIV/AIDS Treatment Information Service

(800) HIV-0440 (800-448-0440)

(800) 243-7012 (TDD/Deaf Access)

<http://www.hivatis.org/atinfo.html>

- This service provides information on federally-approved treatment guidelines on HIV/AIDS. It operates from 9 a.m. to 7 p.m. Eastern Time, Monday through Friday. Spanish-speaking specialists are available.

n National Prevention Information Network

(800) 458-5231

(800) 243-7012 (TDD/Deaf Access).

- Contact this service to get materials for adolescents with HIV or for more information about adolescents and HIV.

n Centers for Disease Control and Prevention

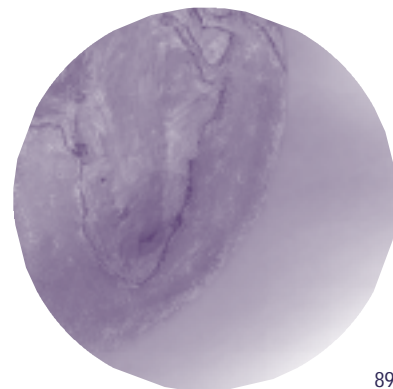
(800) 342-AIDS

(800) 344-7432 - Spanish

(800) 243-7889 - TTY Service

<http://www.ashastd.org/nah/faqs.html>

- This Website provides answers to frequently asked questions and tips on how to live with HIV/AIDS.



- n Bastyr University AIDS Research Center
<http://www.bastyr.edu/research/buarc/>
 - This center is funded by NIH's National Institute of Allergy and Infectious Disease (NIAID) and the National Center on Complementary and Alternative Medicine (NCCAM). It is dedicated to exploring complementary and alternative healing practices for HIV and AIDS.

Websites

- n MEDLINEplus Health Information
<http://www.nlm.nih.gov/medlineplus/aids.html>
 - MEDLINE is a service of the National Library of Medicine that provides excellent links to Websites for a variety of topics related to HIV and AIDS.



- n U.S. Food and Drug Administration
Office of Special Health Issues
<http://www.fda.gov/oashi/aids/hiv.html>
 - This site is a good source of treatment-related information including information on treatment side effects.
- n American Society of Clinical Pathologists
http://www.ascp.org/general/pub_resources/aids/
 - This site provides understandable disease information presented in a format that is easy to follow.
- n AIDS Education Global Information System (AEGIS)
(949) 248-5843
<http://www.aegis.com/>
 - This site claims to be the largest HIV/AIDS Website in the world and is updated hourly. Although it can be difficult to navigate, it contains information or links to information on every facet of the disease, including patient resources. It also offers a section for newly-diagnosed individuals called "The Basics."
- n About.com
<http://aids.about.com/health/aids/>
 - This is a human Internet directory with comprehensive HIV/AIDS information compiled by a professional editor. It offers links to a host of information, including online bulletin boards and chat rooms.

n The Body: An HIV and AIDS

Information Resource

<http://www.thebody.com>

- This Website provides HIV/AIDS information in over 250 topic areas. It also provides an "Ask the Expert" service and bulletin boards on many AIDS-related topics, including some for caregivers.

n Caring for Someone with AIDS at Home:

A Guide

<http://www.hivatis.org/caring/>

- This online guide was developed by the U.S. Department of Health and Human Services. It offers helpful information for the caregiver such as how to provide care and how to protect against infection.

Español/Spanish Information

n Centros Para el Control e la Prevención de Enfermedades

- <http://www.ashastd.org/nah/sida/faqs.html>

n The Body: Información en Español

- <http://www.thebody.com/espanol.shtml>

n ¡Ayudate! (National Institute of Allergy and Infectious Diseases)

- http://www.niaid.nih.gov/publications/help_span/help.htm

