In the 1980s and 90s, nearly half of all people with HIV developed debilitating and life-threatening conditions of the brain. This was very often due to the lack of potent HIV treatment at that time. The good news is that those conditions are rarely diagnosed today, at least not in countries where HIV regimens are widely available.

However, recent evidence suggests that HIV is still affecting people’s brains—even when HIV levels stay undetectable. This is certainly no reason to panic. Symptoms can be so mild that people don’t notice them. Yet, what even low-level neurological damage means over time is something that science is still trying to understand, such as:

- How often it occurs,
- Who is most vulnerable to HIV-related brain damage,
- Whether and how it progresses from a mild to a more serious disorder, and
- What medications or interventions could slow or minimize this damage.

In the meantime, there are things that you can do—such as reducing alcohol and substance use, treating depression and anxiety, and getting physical exercise. All of these can help keep the brain healthy and functioning well.

What kinds of neurological disorders does HIV cause?

Understanding the full range of possible neurological damage when living with HIV is complex. Many factors can contribute to this brain damage: untreated HIV and ongoing inflammation, high viral load, low CD4 count, AIDS-related viral and bacterial infections, older age, living with HIV over a long period, side effects from certain older HIV meds, HIV meds that don’t cross the blood-brain barrier, and depression and other mental health issues.

Earlier in the epidemic before potent treatment was available, HIV caused serious neurological conditions such as dementia or peripheral neuropathy. (The terms, HIV-associated dementia (HAD) and AIDS dementia complex (ADC), were often used.) For many, the immune system eventually became so damaged that life-threatening brain infections occurred as well, such as progressive multifocal leukoencephalopathy (PML), cytomegalovirus (CMV), toxoplasmosis, herpes and
cryptococcal meningitis.

Today, those conditions are rarely diagnosed but are still possible if a person with HIV isn’t in regular care and on suppressive treatment over time. As many more people are now on treatment, symptoms of brain-related damage are often much more difficult to notice or even diagnose. Today, the umbrella term HAND (HIV-associated neurological disease) is more often used to describe the various problems related to thinking, memory and mood, and sometimes physical coordination and function.

What causes HAND, and how common is it?

HIV infection causes inflammation throughout the body. Even when a person is taking HIV meds, low levels of inflammation continue to occur. This in turn can damage different types of tissues and cells, including the immune cells that protect the nerve cells, which make up the brain, spinal cord and rest of the nervous system. When those cells are damaged, the nervous system stops working the way it should.

In one large study, up to half of people were diagnosed with HAND, with most of them having mild or no symptoms. Other studies have found rates as low as 15%. HAND appears to be more common in older people, people co-infected with HIV and hepatitis C, those with cardiovascular disease, those living with HIV for a long time, and those with uncontrolled HIV.

What are the symptoms of HAND?

HAND can have a range of symptoms, depending upon the severity of the condition in a person. In its most severe form, the damage to the brain may be extensive and make it difficult to recover from. Severe problems with memory and the ability to pay attention for periods of time are common. It can also lead to severe mood swings and loss of physical coordination or even incontinence. For a complete exploration of HAND, click here.

With the milder forms of HAND, symptoms may go unnoticed by the person and only the most sensitive tests may be able to detect them. Often, people may not consider symptoms they do notice as anything important to report to their doctors. In people with noticeable symptoms, they can include:

- Difficulty recalling facts, memories or things that you’ve just read or heard
- Trouble paying attention for stretches of time
- Difficulty learning new tasks
- Feelings of sadness, hopelessness or anxiety
- Slower reflexes
- Feeling “fuzzy headed”
These symptoms can be caused by problems other than HAND, including cardiovascular disease, co-infection with hepatitis C, clinical depression, anxiety, and overuse of alcohol or recreational and prescription drugs. Some medications may also cause some of these symptoms, including HIV meds like efavirenz (Sustiva, Atripla).

Given the range of possible causes of HAND, it may take some time for you and your doctor to sort out exactly what is happening. Most providers prefer to rule out other causes before making a diagnosis of HAND.

Does mild or moderate HAND always progress to a more serious disease?

Though researchers are concerned about the high rates of HAND found in some studies—and what they might mean for people as they reach their 50s and 60s, it’s important to note that data are conflicting and incomplete. Up to 1 in 3 people had at least a slight worsening of symptoms over two years while other studies, particularly in people with undetectable HIV, found less progression of HAND, at least over the short-term.

The brain damage seen in people living with HIV is similar to that seen in HIV-negative people with early Parkinson’s Disease and Alzheimer’s Disease. However, no studies show that either disease is occurring at higher rates in people with HIV. It may be years before a clearer picture emerges because studies will have to follow people with HIV who are older than 60.

How is HAND diagnosed?

Most providers will try to rule out all other causes before settling on a diagnosis of HAND. If HAND is suspected, a diagnosis should be sought from a neurological specialist familiar with HIV, who can conduct the kinds of sophisticated tests necessary to make such a diagnosis. So far, however, most providers don’t suggest using such time-consuming and expensive tests unless people are showing troubling symptoms.

That said, not all clinicians who treat HIV routinely screen for neurological and mental health problems. If you think you are having trouble with your thinking, mood, memory or coordination, it can be quite helpful to document those problems—especially if they persist for more than a few weeks—and then ask your provider for a referral to a specialist.

Can HAND be prevented or treated?

It’s not yet clear whether, or how, HAND can be prevented; but experts believe that a number of factors can greatly reduce the odds of developing HAND.

Control HIV: Staying undetectable with HIV meds appears to help a great deal, especially for HAD. Cases of HAD plummeted as many people started potent HIV treatment in the mid-to-late 90s. Effective treatment also appears to limit even milder forms of HAND.

Some HIV drugs can cross the barrier between the brain/spinal cord and the bloodstream. As a
result, they may help to protect the immune cells in the brain. However, studies have not yet shown whether using one or more of these drugs in a regimen can prevent HAND. So far, the drugs that are known to cross the blood-brain barrier include:

- abacavir (Ziagen, Epzicom, Triumeq, Trizivir)
- darunavir (Prezista, Prezcobix, Symtuza)
- emtricitabine (Emtriva, Atripla, Biktarvy, Complera, Descovy, Odefsey, Stribild, Symtuza, Triumeq, Truvada)
- efavirenz (Sustiva, Atripla)
- fosamprenavir (Lexiva)
- indinavir (Crixivan)
- lopinavir (Kaletra)
- maraviroc (Selzentry)
- nevirapine (Viramune)
- raltegravir (Isentress)
- zidovudine (Retrovir, Combivir, Trizivir)

Treat other causes of neurological problems: Many conditions can worsen brain function, directly or indirectly. CVD—high blood pressure, high lipid levels, gut fat accumulation, etc.—can stress the brain in several ways. First, some forms limit the oxygen that gets to the brain. Second, nearly all CVD causes inflammation throughout the body.

Co-infection with hepatitis B and C can also lead to more inflammation in the brain, as can chronic kidney and liver disease. Researchers also point out that chronic depression, anxiety and other mood disorders are tied to greater inflammation in the brain. Addressing these conditions can sometimes ease neurocognitive symptoms.

Get plenty of physical exercise: Many studies confirm that regular aerobic exercise protects the brain significantly. Though a provider should confirm you are healthy enough for exercise, most people can at least take daily walks. Experts generally recommend at least 30 minutes of exercise that raises your heart rate five days per week in order to see the best benefits in preventing or slowing the development of neurological problems.

Stay socially engaged: This not only promotes longer life spans, but it 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. Volunteering with a charity or a political campaign that works on causes you believe in can also help you connect with others. Other options include joining a local exercise
group, going to church or helping rescue animals. The website meetup.com can be a way to find others who share your interests and hobbies.

If you are unable to get out of your house easily, or if you live in a rural area without many social opportunities, it is possible to connect with others in online forums. Check the POZ Forums for topics that interest you, and begin connecting with others today.

Stimulate your mind: In a number of studies, lifetime learning has been associated with a lower risk or lower severity of dementia as people grow older. No studies have confirmed that the same thing is true in people with HIV, but it certainly couldn’t hurt to engage in things that make you learn new information or skills. Such activities can include enrolling in a class, playing logic and memory games, or joining a book club.

Seek out cognitive rehabilitation therapy: This is designed to help people relearn cognitive skills they have lost as a result of damage to the brain, and to learn new skills if old ones can’t be relearned. A variety of techniques, some involving the use of computers, can be used to help with skills development. 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.

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