

HIV AND HAND

LOOKING AFTER YOUR BRAIN: HIV-ASSOCIATED NEUROCOGNITIVE DISORDER (HAND)

WHAT IS HAND?

HIV can sometimes affect how your brain works.

HIV-Associated Neurocognitive Disorder (HAND) is the group of conditions that affects changes in memory, thinking, movement, or mood that can occur when HIV affects the brain.

These changes can be mild or more serious. Even with HIV treatment that keeps the virus under control, some people may still experience neurocognitive problems because HIV can affect the brain and nervous system.

WHY DOES THIS HAPPEN?

- HIV can enter the brain and cause inflammation.
- Other health problems, such as high blood pressure, diabetes, or depression can also affect brain health.
- If your immune system was very low before starting treatment, some damage may remain.
- Delay in starting HIV treatment.
- Ageing can increase the risk of HAND.

WHAT TO LOOK OUT FOR

HAND can show up slowly.

You might notice:

- Memory changes such as forgetting things more often, trouble focusing or paying attention, slower thinking or finding it hard to follow conversations.
- Mood and sleep changes such as feeling less motivated or more irritable, changes in sleep patterns, anxiety.
- Physical changes such as clumsiness, tripping, or moving more slowly.

If these things start happening more often, don't ignore them. They can have many causes and your doctor can help work out what's going on.

TALKING WITH YOUR DOCTOR

If memory or mood changes are affecting your work, relationships, or daily life, reach out for help.

You can talk to your GP, HIV doctor, or HIV support service.

Early action makes a big difference. It's okay to start the conversation early. You could say: *"I've noticed my memory and concentration haven't been as good lately. Could this be related to my HIV?"*

Your doctor might:

- Ask questions about your symptoms and daily life.
- Do a quick memory or thinking test.
- Order brain scans or blood tests.
- Refer you to a brain specialist (neurologist or neuropsychologist).

WHAT CAN HELP

With appropriate care and support many people living with HAND experience improvement or remain stable over time.

You can:

- Take HIV medicine every day and keep your viral load undetectable. Things that might help are using a pill box, setting a timer, phone reminders.
- Get support for your physical and mental wellbeing. Things that might help are getting a good sleep and staying socially connected.
- Be active - regular exercise supports brain health.
- Eat well - plenty of fruits, veggies, and whole foods.
- Use reminders and routines - calendars, phone alerts, sticky notes and creating a shopping list.
- Join a support group.
- Stay mentally active - read, learn new skills, do puzzles, talk with others.

USEFUL CONTACTS

Pozhet (Heterosexual HIV Service)

Support, information, referrals for heterosexuals living with or at risk of HIV.
Website: www.pozhet.org.au
Email: pozhet@pozhet.org.au

Multicultural HIV and Hepatitis Service (MHAHS)

Information and support for individuals and communities from culturally diverse backgrounds.
Phone: 1800 108 098
Website: www.mhahs.org.au
Email: info@mhahs.org.au

Positive Life NSW

Positive Life NSW is a peer-led and run community organisation which provides free services for all people living with HIV in NSW. This includes peer support (by and for people living with HIV), HIV health, wellbeing, prevention, testing & treatment information, social groups and activities, referrals, & counselling services.
Phone: 1800 245 677
Website: www.positivelife.org.au
Email: contact@positivelife.org.au

ADAHPS

Provides assessment, support, and referral service for people living with HIV and complex needs.
Phone: (02) 9382 8600
Website: www.health.nsw.gov.au/adahps
Email: adahps@health.nsw.gov.au

Bobby Goldsmith Foundation (BGF)

Provides financial and practical support, case management, and programs to help people living with HIV maintain their independence and quality of life.
Phone: (02) 9283 8666
Website: www.bgf.org.au
Email: info@bgf.org.au

HIV/AIDS Legal Centre Inc. (NSW) (HALC)

Provides a free and comprehensive legal assistance to people in NSW living with HIV and Hepatitis.
L5, 414 Elizabeth St, Surry Hills
Phone: 9206 2060
Email: halc@halc.org.au
Website: www.halc.org.au

ACON

An organisation addressing HIV prevention, providing HIV support and health matters for lesbian, gay, bisexual, transgender and intersex (LGBTI) communities.
414 Elizabeth St, Surry Hills
Phone: 9206 2000
Email: acon@acon.org.au
Website: www.acon.org.au