



HIV and Your Whole Health

HIV and Your Brain (HIV-Associated Neurocognitive Disorders)

In the 1980s and 90s, before effective antiretroviral treatment, as many as half of all people with HIV developed debilitating brain conditions. The good news is that these conditions are uncommon today in areas where HIV treatment is readily available.

However, HIV still affects people's brains—even when virus levels remain undetectable. In many cases, symptoms can be so mild that people don't notice them. Much remains to be learned about HIV-related brain problems, such as:

- How often they occur
- Who is most vulnerable to them
- Whether and how they progresses from mild to more serious problems
- What medications or interventions could slow or minimize them.

In the meantime, there are things that you can do to keep your brain healthy and functioning well.

What kinds of neurological problems affect people with HIV?

Before effective treatment was available, HIV caused serious neurological conditions including dementia. The terms HIV-associated dementia and AIDS dementia complex were often used. What's more, people with severe immune system damage were at risk for life-threatening brain infections such as progressive multifocal leukoencephalopathy, toxoplasmosis and cryptococcal meningitis. Today, those conditions are uncommon in the United States but still may occur if a person with HIV isn't on suppressive treatment.

Today, the umbrella term HAND (HIV-associated neurological disorders) is used to describe a full spectrum of neurological problems related to thinking, memory, mood, and sometimes physical coordination and mobility. These can range from mild forgetfulness and difficulty concentrating to more debilitating conditions such as dementia.

What causes HAND, and how common is it?

Many factors can contribute to brain problems in people with HIV, including high viral load, low

CD4 counts, AIDS-related illnesses, side effects from HIV meds, persistent inflammation, aging, and depression and other mental health issues.

HIV can pass into the brain, and some studies show that this may happen as soon as two days after the virus first enters the body. HIV can damage nerve cells in the brain, although researchers don't fully understand how this happens.

What's more, HIV infection—even when controlled by antiretroviral treatment—causes inflammation throughout the body. This can damage cells and organs throughout the body, including immune cells that protect the brain, spinal cord and rest of the nervous system.

HAND can happen at any CD4 count, although it occurs more often at levels below 200 as a weakened immune system leaves the brain susceptible HIV and other organisms.

Studies have reported widely varying rates of HAND among people with HIV, ranging from about 15% to around half. One reason for this variability is that many people have mild symptoms that can only be detected using specialized tests. HAND is more common among older people, especially those who have lived with HIV for a long time. The risk appears to be higher among people who have HIV and hepatitis C coinfection, cardiovascular disease and other coexisting health conditions.

What are the symptoms of HAND?

HAND can have a range of symptoms, including changes in the ability to understand and process information (cognition), concentration, memory, emotions (mood), behavior and ability to move the body (coordination).

Some people have such subtle symptoms that they can only be detected using specialized neurological and neurocognitive tests. Others have mild symptoms, such as difficulty recalling names or trouble paying attention. Still others have more severe and progressive symptoms, with dementia being the most advanced form.

Some decline in cognitive function and memory is normal as people age, and it may have nothing to do with HIV. It is not yet known whether people with mild symptoms are at greater risk of progressing to severe dementia. The picture will likely become clearer with more research as the HIV population ages.

Symptoms of mild to moderate HAND may include:

- Slower thinking
- Brain fog (feeling “fuzzy headed”)
- Trouble concentrating or paying attention
- Difficulty recalling facts, names or new information

- Difficulty remembering things that happened in the past
- Trouble learning new tasks
- Sleep disturbances
- Slower reflexes
- Impaired coordination
- Unsteady gait or difficulty with balance
- Feelings of depression, anxiety or irritation

Symptoms of more serious HAND or dementia may include:

- Mental confusion and disorientation
- Trouble solving problems or handling complex tasks
- Inability to concentrate
- More severe memory loss
- Difficulty with speech and communication
- Difficulty with vision and spatial ability
- Insomnia
- Difficulty standing or walking
- Muscle weakness
- Loss of bladder control
- Mood changes including mania, paranoia (excessive fearfulness) or agitation
- Personality and behavior changes
- Isolation and withdrawing from life

Many of these symptoms can be caused by problems other than HAND, including overuse of alcohol and street drugs, clinical depression and coexisting health conditions such as cardiovascular disease or hepatitis C. Some medications can cause some of these symptoms, including HIV meds like efavirenz (Sustiva, Atripla). Older people with HIV may develop dementia that is unrelated to HIV (for example, Alzheimer's disease), and it can be hard to tell them apart.

Let your health care provider know if you experience these symptoms, especially if they are getting worse. Given this wide range of symptoms and possible causes, it may take some time for you and your doctor to figure out exactly what is happening. But determining the cause is the first

step toward appropriate management.

How is HAND diagnosed?

Your doctor will try to rule out all other causes of symptoms before settling on a diagnosis of HAND. If you're having trouble with thinking, memory, mood or coordination, it can be helpful to document those problems in a diary. If HAND is suspected, it may be helpful to consult a neurological specialist familiar with HIV. Tests for HAND include:

- Mental status exam: This includes game-like tests to check cognition, short- and long-term memory and concentration.
- X-rays, CT scans and MRIs: These tests provide images of the brain and spinal cord that can help experts distinguish one type of problem from another.
- Spinal tap: A needle is inserted into the spinal column to collect a small amount of cerebrospinal fluid—the liquid that surrounds the brain and spinal cord. The fluid can be tested for organisms, including HIV, that might be causing problems.

Can HAND be prevented?

It's not yet clear whether, or how, HAND can be prevented, but there are steps you can take to keep your brain sharp and improve your overall mental health.

Maintain an undetectable viral load with HIV meds: Starting and staying on effective antiretroviral treatment is the best way to prevent HAND. Some HIV drugs can cross the barrier separating the bloodstream from the brain and spinal cord. Although it was once considered important to select meds that cross the blood-brain barrier, modern antiretrovirals control HIV throughout the body.

Manage other causes of neurological problems: Many conditions can worsen brain function, directly or indirectly, including cardiovascular disease, high blood pressure, high blood sugar or lipid levels and obesity, especially abdominal fat accumulation. Managing cardiovascular disease helps insure adequate blood flow to the brain. Hepatitis C can be cured with antiviral drugs taken for two or three months. Treating underlying conditions can lessen inflammation that contributes to brain problems.

Get plenty of exercise: Research shows that regular physical activity protects the brain. Experts generally recommend getting at least 150 minutes of moderate aerobic activity or 75 minutes of vigorous aerobic exercise each week. This can include everyday activities such as walking the dog and gardening.

Eat a healthy diet: A healthy diet includes lots of fruits, vegetables and whole grains. Experts recommend limiting consumption of red meat, processed foods and unhealthy fats. Maintaining a healthy weight can improve your overall health and reduce inflammation.

Limit smoking, alcohol and recreational drug use: Smoking cessation improves overall health, and that includes the health of your brain. Ask your provider for help to quit. Limiting alcohol consumption—experts recommend no more than two drinks a day for men or one drink a day for women—and recreational or street drug use can help stave off brain problems.

Stimulate your mind: Research shows that lifetime learning lowers the risk of dementia as people age. Exercising your mind—for example, doing puzzles, playing memory games, joining a book club, taking a class or learning a new language—can help keep your brain sharp.

Stay socially engaged: Social engagement not only promotes a longer life span, but also helps to keep your brain in tip-top shape. Some [AIDS service organizations](#) have support groups for people with HIV to connect with one another. Other options include volunteering with a charity or a political cause, joining a local exercise group, attending religious services, participating in hobby clubs or helping rescue animals. If you're unable to get out of the house easily or if you live in a rural area without many social opportunities, you can connect online. Check the [POZ Forums](#) and connect with others today.

How is HAND treated and managed?

Several approaches can be used to improve HAND symptoms and lessen their impact on quality of life. Recognizing and addressing symptoms early can lead to better outcomes, but advanced HAND or dementia may not be reversible.

Optimize HIV treatment: Effective antiretroviral therapy is key to managing HAND. HIV treatment keeps the virus in check and reduces inflammation. While modern antiretrovirals control HIV throughout the body, switching to or adding HIV drugs that more easily cross the blood-brain barrier may be an option for some people with HAND symptoms that don't improve.

Learn strategies to cope with cognitive and memory problems: There are many tips for dealing with poor memory or difficulty concentrating. These include:

- Keep a diary to write down things you want to remember or need to do. Also make notes about your symptoms to review with your doctor.
- Keep weekly and monthly checklists to help you remember important chores, regular errands and bills that need to be paid.
- Use a pill organizer to sort medications. Fill a weekly pill box with the meds you will need that week and leave it somewhere you'll see it.
- Write reminders or record voice memos on your phone about things that are easy to forget. Did

you take out the garbage? Do you have your keys when you leave the house? Leave sticky notes where you're most likely to see them, such as on the bathroom mirror or on the front door.

- Organize important items you use often. Keep your wallet or purse, keys and eyeglasses in one central place.
- Label cupboards and drawers to remind you of their contents.
- Notify utility companies. At your request, many utility companies will send notices to a family member or friend in the event of overlooked bills.

Make your home safer. People with HAND may have problems with vision or coordination, making kitchens and bathrooms hard to navigate. Organize items into drawers and cupboards and label their contents. Remove throw rugs and don't leave clutter on the floor. Showers can be fitted with grab bars, seats and handheld sprayers. Forgetting to turn off the oven or snuff out candles can be dangerous so install gas detectors and smoke alarms to alert you to trouble.

Seek out cognitive rehabilitation or occupational therapy: This type of therapy is designed to help people relearn cognitive or physical skills they have lost as a result of damage to the brain, and to learn new skills if old ones can't be relearned. Therapists will generally also focus on practical tips for dealing with problems handling everyday tasks. To learn more about cognitive rehabilitation therapy or to find a trained professional [click here](#).

Consider other medications: While HIV meds address the underlying cause of HAND, they may not effectively treat its symptoms. Some drugs for related conditions include antidepressants such as fluoxetine (Prozac) and bupropion (Wellbutrin); antianxiety meds; methylphenidate (Ritalin) to help maintain concentration; and antipsychotic drugs to manage agitation and stabilize severe behavior problems.

Join a clinical trial: Neurological problems among people with HIV is an active area of research, and several experimental therapies are under study. To learn about clinical trials of new treatments for HAND, visit [ClinicalTrials.gov](https://clinicaltrials.gov), call the toll-free number at 1-800-HIV-0440 (1-800-448-0440) or email contactus@aidsinfo.nih.gov.

Find support. It's okay to ask for help or simply talk to others about your fears and concerns. Friends and family members may be a good source of support and help, or you may want additional assistance from a volunteer or paid caregiver. Remember, you do not need to tell everyone in your family—or all of your friends—about your condition.

How do I care for someone with HAND?

People with HAND often do not require full-time care but can use help to help themselves. Offer reminders about chores, errands, medication and bills, as well as practical help. But allow people

with HAND to do as much as they can. Don't rush to finish someone's thoughts if they have trouble finding words, and give them time to respond. Make sure you have someone's full attention before conveying important information. Be patient, as they may require more time to carry out everyday tasks.

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