



COPING WITH HIV AND AIDS

An Overview

The Human Immunodeficiency Virus (HIV) causes acquired Immune Deficiency Syndrome (AIDS). The virus attacks and eventually destroys certain white blood cells, a part of the body's immune system that we need to fight off infections.

The immune system makes antibodies to combat the HIV virus. Their presence in the blood can be measured. If a person has the antibodies, they are called "HIV positive" because they have been infected with the HIV virus. However, the person may remain healthy for a long time, even many years. AIDS is the late stage of the illness known as HIV disease, and it occurs when so many white blood cells have been destroyed that the immune system cannot do its job well. The person with AIDS develops infections, even from unusual organisms (opportunistic infections) and various malignancies. HIV virus also can affect the brain and nerves.

There are medications to control the infections and malignancies. There are also medications to slow the growth of HIV. However, right now there is no cure and no vaccination to prevent infection. New treatments are being developed and there is hope that medical research will rapidly find better forms of treatment and prevention.

HIV is spread through the transmission of contaminated body fluids into the body of another person. The entry occurs through broken skin and mucous membranes. Any sexual contact with an infected person (including heterosexuals) can spread the virus. Any cutting into the body with contaminated instruments can cause infection; this includes needles used by IV drug users, unsterilized medical and dental equipment, as well as ear piercing, tattooing and manicure equipment.

Take precautions. **Always** ask if equipment used in medical or cosmetic procedures is sterilized, new or disposable. **Always** practice safe sex. Mothers infected with HIV should also know that they could pass the infection to their children during pregnancy and breast-feeding. However, the virus is not spread by casual contact, such as hugging, holding hands, close conversation, sharing a meal, etc.

Don't assume AIDS can't happen to you or your loved ones. It can. The only absolute treatment is prevention. We must try hard not to stigmatize and isolate those who are infected with HIV or have developed AIDS. If you have questions about what is safe, consult your physician.

Should I be tested for HIV Antibodies?

It is important that you know your HIV antibody status. There are many places where you can take a test anonymously and where no record is kept of your results. Taking the test is also important because early diagnosis and treatment of HIV disease can prolong life and reduce disability. Those who engage in high-risk behavior - such as IV drug use or unprotected (without a condom) hetero or homosexual intercourse should consider taking the test immediately.

In addition, anyone who received blood or blood products prior to screening of the blood supply in 1985 may have been exposed to the HIV virus.

You should never take the test without careful preparation and counseling, however. You should consider the emotional, social, legal, financial and insurance consequences. It often helps to bring along a knowledgeable person whom you trust to help you ask questions that will get you the information you need to make an informed decision in the event you test positive. It is a good idea as well to have an expert with whom you can discuss your results.

What should I do with my test results?

If you are HIV positive, find a physician who knows about HIV disease and with whom you feel comfortable. You will need to work together very closely and will want someone who cares about what happens to you.

If you are HIV negative, consult your physician about the need for future testing and about lifestyle changes you may need to make in order to stay HIV negative.

If I'm HIV positive, should I tell other people?

It is important to tell those whom you may have exposed through sexual contact, needle sharing or other risky behavior. They need to be tested and have the knowledge that allows them to seek medical care. This can be very difficult to do and counseling can help.

You will profit from a network of helpful and supportive people. However, you do need to be careful who you tell. Some people have very strong reactions. Telling your boss and co-workers can have financial and legal ramifications. It is best to start with a few friends or family with whom you feel close and whom you can trust not to tell others. Developing a community of support is a process and takes time. There may be HIV-positive support groups in your area or HIV hotlines that provide education and helpful support.

How does it feel to be HIV positive?

It is normal to have strong reactions such as fear, anger and feeling overwhelmed. Some people even have suicidal thoughts. It is understandable that you might feel helpless and fear illness, disability and death. Other reactions might include:

Denial

Often people who find out they are HIV positive will handle the news by denying that it is true. This denial may come up soon after the diagnosis is made. Denial can be helpful, it can give you time to get used to the idea of infection. But if it goes on too long it can get in the way of your getting the assistance and medical attention you need.

Guilt

It is not unusual for people to blame themselves for illness and to feel it is punishment. This guilt can be worsened by society's prejudice and ignorance about HIV and AIDS. It is important, if you are HIV positive, to seek out those who are accepting and supportive.

Sadness

HIV disease means life changes and losses of one kind or another. Sadness is an understandable reaction. Sadness lifts for most people as they adjust. On the other hand, it can turn sometimes quickly into a more serious problem - depression.

If you are feeling depressed, it is important that you talk about your feelings. Your physician, as well as knowledgeable and supportive friends and loved ones, can help. Remember that there is always help through counseling, and any strong and lasting reaction calls for some kind of assistance.

What other psychiatric reactions are possible with HIV disease?

Many people with HIV disease do not develop serious emotional problems. However, if you develop any of the following reactions it is important that you seek treatment.

Depression - Characterized by prolonged periods of sadness and crying; feeling low or Despairing; feelings of guilt and lowered self-esteem; a tendency to see only the negative side of things; also fatigue, decreased ability to concentrate, loss of pleasure in activities, changes in appetite and weight, trouble sleeping and sometimes, thoughts of suicide.

Anxiety - Characterized by excessive worry, feelings of always being on edge, muscle tension, restlessness and other physical symptoms such as shortness of breath, sweating, rapid heart rate, nausea and diarrhea. They may also appear as sudden attacks of intense anxiety.

Mania - Characterized by an abnormally and persistently elevated mood, or great shifts of mood, often with marked irritability. There is decreased need for sleep, over-activity, rapid talking, poor concentration and racing thoughts. People experiencing mania may also have grand and sometimes bizarre ideas about themselves and impossible schemes for making money and becoming famous. They may engage in spending sprees and other impulsive behavior. They may become very disorganized in their thinking and behavior and be unable to take care of themselves.

Psychotic symptoms - People may have hallucinations; seeing things or hearing things that other people do not. They also may become “delusional,” developing strange, unrealistic, and very unlikely ideas. For example, they may think that even their closest friends are plotting to harm them or that secret organizations are spying on them, bugging their telephone or sending messages by television or radio. These are just a few examples of the many forms psychosis can take.

Alcohol and Drug Abuse - Some people may try to numb their feelings by abusing drugs and alcohol. At times, the person has a history of such problems. At other times, they begin to abuse drugs and alcohol after they learn they are HIV positive or develop symptoms of AIDS.

Difficulties with memory and thinking

Infections, malignancies and nutritional deficiencies that are the results of AIDS can affect brain functioning. Some medications used to treat HIV infection or its complications can also have these effects. HIV itself can infect the brain, causing a condition doctors call AIDS Dementia Complex. Symptoms that might be a signal of trouble include : forgetfulness ; confusion ; difficulty paying attention ; slurred or changed speech ; sudden changes in mood or behavior ; clumsiness or difficulty walking ; muscle weakness or strange sensations, like numbness or tingling. If you have any of these problems you should discuss your concerns with your physician. He or she may suggest the help of a psychiatrist or other mental health professional.

How can a psychiatrist help me?

A psychiatrist will talk with you and take a history in which he or she will ask about your current problems and how you managed your problems in the past. He or she will need to know about any past or present alcohol or drug abuse and whether there is any family history of emotional problems or substance abuse.

The psychiatrist, who is a medical doctor, will need to speak with your other physician(s) and review your medical history. The psychiatrist will ask specific questions to test memory, attention and other aspects of thinking and problem solving. Your psychiatrist will tell you and your physician what he or she thinks is the nature of your problem and will make recommendations for treatment. With your agreement, he or she may provide the recommended treatment if the expertise of a psychiatrist is required.

What treatments are available?

Various forms of psychotherapy may be useful, alone or in combination with medications, in helping people with HIV disease express and understand their emotional reactions and find better ways to cope.

Some problems can be treated with medications. There are anti-anxiety medications and antidepressants, including psycho-stimulants that are safe and effective for use in people with HIV disease. People with mania may need a mood stabilizing medication and those with psychotic symptoms may need an anti-psychotic medication.

There is substance abuse counseling for those with alcohol or drug abuse problems. In some areas of the country, there may be support groups or AA groups for people who have both HIV and substance abuse problems.

Are there other forms of help?

Many areas have community groups that provide services such as food preparation, housing, buddy networks, hotlines and information on how to access medical care. There are also self-help support groups where people with HIV or AIDS can meet with others coping with the same or similar problems. Groups are also available to provide support and services for friends and family members.

If you are HIV positive, are there things you can do to help yourself?

It is important that you see your doctor regularly and that you follow his or her recommendations. You can help by making some lifestyle adjustments. It is important to maintain good nutrition and to get enough rest. If you smoke, try to stop. It is helpful to stop or reduce alcohol use. It is very important to develop social contacts and to enlist the support and help of friends and family.

If you feel that you are alone, it is important to recognize that help and companionship are available. A local community group or hotline that specializes in helping those with HIV disease and AIDS can be a good place to start.

What sort of reaction should I expect from my family and friends when I tell them I'm HIV positive?

Your family and friends will be affected by the consequences of your HIV infection, too. They may also experience feelings of denial, anger, fear and grief. Some, unfortunately, will suffer from the same misunderstandings and prejudices that exist in society at large concerning people with HIV disease. They may also have questions about how they can prevent the spread of the infection, as well as questions about what is to be expected as the consequences of infections.

Discussion with your physician can be helpful. It is important to remember that counseling - including couples and family counseling - is available and can be useful. There are also support groups for spouses, partners and close friends of those with HIV disease.

Resources

- 1) Public Health Service AIDS Hotline: 1-800-342-2437
- 2) National Institute on Drug Abuse Hotline: 1-800-662-4357
- 3) National Sexually Transmitted Diseases Hotline: 1-800-227-8922
- 4) National Gay & Lesbian Task Force AIDS Information Hotline: 1-800-221-7044
- 5) Pediatric AIDS Hotline: (212) 430-3333
- 6) AIDS Support Group - for family members of people living with AIDS, call 513-948-2544 for more information.
- 7) AIDS Volunteers of Northern Kentucky offers several groups; call 513-483-5757 for more information.
- 8) P-FLAG - group for parents, families & friends of lesbians & gays, call 513-755-6150.

Information Sources

- 1) National Association of People with AIDS
1413 K Street, NW, 10th Floor
Washington, D.C. 20005
(202) 898-0414
- 2) AIDS Action Council
1875 Connecticut Ave, NW, Suite 700
Washington, D.C. 20009
(202) 986-1300
- 3) Mothers of AIDS Patients (MAP)
c / o Barbara Peabody
3403 E Street
San Diego, CA 92102
(619) 234-3432
- 4) American Association of Physicians for Human Rights
P.O. Box 14366
San Francisco, CA 94114
(415) 558-9353