**AIDS dementia complex**

Dementia is a brain disorder that affects a person’s ability to think clearly and can impact his or her daily activities. AIDS dementia complex (ADC)—dementia caused by HIV infection—is a complicated syndrome of different nervous system and mental symptoms. These are somewhat common in people with HIV disease.

The frequency of ADC increases with advancing HIV disease and as CD4 counts decline. It’s fairly uncommon in people with early HIV disease, and more common in people with severely weakened immune systems. Severe ADC is almost exclusively seen in advanced HIV disease.

ADC consists of many conditions. These can easily be mistaken for symptoms of other common problems including depression, drug side effects or infections like toxo or lymphoma. Because ADC varies so much from person to person, it’s poorly understood and there’s no way to tell how a person will progress with ADC.

**What is ADC?**

ADC is characterized by severe changes in 4 areas: a person’s ability to understand and remember information (cognition); behavior; ability to move their bodies (motor coordination); or emotions (mood). These changes are called ADC when they’re believed to be related to HIV itself rather than other factors.

*Cognitive impairment* often appears as memory loss, speech problems, inability to concentrate and poor judgment. These are often the first symptoms a person will notice. They include the need to make lists in order to remember routine tasks or forgetting, in mid-sentence, what one was talking about.

*Behavioral changes* are the least understood. They can be described as impairments in one’s ability to perform common tasks and activities of daily living. These changes are found in 30–40% of people with early ADC.

*Motor impairment* is often characterized by a loss of control of the bladder; loss of feeling in and loss of control of the legs; and stiff, awkward or obviously slowed movements. It’s not common in early ADC. A change in handwriting may be an early sign.

*Mood impairments* are defined as changes in emotional responses. In ADC, this is associated with several conditions, such as severe depression, severe personality changes (*psychosis*) and, less commonly, intense excitability (*mania*).

**The symptoms of ADC**

Diagnosing ADC is heavily dependent on the keen judgment of doctors, often together with psychiatric, brain or neurology experts. It’s difficult to determine impairments in mood and behavior since there’s no standard course of ADC. In one person it may be very mild with periods of varying severity of symptoms. In another it can be abrupt, severe and progressive.

Sometimes symptoms are overlooked or dismissed by caregivers, who may believe the symptoms are due to advanced HIV disease or depression. ADC symptoms may include poor concentration, forgetfulness, loss of short- or long-term memory, social withdrawal, slowed thinking, short attention span, irritability, apathy (lack of caring or concern for oneself or others), weakness, poor coordination, impaired judgment, vision problems and personality change.

ADC occurs more commonly in children with HIV than adults. It presents similarly and is often more severe and progressive.
Possible early stage symptoms

- Difficulty concentrating
- Difficulty remembering phone numbers or appointments
- Slowed thinking
- Longer time needed to complete tasks
- Reliance on keeping lists
- Mental status tests and other mental capabilities may be normal
- Irritability
- Unsteady gait (walk) or difficulty keeping balance
- Poor hand coordination or writing
- Depression

How does HIV cause ADC?

While it is clear that HIV can cause serious disease in the nervous system, how it causes ADC is unclear. In general, nervous system and mental disorders are caused by the death of nerve cells. While HIV does not directly infect nerve cells, it’s thought it can somehow kill them indirectly.

Macrophages—white blood cells that are common in the brain and act as large reservoirs for HIV—appear to be HIV’s first target in the central nervous system. Infected macrophages can carry HIV into the brain from the bloodstream. From there, these cells likely cause damage in many different ways.

Possible middle stage symptoms

- Symptoms of muscle weakness
- Poor performance on regular tasks
- More concentration and attention required
- Slow responses and frequently dropping objects
- Feelings of indifference or apathy
- Slowness in normal activities, like eating and writing
- Walking, balance and coordination requires a great deal of effort

Possible late stage symptoms

- Loss of bladder or bowel control
- Difficulty walking
- Loss of initiative or interest
- Withdrawing from life
- Psychosis or mania
- Confinement to bed

What if you think you have ADC?

- Don’t be afraid to tell your doctor or any other providers that you suspect something is wrong. Find a second opinion if you need one.
- Keep a notepad with you and write down your symptoms whenever they occur. This will greatly help your doctor to help you.
- Build as much support as possible, including friends, family and professionals. Although it’s possible to treat ADC, it may take awhile for some symptoms to go away.

Incidence

Anecdotal reports indicate that there are fewer people with ADC since HIV therapy became standard. People who develop ADC today tend to be “sicker” than those before the use of HIV therapy. The rate of ADC dropped from 53% in 1987 to 3% in 1988 (after the first HIV drug was approved).

Early in the epidemic, many new AIDS cases were attributed to ADC. Many doctors now report that they’re no longer seeing people who have just ADC. It has increasingly become a disease of late-stage AIDS when people suffer from multiple infections.

Diagnosing ADC

Three tests are required to diagnose ADC accurately: a mental status exam, one of the standard scans (CT and/or MRI) and a spinal tap. These may also help tell ADC apart from other brain diseases like toxo, PML or lymphoma. However, ADC can occur along with these other brain diseases, so diagnosing multiple conditions can be more difficult.

A mental status exam helps reveal problems like short- or long-term memory loss, difficulty concentrating and abstract thinking as well as swings in mood. Imaging scans of the brain are also used. Certain lab tests can examine cerebrospinal fluid (CSF) that’s been obtained by a spinal tap.
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CT scans are x-rays that can show signs of destroyed brain tissue. MRI, or Magnetic Resonance Imaging, is a more sensitive scan. Results from both tests can help rule out other causes for the symptoms.

Testing CSF may help determine ADC, but they’re not conclusive. Mostly they’re used to rule out other causes of the symptoms. Many people with ADC have higher levels of certain proteins or white blood cells in their CSF. However, not everyone with these levels turn out to have ADC. Also, people with advanced ADC are more likely to have higher HIV levels in their CSF, though this is also not conclusive.

Treating ADC
The best therapies to treat ADC appear to be HIV drugs, and high-dose Retrovir (zidovudine, AZT) is the most studied drug for it. However, many specialists contend that how well a potent regimen controls HIV overall is more important than the actual drugs used. This may or may not include using standard, or even high-dose, Retrovir as part of the regimen.

Generally speaking, creating an HIV regimen to treat ADC follows 3 principals:
1. Start a potent regimen (usually 3 drugs) to decrease viral load to undetectable levels;
2. In people on HIV therapy, consider their drug history and resistance test results; and
3. If possible, use HIV drugs that cross the blood-brain barrier as part of the new regimen.

It’s believed that an HIV drug that crosses the blood-brain barrier might help prevent or treat ADC. Findings from earlier in the epidemic show that high-dose Retrovir (1,000–1,200mg/day) can cross the blood-brain barrier and effectively treat it. Several researchers have reported improvements in symptoms. However, many with HIV are often unable to tolerate its side effects.

While Retrovir may be the most researched drug, other HIV drugs that cross the blood-brain barrier may be equally useful. These include Zerit, Ziagen, Viramune, Agenerase and to a lesser degree Crixivan and Epivir. Sustiva does not cross it to a significant degree, but some experts speculate it may be useful in treating ADC.

Treating the symptoms
Psychoactive drugs are often used to treat ADC symptoms: anti-psychotics, anti-depressants, anxiolytics, psycho-stimulants, anti-manics and anti-convulsants. These drugs do not treat the underlying cause of ADC, or even stop its progression. However, they may ease some of its symptoms. Hal-dol (haloperidol) is often used though it has many side effects, so smaller doses of 5–10mg daily should be used.

Ritalin (methylphenidate) has been used successfully in people with ADC to ease apathy and to increase energy, concentration and appetite. Daily doses of 5–10mg are often enough.

In cases of severe behavior disorders, drugs like thorazine and mel-laril can be used to control agitation. Ativan (lorazepam) and Valium (diazepam) may also be used for sedation and controlling anxiety. Others include Trilafon (perphenazine), Navane (thiothixene), Moban (moli-dole) and Prozac (fluoxetine) with Wellbutrin (bupropion).

Credits
Special thanks goes to GMHC, Dr. Richard Price of UCSF General Hospital, and Dr. Justin McArthur of John Hopkin's University for their editorial support.

National HIV Health InfoLine: 1-800-822-7422 (toll-free) 10a–4p, Monday–Friday, Pacific Time

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