

For a person who is living with HIV, it is normal to have strong reactions such as fear, anger, and a sense of being overwhelmed. Some people even have suicidal thoughts. It is understandable that you might feel helpless and fear illness, disability and even 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. Denial can be helpful: it can give you time to get used to the idea of infection. It can, however, cause problems for oneself and others if one engages in risky behavior. And 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 slowly and subtly, sometimes quickly --- into a more serious problem, called depression.

If you are feeling depressed, it is important that you talk your feelings out. Knowledgeable and supportive friends and loved ones can help. The California AIDS Hotline (800-367-2437) can refer you to support groups. If your depression is more advanced, ask your physician about it and obtain referrals for professional counseling. Remember that any strong and lasting reaction calls for some kind of assistance, and there is always help through counseling.

NAMI's public policy on HIV and mental illness

NAMI believes that all persons with brain disorders should be encouraged to be tested for HIV. NAMI believes that persons who test positive should receive appropriate treatment for both their brain disorders and HIV-related illnesses in the least restrictive setting that is safe for all concerned. The results of testing should be shared only on a "need to know" basis and should include families if they are primary caregivers. If families are not primary caregivers, persons with brain disorders should be encouraged to share this information on a voluntary basis.

Persons with brain disorders living in institutional settings have been identified as high risks for HIV infection. Therefore, NAMI believes that all persons with brain disorders in institutional settings should be tested for HIV infection.

NAMI urges that education, counseling, and peer support should be made available not only to the person with a brain disorder who tests HIV positive, but to their family and staff as well.

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San Diego's Voice On Mental Illness

HIV/AIDS and Mental Illness

People with untreated mental illnesses have reduced capacity to deal with additional threats to their well-being, including infection from HIV. Conditions surrounding lack of treatment such as impaired judgment, homelessness and substance abuse make them particularly vulnerable to infection. When combined with secondary naivete about social realities and negligence toward personal safety and health, the risks escalate even further.

HIV/AIDS is epidemic among people with mental illness.

"The average HIV infection rate among adults with severe mental illness is 7.8 percent, nearly 20 times the .4 percent rate estimated for the general population."

Kinnon, Karen; Cournos, Francine, "HIV Infection Linked to Substance Use Among Hospitalized Patients with Severe Mental Illness," Psychiatric Services, Oct. 1998, Vol. 49, No. 10.

"Studies indicate a high prevalence of concurrent tuberculosis infection among mentally ill persons with HIV."

Saez, Helga, et al, Letter to the Editor, American Journal of Public Health, Sept. 1996, Vol. 86, No. 9.

"Across studies, psychiatric patients with identified comorbid alcohol or other drug use disorders have a significantly higher rate of infection from HIV than those without."

Kinnon, et al.

"Generally homeless individuals with mental illness have a greater chance of HIV infection than homeless people without mental illness."

Townsend, Mark; Stock, Mary; Morse, Edward; Simon, Patricia, HIV, TB, and Mental Illness in a Health Clinic for the Homeless, J La State Med 148, June 1996, pp. 267-70.

What other mental health problems are possible with HIV disease?

Many people with HIV disease do not develop serious emotional illness. 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 disorders

Characterized by excessive worry, feelings of being always 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 desire for sleep, overactivity, rapid talking, poor concentration, and racing thoughts. People with this disorder 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 develop 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
- slowed thinking and difficulty finding words

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 specialist.

How can counseling help me?

There are varying levels of professional psychiatric assistance, but in most cases, the counselor you choose will talk with you and take a history in which he or she will ask about your current problems and how you managed 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.

A psychiatrist, who is a medical doctor, will need to speak with your other physicians 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, which can help 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. Support groups and Alcoholics Anonymous groups are also available for persons with HIV and substance abuse problems.

Are there other forms of help?

All major metropolitan areas have community groups that provide services such as meal delivery, housing, buddy networks, case management, hotlines, emergency assistance, financial guidance, and information on how to access appropriate 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 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. Studies show it can also be beneficial if you pursue supplemental resources for medical information, and take a pro-active position in your medical care. 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, even if you need a supportive program to do so successfully. 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. Calling one of the AIDS Hotlines is a good place to start obtaining information on organizations and the services they provide.

What sorts of reactions should I expect from 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 consequence 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 persons who have HIV infection.