

## HIV and the Brain

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The brain is a very important organ. It controls every function in our bodies and allows us to think, see,

feel, touch, hear, smell, and move. The brain and the spinal cord (inside your bony spine) make up the central nervous system (CNS).

While we do not know exactly how it happens, scientists believe that HIV enters the central nervous system soon after a person acquires HIV. Afterwards, the virus can lie hidden and inactive in the brain for a long time. Studies have shown that the earlier people start HIV medications once they know they are living with HIV, the less likely brain cells are to be damaged.

Sometimes HIV can damage certain sections of the brain, which can lead to mild cognitive (thinking) problems. This can include difficulty concentrating, confusion, and memory loss. However, this generally does not happen unless a person [has had HIV for a long time](#), has not been taking HIV medications, or has been living with a very high [viral load](#). Over time, these cognitive problems can lead to a more severe problem, HIV-associated dementia. Dementia is a long-lasting condition that can include memory loss, problems with reasoning, and personality changes.

## HIV-Associated Brain Problems

Mild cognitive problems are not uncommon in people living with HIV. HIV-associated neurocognitive disorder (HAND) is a term used to describe a group of conditions that include some combination of thinking, movement, mood, and/or behavior problems. HAND has several forms, ranging from mild to severe, and has a range of symptoms, including:

- reduced ability to think clearly
- difficulty remembering things
- trouble performing movements that require coordination of eyes and hand
- changes in behavior or mood

[Older people](#) may also have some of these symptoms from many causes, whether or not they are living with HIV. This does not mean they have HAND. The diagnosis of HAND is only given to a person living with HIV if other causes have been excluded (such as a stroke, a severe bump to the head, or an infection). See the section below on [Diagnosing HIV-Associated Neurocognitive Disorder](#) for more information.

A more serious form of HAND, called HIV-associated dementia, occurs less frequently, especially since newer HIV medications have become available. People who have a [CD4 cell](#) count below 200 are at risk of developing this condition – generally, the lower the CD4 count, the greater the risk.

HIV-associated dementia refers to a mental and physical state in which a person cannot perform normal activities of daily living without assistance (e.g., counting money, taking medications, preparing meals). This condition can show up suddenly as a dramatic change in behavior, thinking, and movement, or a milder neurocognitive condition can progress to dementia as the immune system slowly gets worse.

## Diagnosing HIV-Associated Neurocognitive Disorder (HAND)

The initial signs of HAND can be very difficult to notice. If you are experiencing memory problems or your family and friends comment on changes in your behavior or coordination, it is a good idea to start keeping a log. Note any problems you are having with:

- Balance or coordination
- Vision
- Memory
- Concentration or attention
- Completing tasks

- Getting lost in familiar places
- Forgetting telephone numbers
- Simple math

It will be important to bring this log to discuss with your health care provider as soon as possible. Even if you feel there is an explanation for the problems, it is important to tell your provider.

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If your health care provider believes you may have memory loss, he or she will likely refer you to a specialist such as a neurologist (a physician who specializes in the brain and nervous system), a psychiatrist (a physician who specializes in mental and emotional health), or a neuropsychologist (a professional who specializes in testing how the mind functions) for a complete exam. This will include "neurocognitive" testing (tests your memory and concentration, reasoning, coordination, and problem solving). These tests can detect small changes in your cognitive ability and provide important information.

You may also need to have a test called a lumbar puncture (also known as a spinal tap) to get a sample of cerebrospinal fluid (a fluid found in the brain and spine). A needle is inserted between the bones of the spine and a small amount of fluid is removed. Lumbar punctures are done with local pain medication so there is not much pain. Many people avoid getting this procedure because it sounds frightening, but the information gained can be very helpful in making a diagnosis and selecting treatments.

Often, diagnosing HAND is a process that involves making sure your problems with memory or thinking are not the result of other, more common causes. There are many factors other than HIV that can cause changes in mental function, including other forms of dementia like Alzheimer's that are not related to HIV. Based on your test results, your provider can identify certain conditions or problems that may be causing these changes, such as [depression](#) or other psychological problems, tumors, excessive fluid in the brain, or injury to the brain.

People living with HIV may be at increased risk for infections of the central nervous system such as:

- Neurosyphilis (syphilis in the brain)
- Cryptococcal meningitis
- [Tuberculosis \(TB\)](#)
- Toxoplasmosis (Toxo)
- Cytomegalovirus (CMV)
- Primary CNS lymphoma
- Progressive Multifocal Leukoencephalopathy (PML)

Some of these conditions can be treated with drugs, or other medical interventions. If these conditions are not the cause of your symptoms, your health care provider may conclude that you are experiencing a form of HAND.

## **Treatment for HIV-Associated Neurocognitive Disorder**

The best way to treat HAND is to control HIV by using HIV medications. It is important to have an open discussion with your health care provider about your ability to take HIV drugs on a regular schedule. If you miss doses, your HIV may become [resistant](#) to the drugs you are taking, and they can stop working. If you are having trouble remembering to get or take your HIV drugs regularly (also known as

[adherence](#)), friends and family members or technologies, such as reminder apps, may be able to help. There are also some tips below for help with memory problems.

Your provider will also consider the specific HIV drugs that you are taking. There is a natural protective barrier, known as the blood-brain barrier, which makes it difficult for many substances, including HIV drugs, to enter the central nervous system. Some HIV drugs cross the blood-brain barrier better than others. Your provider will choose the best HIV drugs for your overall treatment.

You can also consider taking medications to treat the individual symptoms of your HAND, such as memory, behavior, and movement problems. There are medications that can help with each specific area:

- Concentration problems – stimulants such as Ritalin (methylphenidate) and Adderall (dextroamphetamine and amphetamine). It is important to know that people who take these stimulants often become dependent on them.
- Social withdrawal – anti-depressants such as Prozac (fluoxetine) or Zoloft (sertraline). It is important to know that stopping anti-depressants abruptly may cause withdrawal symptoms.
- Behavior that is disruptive or offensive – antipsychotic agents such as Risperdal (risperidone), Quetiapine (Seroquel), and Aripiprazole (Abilify)
- Agitation and anxiety – some anti-depressants can help with anxiety, as can some anti-anxiety drugs.

Several non-HIV medications have been or are being studied to see if they help reduce the symptoms of HAND. Unfortunately, none of them currently offer a meaningful solution to cognitive disorders associated with HIV.

## Help for Memory Problems

Whether you have memory problems due to an HIV-associated neurocognitive condition, another condition, or the normal aging process, it can be very frustrating to have trouble remembering. There are things that you can do without medications that may help. The following tips may be useful:

**It can be very frustrating to have trouble remembering. There are things that you can do without medications that may help.**

- Take time to learn new information – try not to force yourself to remember things when you are under pressure, distracted, or tired
- Use small recorders or note pads to keep track of things
- Put up 'post-it' or 'sticky' notes in important locations
- Use your cell phone to set daily alarms for HIV drugs or other things that you need to remember to do on a regular basis
- Find a system of organizing new information so that it has a connection with an idea, image, or another memory. For example, try associating someone's name with the shape of their face or a letter of the alphabet
- Try new activities during the time of the day when you are at your best
- Remembering involves all five senses. Seeing a name, saying it aloud, and writing it down several times increases the chances of remembering the information
- Break large tasks into smaller sections
- Ask friends or family members to help you remember important things, like taking your HIV drugs regularly. They can remind you of things directly and can help you develop a system for remembering.
- You can also set smart home devices, such as Alexa or Nest, to remind you of daily tasks, such as taking your drugs, or to alert you to upcoming appointments.

You can also keep your brain more agile and healthy by keeping it active and exercising it, just as you would a muscle. Brain exercises include working puzzles (word, number, or jigsaw), playing cards, learning a new language, juggling, playing online brain games or any activity that is new to you – from playing music to dancing to knitting.

## Taking Care of Yourself

Experiencing the symptoms of an HIV-associated neurocognitive condition can be confusing and even frightening. One of the most important things you can do is ask for help. Do not be afraid to start a conversation with your health care provider, family, or close friends about any symptoms you may be experiencing that involve your thinking, behavior, or coordination. Seeking medical help early to find out what is causing the problem and starting treatment, if needed, is very important. People with severe HAND may need to go to a full-time assisted living facility for their own safety and well-being.

**Do not be afraid to start a conversation with your health care provider, family, or close friends about any symptoms you may be experiencing that involve your thinking, behavior, or coordination.**

Taking effective HIV drugs to keep the virus under control is also necessary. However, people with central nervous system problems may need extra help remembering to take their medications. This is where support from family and friends may come in. You can also ask your health care provider and local AIDS service organization for help. Finally, taking your HIV drugs regularly may be the best way to treat and prevent HIV-associated brain problems.

## Additional Resources

Select the links below for additional material related to HIV and the brain.

- [What Can I Do to Keep My Brain Healthy? \(Hello Brain\)](#)
- [HIV and Your Brain \(HIV-Associated Neurocognitive Disorders\) \(POZ\)](#)
- [CROI 2014: Neurocognitive Problems, Depression, and Early ART in People with HI...](#)
- [10 Incredible Foods to Keep Your Brain Healthy \(One Green Planet\)](#)
- [Lumbar Puncture \(Spinal Tap\) \(Mayo Clinic\)](#)
- [Three Promising Diets to Improve Cognitive Vitality \(Cognitive Vitality\)](#)
- [Neurological Complications of HIV \(Johns Hopkins Medicine\)](#)
- [HIV-Associated Neurocognitive Disorder \(HAND\) \(Family Caregiver Alliance\)](#)
- [Human Immunodeficiency Virus \(HIV\) and the Brain \(Encephalitis Society\)](#)
- [Nervous System Effects of HIV \(University of Rochester Medical Center\)](#)
- [Neurological Complications of HIV and AIDS Fact Sheet \(US National Institute of...](#)
- [HIV and Dementia \(Johns Hopkins Medicine\)](#)
- [Neurological Complications of HIV \(University Hospitals\)](#)

