

AIDS-related dementia - *Factsheet*

Dementia web 
Information resource for carers, professionals and you

www.dementiaweb.org.uk



AIDS-related dementia

Dementia is not an illness in itself, but a term for a collection of signs and symptoms which are caused by damage to the brain by a number of illnesses, conditions or traumas.

AIDS (acquired immune deficiency syndrome) is caused by HIV (human immunodeficiency virus). The virus attacks the immune system leaving the person less able to protect themselves against a range of infections. Their immune system is suppressed. There is still no cure for AIDS, but a combination of various drugs can reduce the virus which causes AIDS to almost undetectable levels.

AIDS-related dementia (also known as AIDS dementia complex, HIV-related cognitive impairment, and HIV-associated dementia) is a spectrum of conditions ranging from mild to severe, all of which cause symptoms, including problems with mental and physical functions and behaviour changes which are typical of dementia.

It is still unclear how HIV enters the brain, but once there, it causes the death of neurons in the region of the brain which is involved in such functions as judgement, language, memory, motor function and socialisation.

Doctors have known about AIDS related dementia since the early stages of the AIDS pandemic and initially up to 30% of HIV-positive people were affected by it. Now, the development of highly active antiretroviral therapy (HAART) has helped the initial figure of 30% to drop to 10% in areas with high HAART availability. If people are able to access early and sustained antiviral treatment, the development of severe dementia can usually be prevented.

Unfortunately, a less severe form of the disease, called minor cognitive motor disorder (MCMD) has become more common. So AIDS-related dementia is not disappearing, and whereas cases of severe dementia have decreased, a greater number of people are living with a milder form.

Different people with HIV can experience different types and severities of dementia. It is estimated that 15 – 30% of people who are infected experience mild neuropsychological problems. In fact, these symptoms can be so mild that the person is not even aware of them. However, as the symptoms worsen it might be an indication that the infection has progressed and the person has now developed AIDS. Severe dementia showing the person has moved from HIV to AIDS is believed to occur in about 20% of older people who are HIV positive.

What are the symptoms of AIDS-related dementia?

There is considerable variation from person to person, both in symptoms and in the speed at which the condition progresses. In general, four different areas of brain function are affected. These are:

- thinking abilities
- behaviour

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- co-ordination and movement
- mood

Symptoms can include:

Impaired judgement
Lack of concentration
Short attention span
Irritability
Forgetfulness
Inappropriate emotional responses
Lack of caring or concern for oneself or others
Unsteady gait, or problems with balance
Social withdrawal
Apathy
Loss of appetite
Slowed thinking
Problems with short term memory
Poor judgement
Hallucinations

In the later stages there may be more severe symptoms, such as:

Extreme mood swings
Psychosis
Loss of bladder and bowel control
Weakness of the lower extremities

How is AIDS-related dementia diagnosed?

It can be difficult to diagnose AIDS-related dementia because the signs and symptoms can be similar to other HIV-related problems, such as the side effects from drugs, the existence of tumours or infections. Sometimes people are misdiagnosed as having depression or other neurological or psychiatric conditions. There may be more than one HIV-related problem causing the same symptoms.

No single test is available to confirm the diagnosis, but experienced clinicians can usually reliably establish a diagnosis by taking into account history, laboratory findings and examination.

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Sometimes, though not often, people do not know they are HIV-positive, and only find out when they begin to show symptoms of dementia. Therefore, if the person has not already been diagnosed, a blood test to establish the presence of the HIV virus could be the first step.

If it is thought that AIDS-related dementia is a possibility there are a number of tests which can be carried out, probably starting with a mental state examination in which the person has to answer questions and perform various tasks. This test may disclose problems such as memory loss, mood swings and difficulty with abstract thinking.

A CT scan (which uses X-rays to examine inside the brain) or an MRI scan (which uses magnetism, radio waves and a computer to produce images of the inside of the brain) can help rule out other possible brain disorders. These may include lymphoma which is a type of cancer, or toxoplasmosis which is a parasitic infection.

A lumbar puncture involves examining cerebrospinal fluid from the spinal canal and can help to rule out other problems.

Psychological tests can measure the function of different parts of the brain and, very rarely, a brain biopsy could be carried out.

What treatment is available?

Anti-retroviral therapy

There is currently no cure for HIV or AIDS and despite years of research and a great deal of progress being made, much still remains unknown. However, thanks to the latest “combination therapy” in which a cocktail of drugs is given, many people with HIV and AIDS now have a hugely improved life expectancy and quality of life.

Many scientists have been investigating treatments to prevent or slow the progression of AIDS-related dementia, and it has been found to respond best to the antiretroviral medications that are used to attack HIV. HAART (highly active antiretroviral therapy) is the most effective approach. It may prevent or delay the onset of AIDS dementia complex, and if someone already has it, it may actually improve mental function. This combination of drugs will reduce the amount of the virus in the bloodstream and stop or slow the ability of the virus to enter the brain and cause damage.

Medication may be prescribed which can directly reach the brain itself, by crossing what is known as the blood-brain barrier. The blood-brain barrier is a layer of tightly linked cells which carefully regulate what enters the central nervous system. Zidovudine, or AZT, is a medication which can cross this barrier. If high-dose AZT causes problems, there are other medications which can be tried. Sometimes, some of these drugs might interact with each other and cause side effects, so constant monitoring will be required.

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Other medications

Other drugs which might be prescribed for people with AIDS-related dementia include:

- Haloperidol, to ease general symptoms of AIDS-related dementia complex.
- Methylphenidate to ease symptoms of apathy, lack of energy and concentration.
- Antidepressants such as fluoxetine, paroxetine, citalopram and venlafaxine which may improve motivation and appetite.
- Chlorpromazine, to control agitation
- Diazepam, to control anxiety
- Neuroleptics, such as risperidone, which can relieve agitation and hallucinations.

What to do

In the vast majority of cases the person will have already received a diagnosis of HIV infection or AIDS, so they will be receiving monitoring, treatment and support from specialised medical professionals. If someone thinks they may be developing AIDS-related dementia, it is a good idea to write down symptoms to share with the medical team. There are many other HIV-related problems which could be causing the symptoms, so it would be premature to conclude immediately that AIDS-related dementia is inevitable.

It is also important for anyone with a diagnosis of HIV, as it is for everyone, to try to stay strong and healthy by enjoying a good diet and taking exercise. If a person does develop HIV-related cognitive impairment, and is successfully treated with drugs to halt or delay the progress of the condition, they may be able to undergo a rehabilitation programme to help them to re-learn daily living skills. It is very important to keep as well as possible, in order to maximise the success of any rehabilitation programme.

Who can help?

Guideposts Trust provides specialist information and care services for people with dementia and their carers. www.dementiaweb.org.uk

Contact the Helpline number: **0845 4379901** available Monday to Friday office hours, answer service at other times or by email at info@dementiaweb.org.uk

The Terrence Higgins Trust is the leading HIV and AIDS charity in the UK, providing a very wide range of care and support services.

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It has offices across the United Kingdom. Telephone **0845 12 21 200** between 10 am and 10 pm Monday to Friday or 12 noon to 6 pm on Saturdays and Sundays.

Or access all information via its website: www.tht.org.uk where there is also an email enquiry form.

Mildmay Hospital provides inpatient and day care services for people with HIV cognitive impairment. Referrals must be made by other community or hospital services.

Mildmay UK

Spencer House
Austin Street
London E2 7NB

Telephone: **020 7613 6300**

www.mildmay.org

Admissions/Referrals

Telephone: **020 7613 6347**

email: admissions@mildmay.org

The Alzheimer's Society is a care and research charity for people with Alzheimer's disease (and other forms of dementia) and their families. As well as a national helpline, there are over 250 local branches.

Helpline: **020 7423 3500**

Email: enquiries@alzheimers.org.uk

Website: <http://alzheimers.org.uk>

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Dementia Information Service for Carers

Helpline Number **0845 1204048**

Call in normal office hours. Answer phone at other times.

Email: info@dementiawebgloucestershire.org.uk

Web: www.dementiawebgloucestershire.org.uk

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