



What was your name again? AIDS Dementia Complex

We didn't want to use the word "dementia", but we had to. Doctors still use it, and so do all the pamphlets and books on the subject. So, we're stuck with it. But if, when you see the word "dementia", you think of a psycho in a goalie mask with a chainsaw - well, my friend, "it ain't necessarily so".

The word "dementia" sounds a lot worse to us, the general public, than it does to medical people. To them it refers to conditions where the brain isn't working as well as it usually does. In fact, there are quite a few different names for these conditions. But, as usual with medical terms, they can be a mouthful - like "HIV-associated cognitive & motor complex". So to keep things simple, we'll say "AIDS Dementia Complex", or **ADC** for short. Just don't let the "D" word scare you.

1 : What are the symptoms of ADC?

Some of the symptoms of ADC are:

- your mind wanders a lot, and it's hard to concentrate
- you can't remember something that just happened
- you can't remember things you've known for a long time
- your mood changes quickly for no reason (you're happy one minute, bummed out the next)
- you feel clumsy, or like you're moving in slow motion.

Now, these things happen to everybody all the time. So don't panic the next time you forget your car keys or your lover's birthday. But if these symptoms seem to keep happening to you a lot, over a long period of time, then maybe you should get suspicious.

2 : What should I do if I suspect ADC?

Statistics on ADC don't always agree, because the people who do the studies don't always measure things the same way. Roughly, about 5 - 7% of people with AIDS will get ADC each year. Quite a few more people will develop milder versions of the same problems. But, unlike a lot of other AIDS-related problems, having a mild form of dementia does not necessarily mean it's going to get worse. So first of all try to relax. Then let your doctor know, so you can get tested.

This kind of testing often means doing a whole bunch of things that may seem like children's games. For example: trying to remember lists of names, matching words with pictures, drawing pictures from memory, or putting funny-shaped pegs in holes. This kind of testing tells the doctor more about the exact kind of problems you have, and how bad they are. It can also help them decide what's causing it.

Since a lot of symptoms can be mistaken for ADC, it is the doctor's job to make sure the symptoms aren't being caused by something else. Symptoms that are similar to ADC fall into 2 groups:

- Psychological: Maybe you are just generally stressed out - life can do that, you know. Perhaps you are depressed or anxious for a very good reason. This can make it hard for you to concentrate.
- Physical: Maybe something is wrong with your body. This could be a run-of-the-mill disease like the flu, or another AIDS-related illness like toxoplasmosis. It could also be malnutrition - your brain uses a lot of energy, and if you aren't getting enough energy from the food you eat, your brain can't work as well.

So the doctor is going to try to "blame" your symptoms on something else that seems likely, and try to fix that. If this works, and the problems go away, great. But if the symptoms won't go away, then it's

more likely that the problems are caused by the HIV virus itself, damaging cells in your brain. This is what is called AIDS dementia complex, or ADC.

3 : How do they treat ADC?

If it turns out that your problem really is ADC, the doctors may try high doses of AZT. This is because AZT can get into your brain better than many other drugs. Once it's in your brain, it can fight against the HIV that's in there.

Doctors can often help with the symptoms, even if they do have a hard time treating the cause. Here are some possibilities:

- **haloperidol** (Haldol) can help if you get upset easily. (Not too much if you don't want to be a zombie!)
- **Ritalin**, a kind of "speed", can help with slow thinking or slow motion.
- **diazepam** (Valium) or something similar can deal with anxiety.
- **vitamin B12** can be helpful, and **vitamin B6** might be as well.

New drugs do keep appearing, so keep up with the latest by asking your doctor and doing some reading on your own.

4 : What can I do to help myself?

There are lots of things you can do to make ADC easier to deal with. You may notice that many of them are things that people without ADC do anyway:

Buy a date book to write down important appointments, things you have to do, etc. Get in the habit of checking it often.

Don't try to do lots of things at the same time. Cooking dinner, feeding the cat, talking on the phone, and reading the mail all at the same time is not a good idea!

Don't leave the kitchen if the stove is on. If the phone rings, or the doorbell rings, turn off the heat first before answering. Better a ruined souffle than a house on fire.

Don't leave the bathroom while the tub is filling, unless you like the waterfall down the stairs.

Traffic is one of the most dangerous situations you can face (even if you don't have ADC!). Think back to the days when you learned how to walk to school. Those were good rules: follow them even if it makes you a little late. Better late than never.

Don't J-walk or dodge in and out of traffic to cross the street. Cross at the corner, **with** the green light, **with**

the walk sign lit. If you're still a bit uncertain or confused, don't panic. Just walk next to another person who is also crossing (be careful about trying to hold their hand!). Best choose a little old lady who wouldn't dream of breaking a traffic rule.

If you forget where you keep things at home, label your cupboards and drawers. Tie long strings to things that easily get misplaced, like the TV remote.

Keys: be a "latch key kid". Put them on a long, strong string around your neck. If you have a lot of keys, you can buy special key holders like security guards use that clip to your belt loops. Wallets: attach a key holder to your wallet. You can buy cheap key/wallet holders at most variety or dollar stores.

A real help is a pill box that divides your medications into times and days. You can even get ones that beep when it's time to take something. Some pharmacies will package medication for you already divided up this way (sorry, no beeps).

Avoid stress. Stress makes you worry about too many things at once. Take time to relax. Exercise regularly. Exercise not only reduces stress, it helps keep you coordinated. And, if you're working out at a gym, think of all those new friends you'll make in the locker room.

If your situation gets a bit more serious, don't be afraid to ask friends to help out. Many people use a "buddy" system. Choose a good, reliable friend to keep an eye on you - drop in to see you often, maybe run some errands, and things like that. The buddy you choose may want to read up some more on the problem so they can be the most help to you.

You may also be able to get professional services like home care, or "occupational therapists" who can help you work out ways to do things more easily.

Yes, for a few people, ADC can get so serious that they need constant caregiving. But remember those statistics: the percentage of people who are seriously affected is quite small. Let's close with some upbeat news from the *Western Journal of Medicine*, January 1994: "Although [ADC] is not considered curable, interventions can stabilize or reverse symptoms and improve living function, even with advanced symptoms."

Now where did I put my pen?

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