

HIV-Associated Neurocognitive Disorder (HAND)

Early assessment, diagnosis and treatment are key

The Facts

- When a person first contracts HIV, the virus immediately affects many different cells and organs throughout the body, including the brain.
- When a person living with HIV develops symptoms that cause cognitive, motor, and/or mood problems which impact a person's attention, concentration, and memory; causing a loss of motivation; irritability; depression; and slowed movements, this is normally diagnosed as HIV-Associated Neurocognitive Disorder (HAND).
- While HAND is a HIV-related condition that around 20-40% of people living with HIV *might* develop over time, *not all* people living with HIV will develop HAND *or have* the same risk for HAND.
- Early assessment, diagnosis and treatment are the keys to a better outcome for anyone diagnosed with HAND.
- Starting HIV medication early after diagnosis, and staying on HIV medication as prescribed, is the best way to reduce the risk of HAND.
- Research shows that the most cognitive changes in people living with HIV are due to non-HIV causes, such as ageing or age-related comorbidities (two or more medical conditions).

HAND Symptoms

- For most people living with HIV who are stable on HIV treatment, HAND cognitive symptoms can be subtle and not noticeable unless a neuropsychological assessment is conducted.
- In rarer instances it can be more severe and obvious. In this case, you should consult a doctor as soon as possible.
- Most common symptoms of HAND in people who are stable on HIV treatment includes difficulties with short-term memory, slower thinking, and difficulty in learning new information.
- People can be aware of those symptoms, but not always, in some instances other people will be the first to notice.



Adahps

A free confidential service for NSW residents which offers assessment, support, and referral service for people living with HIV and complex needs.

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Monday - Friday 8:30am - 4:30pm

HAND Symptoms cont'

- The **cognitive changes** in your thinking, can show in your everyday life, as forgetting things more often, losing track of conversations, difficulty finding your words, or missing appointments and having difficulty organising stuff in your life.
- **Mood changes** can also happen such new or increasing levels of depression, anxiety, irritation or apathy, or greater frustration and intolerance of things that didn't bother you before.
- There can also be **physical changes** like tripping or falling over more, bumping into things, unexplained bruises or losing track of time, although those are more common in people with more severe HAND.
- Whether these changes are due to only ageing or HIV **and** ageing, the best strategy is to prevent as many changes as possible regardless of their causes.
- The best way to prevent HIV-related cognitive change is to receive early treatment, therefore if these changes have started to happen more often for you in the last twelve months, particularly if a partner, friend or family member says something, then it is time to talk with your doctor.
- For this meeting, it's a good idea to take a support person with you when you see the doctor and prepare what you're planning to say.

Testing and Diagnosis

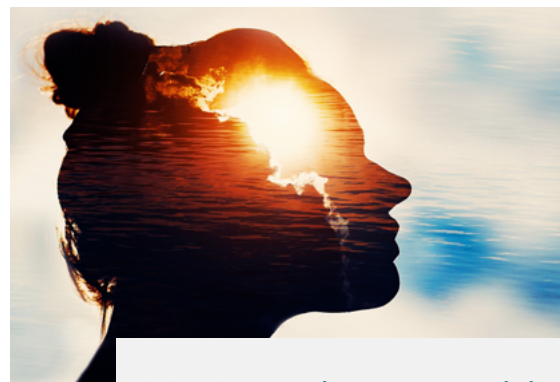
- You should visit your GP and get a referral to a neurologist (brain, spinal cord and nerve specialist doctor). A HIV Neurological Specialist is best to assess you for HAND.
- HAND is diagnosed through a series of painless, non-invasive assessments.
- Diagnosis is a combination of excluding other causes such as depression, sleep apnea, substance use, or various types of neurological illnesses including non-HIV dementia and working out what needs more investigation.
- Assessment for HAND also includes a neuropsychological evaluation which is a question and answer type screening test and a brain scan (MRI), and if necessary a lumbar puncture.
- A diagnosis of HAND does not mean your life is going to significantly change. It can mean a change in your HIV medication. It also means that you will start to learn skills to manage your thinking changes with the appropriate specialists that the neurologist will refer you to.

Treatment

- Adapting your HIV treatment for HAND can result in improving your symptoms, slowing them down or even reversing them.
- Treatment for HAND means you'll be able to get help to develop some new strategies and techniques to manage the impact of HAND on your life – socially, at work and home. These can include reminder alerts, brain training activities, and healthy changes to diet and exercise, and being proactive about mental health as well.
- Most people continue living productive and engaged lives with HAND.
- Research suggests that a combination of a heart-healthy diet, good nutrition, regular physical exercise, along with mental and social engagement can boost benefits for people diagnosed with HAND.

If you're concerned or worried

- An early assessment can put your mind at rest. The sooner you know what's going on, the better position you're in to deal with it, manage it and get on with life.
- If you have some concerns, talk about these with people closest to you and bring them up with your doctor and ideally bring a support person with you.
- Avoiding the problem will only make it worse and add to your feelings of anxiety.
- A HAND diagnosis does not always mean you need to stop working. Rather, it will more likely mean re-think the kind of work you do, reduce the demands in your role, or the number of hours you work.
- Positive Life NSW can offer support and understanding for anyone living with HIV who might be concerned about symptoms or being diagnosed with HAND.



“The best thing anyone living with HAND can do, is to maintain a good diet and remain engaged, productive and physically active. “

For more information phone 02 8357 8386 or 1800 245 677 (freecall) or visit www.positivelife.org.au

Updated November 2024

The voice of all people living with HIV

Positive Life NSW