

# HIV associated dementia

**This help sheet describes HIV associated dementia and related conditions, their causes, symptoms, diagnosis and treatment.**

## What is HIV associated dementia?

Dementia describes a syndrome involving impairments in thinking, behaviour and the ability to perform everyday tasks. People who are HIV positive (that is, who have the human immunodeficiency virus) may develop HIV Associated Dementia (HAD). This was formerly known as AIDS dementia complex. The condition is associated with severe cognitive, motor and behavioural problems that impair day to day functioning, reducing independence and quality of life.

HAD is the most severe form of HIV Associated Neurocognitive Disorder (HAND). Milder forms affect cognitive functions (thinking skills such as memory, language, attention and planning), but not to the extent that a diagnosis of dementia is warranted. In HAD, cognitive functions are severely affected and this has a significant impact on the person's daily functioning.

In Australia, where most people who are HIV positive receive treatment with combination antiretroviral therapy, HAD is fortunately uncommon. However, the milder forms of HAND affect many HIV positive people despite effective treatment.

## What is the cause?

When someone becomes infected with HIV, the virus is transported into the brain. It infects cells in the brain, but not the nerve cells that control our body, thoughts and actions. These are indirectly damaged, mainly through toxicity and inflammation that occurs due to the infection in other cells. Connections between nerve cells are also damaged, resulting in impaired communication in the brain and impaired cognitive function. Brain damage occurs progressively and mainly in the deeper (subcortical) parts of the brain.

However, it must be remembered that not everyone with HIV develops cognitive impairment, and thanks to modern treatments very few develop dementia. It is thought some people may develop HAND as a consequence of inadequate brain levels of antiretroviral drugs.

HIV also seems to accelerate the ageing process. Research suggests that cognitive performance in those with HIV is, on average, equivalent to that of people 10 years older without HIV. Additionally, HIV may facilitate the development of degenerative brain diseases associated with ageing, including Alzheimer's disease and Parkinson's disease. Levels of the abnormal proteins that build up in the brain in these diseases are increased in people who are HIV positive. It is not yet known why HIV does this, but these effects may contribute to the development of HAND.

### **What are the symptoms?**

The symptoms of HAND vary from person to person and can fluctuate from time to time. A wide range of cognitive functions can be affected, including:

- Information processing speed
- Short-term and long-term memory
- Ability to learn new skills and solve problems
- Attention and concentration
- Logic and reasoning abilities
- Ability to understand and express language
- Spatial skills and coordination
- Planning and organising abilities

**Signs that someone may be affected by HAND can include:**

- Difficulty adhering to medical advice and taking medications
- Worsening performance at work
- Difficulties with managing finances or organising meals
- Impaired driving

When cognitive functions are mildly affected and only detectable on neuropsychological testing (the person and others don't notice any symptoms), this is called HIV-associated asymptomatic neurocognitive impairment. When cognitive functions are mildly affected and this interferes with work, home or social activities, this is called HIV-associated mild neurocognitive disorder. When cognitive functions are severely affected and this significantly interferes with activities of daily living, this is called HIV associated dementia (HAD).

Symptoms of cognitive impairment can leave the person confused, frustrated, anxious or depressed. Behaviour and personality changes can also occur, especially in HAD. Apathy, vision problems and movement disorders are also common features.

**How is it diagnosed?**

HAD or the milder forms of HAND should be diagnosed by a medical specialist, usually a neurologist. The diagnosis is usually made by excluding other possible causes of the symptoms. These can include depression, infection, substance abuse and other forms of dementia such as Alzheimer's disease and vascular dementia.

Tests used in diagnosis will include a full medical history and a neurological assessment. Neuropsychological testing can help determine the presence and severity of cognitive impairment, but is not always available or practical. Briefer tests of mental abilities are also useful.

A HIV dementia scale that assesses cognitive symptoms is sometimes administered. While this is useful in the diagnosis of HAD, it may miss the milder forms of HAND. Information about the person's symptoms and their effects on daily function will usually be sought from both the affected person and those close to them such as family, friends or carers.

Laboratory tests of the blood or cerebrospinal fluid can provide useful information. Brain scans are usually an important element of the diagnostic process. Abnormalities characteristic of HAD may be detected using magnetic resonance imaging (MRI) brain scans.

No one test can definitively diagnose HAND. Instead, the doctor will make an assessment based on the results of all the tests available to them. An early diagnosis is important as the symptoms can be caused by other conditions and illnesses common to people with HIV, many of which may be treatable. If an early diagnosis of HAND is made, appropriate treatment and management can be started.

## **What is the treatment?**

HAND is treated using combination highly active antiretroviral therapy. Not all antiretroviral drugs penetrate the brain and some stay in the brain more than others, so it is important that the right combination of drugs is selected for the most effective treatment.

For many people, treatment is effective in reducing cognitive symptoms. Over 50% of people with HAD experience significant recovery when treated with combination antiretroviral therapy. They may report “coming out of the fog”.

Other drugs that protect the brain from further damage or enhance cognitive function might also be beneficial in some cases. Research is continuing into which therapies may be most helpful. Drugs such as antidepressants may be needed to treat secondary symptoms.

Non-drug therapies such as counselling and learning strategies to compensate for reduced cognitive abilities can also be very useful.

Optimising cardiovascular health by treating conditions like diabetes, high cholesterol or high blood pressure is also very important, as these can have an impact on cognitive function. Regular exercise and a healthy diet can also improve brain health.

With the advent of highly active antiretroviral therapy, the incidence of HAD has decreased significantly, suggesting effective HIV treatment helps to prevent severe brain damage and its consequences.

## Who gets HAND?

All people who have HIV are at risk of developing HAND. Other factors that seem to increase the risk include having diabetes, having other infections or poor health, being older when HIV is contracted, and a higher degree of immunodeficiency caused by HIV. Regular screening for changes in cognitive abilities in people who are HIV positive is recommended.

In Australia, where the vast majority of those who are HIV positive receive modern treatments, HAND still affects up to 30% of this population. HAND is relatively uncommon, affecting an estimated 7%.

## Further Information on AIDS

The AIDS Council in your state or territory provides information and support for people living with HIV, their families and carers.

The Australian Federation of AIDS Organisations is the national organisation representing Australia's community response to HIV/AIDS. Its members include the state and territory AIDS Councils.

Visit [afao.org.au](http://afao.org.au)

### Further Information

Dementia Australia offers support, information, education and counselling. Contact the National Dementia Helpline on **1800 100 500**, or visit our website at [dementia.org.au](http://dementia.org.au)



For language assistance phone the Translating and Interpreting Service on **131 450**