HIV-Associated Neurocognitive Disorders (HAND) refers to a spectrum of neurological diseases of the brain. Earlier in the epidemic, the phrase AIDS dementia complex (ADC) was used, as well as HIV-associated dementia (HAD). Today, HAND is used to describe a range of diseases of varying severity—from milder forms of cognitive impairment to more debilitating conditions such as dementia. Most AIDS-related illnesses are caused by other infections such as bacteria, fungi, viruses, etc., but HAND is one of few illnesses directly caused by HIV.

HIV can pass into the brain. In fact, some studies show that HIV enters the brain in as few as two days after the virus first enters the body. The virus can damage nerve cells in the brain, although researchers don’t fully understand how this happens.

HAND can happen at any CD4 count, although it occurs more often at counts below 200. This is because the immune system plays a major role in protecting the nerves in the brain. If the immune system weakens, HIV and other organisms can damage these nerves and affect the way the brain works.

It has been estimated that 20–35 percent of all people living with HIV will eventually develop some symptoms of HAND. However, the number of cases of HAND is much lower today, thanks to the availability of potent HIV treatment.

What are the symptoms?

There’s no standard course of how HAND develops, so it can vary quite a bit from person to person. In one person it may be very mild with periods of varying difficulties, while in another it can be abrupt, severe and progressive.

HAND is described by changes in four areas: a person’s ability to understand and remember information (cognition); behavior; ability to move their bodies (coordination); and emotions (mood). When symptoms are related to these areas, then HAND may be the cause.

Sometimes symptoms—especially mild ones—are overlooked or dismissed by providers. What can help is to write down symptoms and the dates as you experience them and show the diary to your health provider.
The symptoms of early dementia include:

- Slowed thinking
- Trouble learning new things
- Difficulty remembering things that happened in the past
- Difficulty concentrating
- Changes in behavior
- Confusion
- Depression
- Feeling irritated
- Unsteady gait or difficulty keeping balance

If dementia progresses, it can cause the following symptoms:

- Speech problems
- Vision problems
- Walking, balance, coordination and concentration takes a lot of effort
- Symptoms of muscle weakness
- Loss of bladder control
- Mania (an exaggerated feeling of well-being) or psychosis (a loss of contact with reality)
- Isolation, withdrawing from life
- Confinement to bed

How is it diagnosed?

It is important to remember that brain-related symptoms can have many different causes, such as depression or other infections such as PML, lymphoma and toxoplasmosis. So, it is often necessary to conduct different tests to determine the actual cause(s) of the symptoms. The most common tests are:

- Mental status exam: This includes game-like tests to check short- and long-term memory, concentration and mood swings.
- X-rays, CT scans, and/or MRI: All are painless and provide doctors with images of the brain and
spinal column. Different diseases cause different types of damage to the brain and/or spinal column, so experts can usually distinguish one type of image from another.

- **Spinal tap**: A needle is inserted into the spinal column to drain a small amount of cerebrospinal fluid—the liquid that surrounds the brain and spinal column. The fluid can be tested for organisms that might be causing symptoms, including HIV.

**How is it treated?**

Potent HIV treatment is the most effective treatment for HAND. This helps to prevent HIV from producing at a level that can overwhelm the brain and cause symptoms of HAND. However, some HIV meds may be more effective than others.

Although using meds that cross the blood-brain barrier to treat infections like PML was effective earlier in the epidemic, it’s unclear whether this is still necessary today. Newer medications appear to control HIV throughout the body more durably over time, which may limit the need for using HIV drugs that can reach the brain. Still, for some people with HAND symptoms that don’t improve, switching or adding HIV drugs that penetrate the blood-brain barrier may be an option.

These HIV meds cross the blood-brain barrier and may help stop or slow HIV damage in the brain:

**Nucleoside Reverse Transcriptase Inhibitors (NRTIs):**

- **Retrovir** (AZT)
- **Zerit** (d4T)
- **Epivir** (3TC)
- **Ziagen** (abacavir)

**Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs):**

- **Viramune** (nevirapine), high levels of this drug can cross into the brain
- **Sustiva** (efavirenz)

**Protease Inhibitors (PIs):**

- **Agenerase** (amprenavir)

AZT was one of the first drugs studied for treating ADC, which found that it was helpful for patients with symptoms. Based on these results, experts agree that other drugs that cross the blood-brain
barrier—especially when used together—can help halt or reverse symptoms of HAND.

While HIV meds can treat the underlying cause of HAND, they may not effectively treat the symptoms. Some people may see their symptoms disappear slowly, while others may simply stay the same. Sometimes, symptoms can actually get worse. Thus, it might be necessary to use other medications, such as:

- **Haloperidol (Haldol):** Is used to treat various symptoms often seen in dementia.
- **Methylphenidate (Ritalin):** While used to treat attention deficit disorder in children, it can also be used to help people maintain their concentration.
- **Chlorpromazine (Thorazine), thioridazine (Mellaril):** These anti-psychotic drugs can be used to control agitation and stabilize severe behavior problems.
- **Lorazepam (Ativan), diazepam (Valium):** These are anti-anxiety/sedative drugs.
- **Antidepressants:** These include fluoxetine (Prozac) and bupropion (Wellbutrin). Antidepressants can help boost (or prevent) important electrical impulses in the brain, which may help ease behavioral and emotional symptoms of ADC.

Can it be prevented?

HAND is the result of two situations: immune suppression caused by HIV and the direct effects of HIV in the brain. HIV meds, particularly those in the last section, can help prevent HAND, provided that treatment is started before immune suppression occurs (less than 200 CD4 cells).

Learning to live with HAND is more than just medications. Even though HIV meds are often very helpful, they may not completely reverse the symptoms. It may be necessary to come up with some coping strategies to make your life easier.

Here are some healthy tips for people living with HAND:

- **Find support.** It’s okay to ask for help or to simply have people to talk to about your fears and concerns. Friends and family members are usually a great source of support and help. However, this does not mean that you need to tell everyone in your family—or all of your friends—about your condition.
- **Learn about dementia.** As is true with almost every aspect of HIV and AIDS, you have a right to know about your condition and what may happen in the future. It’s important to talk with your doctor about your progress and discuss treatment options that may be available to you.
- Keep active! One of the first things that many people with dementia do is to withdraw from certain activities—whether it’s spending time with relatives, visiting friends, spending time outdoors, or hobbies. Having HAND can cause anxiety, so many people limit their activities as to reduce frustration or feel as if they are burdening others. But these activities are very important. Everyone needs to feel useful and to have a sense of purpose.

- Keep a diary. It can be very helpful to write down things you want to remember or need to do. Keeping these notes in the same place, such as in a notebook or diary, can help you keep your thoughts together or review with your provider.

- Keep a weekly checklist on the fridge. No matter how many times you’ve done the same chores or run the same errands week after week, HAND might impair your ability to remember each and every task. Make a checklist of all your regular chores and errands and make duplicate copies of the list. Check off each task you complete. When the list is completed, replace it with a new one.

- Write important reminders to yourself. Do you forget to turn off the oven? Do you forget to walk the dogs? Do you remember to take the garbage out? By writing notes to yourself and sticking them where you’re most likely to see them every day—on the bathroom mirror, above the coffee machine, etc.—you’ll be providing yourself with reminders that are hard to miss.

- Keep important things together. Instead of scattering important things like money, keys, and eyeglasses around the house, it’s best to keep them in one central place. Electronic tags can be attached to these items to help locate them.

- Label cupboards and drawers. It can be very frustrating to know that you have something in your house but you don’t remember where it is. Try putting labels on cupboards and drawers to remind you of their contents.

- Notify utility companies. Forgetting to pay your phone bill, cable bill, or gas/electricity charges every now and then is common. But forgetting to pay the bills on a regular basis can result in service disconnections, which can be scary and frustrating to deal with. Most utility companies can send notices to a family member or friend in the event of an overlooked bill. This can be very helpful, as a reminder from a loved one may be much more pleasant than a warning from
a utility company. You must request this service. It is almost always free-of-charge, although it’s not necessary to disclose the details of your condition to customer service.

- Install gas detectors and smoke alarms. Forgetting to turn off the oven or snuff out candles can be dangerous. Gas detectors and smoke alarms can alert you to trouble before it turns tragic.

To learn more about living with dementia, your doctor can refer you to an occupational therapist.

For people living with HIV who have HAND, learning to cope with the symptoms can be frustrating. It can also be frustrating for friends and relatives who want to help but don’t quite know how. After all, none of us were born knowing how to care for someone with dementia. For more information, we strongly encourage caregivers to seek out the expert advice of an occupational therapist.

Here are some basic tips for people caring for someone with dementia.

- Help those with HAND to help themselves. People with HAND are not infants and do not need to be waited on hand and foot. In the previous section, we discuss ways in which people with HAND can help themselves. Help to put these basic tips into action.
- Patience will be your finest virtue. You must give people with HAND space to keep them doing as much as they can. Don’t take over! Let them make mistakes or fail, but don’t let them feel like a failure. Help them not to give up.
- Don’t let them become overwhelmed. Watch carefully for signs that they are blanking out or becoming anxious about certain functions.
- Post reminders about household chores. People with HAND don’t necessarily need help doing chores around the house. What they may need is help remembering what chores need done. Put signs around the house or weekly checklists on the fridge.
- Make bathrooms and kitchens safer. These rooms are often cluttered places. If someone with HAND has problems with vision or coordination, navigating these areas can be scary and frustrating. Put items into drawers and cupboards and label their contents. Purchase groceries that come in plastic containers, not glass; and transfer products from glass containers into plastic containers. Toilets and showers can be easily fitted with grab bars, seats, and handheld shower sprays.
• Improve communication skills. This is very important. If someone with HAND is watching TV and you want to ask a question or have a conversation, get his or her attention first or mute the TV. It can be difficult to focus on too many things at once. Also, don’t rush into something because they can’t think or speak fast enough to let you know whether they agree. Try to give time to respond.

Are there any experimental treatments?

If you would like to find out if you are eligible for any clinical trials involving new treatments for HAND or ADC or HAD, visit ClinicalTrials.gov, a site run by the U.S. National Institutes of Health. The site has information about all HIV-related clinical studies in the United States. For more info, you can call their toll-free number at 1-800-HIV-0440 (1-800-448-0440) or email contactus@aidsinfo.nih.gov.

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