



LIVING WITH HIV-ASSOCIATED NEUROCOGNITIVE DISORDERS (HAND)

**Information for people living with HIV and HAND,
their partners, families and friends**

**ALZHEIMER'S IS ONE FORM OF DEMENTIA
AUSTRALIA IS TACKLING THEM ALL**

This booklet has been produced by Alzheimer's Australia Vic for people living with HIV and HAND, and their partners, families and friends. It is part of the Dementia and Chronic Conditions Series: HIV-Associated Neurocognitive Disorders Toolkit, which has been developed primarily for community care workers. The information and recommendations it contains are based on independent research, expert opinion and scientific evidence available at the time of writing. The information was acquired and developed from a variety of sources, including but not limited to collaborations with the Burnet Institute and Living Positive Victoria.

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Living with HIV and HAND

HIV stands for human immunodeficiency virus. People with HIV can live well if they take medicines and look after themselves in other ways, such as being physically active, eating well, and being socially connected.

HAND is HIV-associated neurocognitive disorders. Some people with HIV get HAND.

HAND affects people differently, and the support needs of someone living with HAND vary over time. The information in this booklet will be useful at different times. We encourage you to share it with your partner, family and friends, and keep it for future reference.



'I feared getting dementia but testing told me that was not happening and worrying was just making things worse!'

Key Messages

- HIV can damage the brain. This can lead to a range of medical conditions called HIV-associated neurocognitive disorders (HAND). Symptoms of HAND vary from person to person. In most people, symptoms are mild, or may only be picked up with special medical tests.
- **Most people with HIV do not develop HAND; HAND affects approximately one in five, or 20%, of people living with HIV.**
- **HIV treatment is the best way to prevent HAND.**
- **Early diagnosis of HAND and its treatment can lead to regaining abilities.** Be familiar with the signs of HAND and follow up any concerns as soon as possible.
- Signs of HAND may include forgetfulness, lower performance at work, difficulty with finances or organising meals, and reduced driving ability. These signs can also occur in a person with HIV for other reasons, such as depression, anxiety, or alcohol and drug use. The different possible causes should be investigated before any diagnosis is made.
- **For people who have HAND, starting HIV treatment is the best way to treat HAND.** For people with HAND who already take HIV medicines, speak to your doctor. Different HIV treatment may help.
- In a small number of people, symptoms of HAND can be very serious, and these people have HIV-associated dementia (HAD).
- HAND is different from other types of cognitive impairment and dementia such as Alzheimer's disease. The symptoms of HAND are different, and HAND is treatable. **HIV medicines can reduce HAND and allow recovery of functions.**
- Fear of stigma and discrimination can make people with HIV less likely to discuss problems, including those that might be caused by HAND. **Peer support and professional counselling by people experienced in this area can help manage such fears.**
- Support for people living with HAND is available from many organisations and services. These include Alzheimer's Australia, HIV community organisations, Royal District Nursing Services, home care workers and respite services.

What is an HIV-Associated Neurocognitive Disorder (HAND)?

HAND can affect cognitive (thinking) functions such as memory, language, attention, concentration, planning, judgement and doing difficult things. HAND can reduce a person's independence and quality of life.

HAND can be mild to severe, depending on seriousness of symptoms and their impact on daily life.

- **Asymptomatic neurocognitive impairment (ANI)** mildly affects thinking abilities and is only identified with special medical tests. The person living with ANI and those around them do not notice any symptoms.
- **Minor neurocognitive disorder (MND)** affects thinking abilities to a noticeable extent and may mildly interfere with activities of daily living.
- **HIV-associated dementia (HAD)** seriously affects thinking abilities and significantly interferes with activities of daily living.

HAND affects approximately one in five, or 20%, of people with HIV. The most common type of HAND is the mild type (MND); the next most common is ANI. So it is likely that most people with HAND have mild symptoms or no noticeable symptoms. In Australia, where most people who are HIV-positive have access to HIV antiretroviral treatment, the most severe type of HAND (HAD) is rare.

HAND is different from other more common types of cognitive problems and dementia such as Alzheimer's disease. Other types of dementia usually cause a permanent decline in ability; this is not the case with HAND. If a person diagnosed with HAND receives the right HIV medicines, their cognitive function can be stabilised and improve.

What is the cause of HAND?

HIV infects certain cells in the brain. The infection can cause cell damage, inflammation and the production of chemicals that harm other cells in the brain. Damage in the brain can build up over time. Eventually this can affect parts of the brain involved in information processing and thinking.

Excessive alcohol consumption and recreational drug use or medical problems such as diabetes, high blood pressure and high cholesterol may add to the damage that occurs in the brain, in addition to the effects of HIV.

People with HIV are living longer. New information suggests that living with HIV for a long time *itself* may affect how well the brain works.

You should discuss any concerns about your memory or thinking with your doctor as soon as possible. If you are worried that HIV is affecting your thinking abilities, you should have this investigated.



What are the signs and symptoms of HAND?

The signs and symptoms of HAND vary from person to person and can change from day to day.

Thinking signs and symptoms include:

- difficulty planning and organising events or tasks, especially if they are complex (e.g. organising meals, managing finances)
- difficulty following medical advice and taking medicines
- slowed thinking and slowed reaction times
- difficulty with attention and concentration (e.g. when watching television or reading)
- difficulty finding words when speaking or writing
- difficulty remembering names of people, places or objects
- difficulty with memory (e.g. needing to make lists on what to do)
- difficulty doing complex tasks at work, or lower work performance
- difficulty learning new skills (e.g. learning how to use a new mobile phone, or computer).

Movement signs and symptoms include:

- clumsiness (e.g. dropping things easily)
- difficulty with fine motor tasks (e.g. fastening buttons on clothes)
- slowed walking speed
- slowed fine motor movements (e.g. signing your name)
- shaking (rare).

Behaviour and personality changes can also occur in some people with HAND, especially in the most severe type.

The signs and symptoms listed above can occur for other reasons in a person living with HIV. Having these signs and symptoms does not always mean you have HAND. Other possible causes of these signs and symptoms include depression, anxiety, other medical illnesses such as stroke, or use of alcohol and recreational drugs.

Such thinking and moving problems can leave you confused, frustrated, anxious or depressed. This can make thinking problems worse.

If you notice any changes or have any concerns, discuss this with your doctor as soon as possible.

How is HAND diagnosed?

To be diagnosed with HAND, you need to be referred to a specialist. Your doctor knows the correct referral process. HIV community organisations in your state can also give advice about where specialists are located. The diagnosis is usually made by ruling out other possible causes of your symptoms.

Diagnosis of HAND involves the specialist asking questions about your medical history and doing a medical examination, including blood tests and a brain scan. You may also be referred to a neuropsychologist for a series of questions and tests. These tests measure how well your brain is functioning. Also, a lumbar puncture might be recommended for some people, to look at the fluid that surrounds the brain and spinal cord.

No single test can diagnose HAND. Instead, your specialist makes an assessment based on your medical history and the results of the tests mentioned above. An early diagnosis can rule out other illnesses common to people with HIV, many of which are treatable. If you are diagnosed with HAND, you can start appropriate treatment.

If you are worried that you have HAND, discuss your concerns with your doctor. If you are worried about someone you care for, you can discuss your concerns with the person, and encourage them to speak to their doctor.



Treatment of HAND

HIV medicine

Starting HIV medicines is the best way to prevent and treat HAND. People with HAND need to receive HIV medicines that are good at getting into the brain. The doctor who prescribes treatment knows how to choose these medicines for you.

If you already take HIV medicines and are diagnosed with HAND, other medicines and treatments can be tried.

In some people, the medicine they are taking might be effective against HIV in the blood but not against HIV in the brain. If testing confirms this, your doctor may change your HIV medicines to others that work against the virus in both your brain and your blood.

If testing is not conclusive, your doctor may recommend changing your HIV medicines to ones that are good at reaching the brain, in case there is a small amount of HIV infection in your brain. Or your doctor may add an extra HIV medicine to your treatment to try to control any low-level HIV infection in the brain.

The good news is that HIV medicines can reduce problems, and people with HAND can recover well with HIV medicines.



'If I plan things and choose the right moment my brain works very well.'



Other things to consider

- If you have high blood pressure, diabetes or high cholesterol, you should closely manage these conditions.
- Reducing or avoiding alcohol and recreational drug intake can help protect the brain's function.
- Medicines such as antidepressants may be needed if you have depression or anxiety.
- Non-medicine therapies, such as counselling and learning strategies, can help with reduced abilities in thinking, and with the emotional impact of these changes.
- Peer support services can connect you with others who have faced similar challenges and issues. One-on-one peer support, peer support groups and workshops are delivered in Victoria by Living Positive Victoria and the Positive Living Centre.
- Organisations such as Alzheimer's Australia also give support to people with HAND.
- A help sheet with tips about protecting brain health for people living with HIV is available from Alzheimer's Australia Vic (including online).

HIV and HAND are complex conditions. Ask to be referred to support professionals with good knowledge and experience in this area. Your HIV doctor or local HIV community organisations can help you find the right people.

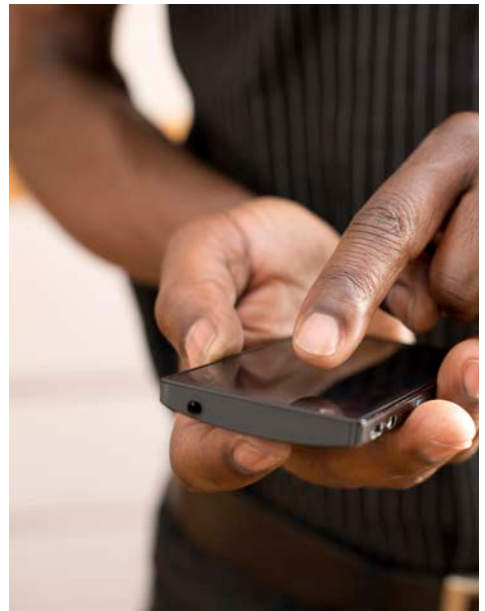
How does HAND affect HIV management?

People with HIV may need to take many medicines and go to regular health-related appointments. People who are diagnosed with HAND may find it more difficult to plan and organise these tasks.

If you have serious problems caused by HAND, or are having difficulty managing your health, you may benefit from daily support from a partner, family, friend or professional carer. If your thinking problems are mild, you may benefit from support strategies for taking medicines and remembering appointments.

Community care and district nursing services can support you. Other services offer support, such as respite for carers, day care programs, and other practical support for people with severe problems caused by HAND. Speak to your doctor if you or someone you know needs support.

See your pharmacist for tips on how to manage your medicines. Alzheimer's Australia Vic also has tips for managing medicines and activities of daily life, and a medicine planner for people living with HIV.



Other resources for people living with HIV

Living Positive Victoria
www.livingpositivevictoria.org.au

- **Poslink magazine**

The latest information on HIV treatment and services, personal stories of living with HIV, and advice on maintaining a healthy lifestyle

National Association of People with HIV Australia (NAPWHA)
www.napwha.org.au

- **A checklist guide for people with HIV**

A checklist guide to help people work in partnership with their doctor on a clear, comprehensive health care plan for living well with HIV

- **Ahead of Time**

A practical guide to growing older with HIV

- **iPlan**

A resource designed to help people living with HIV become active partners in their health care

Australian Federation of AIDS Organisations (AFAO)
www.afao.org.au/

- **HIV Treatment Adherence**

Information for adherence and hints to manage your HIV medications

- **Giving Up Smoking**

The importance of giving up smoking for people with HIV

- **Top Tips for Living Well with HIV**

Provides important information for people living with HIV about the day-to-day management and treatment of HIV



Further information and services

For HIV information and services

Living Positive Victoria

www.livingpositivevictoria.org.au

Peer support and health promotion programs for people living with HIV

Positive Living Centre

www.vac.org.au/community-centre-plc

Social, emotional, recreational, and skills-based services and activities for all people living with HIV

Victorian AIDS Council

www.vicaids.asn.au

National Association of People with HIV Australia (NAPWHA)

www.napwha.org.au

For help managing your HIV at home

Your local council

www.dpcd.vic.gov.au/localgovernment/find-your-local-council

Information about and access to community based services

Royal District Nursing Service

www.rdns.com.au

1300 33 44 55 (24 hours)

HIV-specific nursing and support services in metropolitan areas

For more information or services for neurocognitive disorders and dementia

Alzheimer's Australia

www.fightdementia.org.au

Support, information, education and

counselling for people with cognitive concerns, and their partners, families and friends

The National Dementia Helpline

1800 100 500

A telephone information and support service available across Australia for people with dementia, their carers, partners, families and friends, and people concerned about memory loss

Cognitive, Dementia and Memory Service (CDAMS)

www.health.vic.gov.au/subacute/cdams.htm

A specialist diagnostic clinic that helps people with memory loss, or changes to their thinking, and those who support them

Dementia Behaviour Management Advisory Service (DBMAS)

1800 699 799 (24 hours)

Support for a carer of someone with dementia who is demonstrating behavioural and psychological symptoms of dementia (BPSD) that are having an impact on their care

For emotional or crisis support

Lifeline 13 11 14

SuicideLine 1300 651 251

beyond blue

www.beyondblue.org.au

Carers Victoria

www.carersvic.org.au

Offers support to those caring for others





National Dementia Helpline 1800 100 500
www.fightdementia.org.au

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