



# Fact Sheet

## AIDS DEMENTIA COMPLEX

AIDS dementia complex (ADC) is a complication of HIV/AIDS that occurs in some people, usually those with advanced disease. HIV affects the functioning of the normal brain leading to difficulty with concentration, memory, and speed of thought along with a change in personality usually manifesting as a lack of interest in previously pleasurable activities. In addition, people note a degree of clumsiness of the arms and legs.

Most people first notice poor concentration ability so that they find it difficult to read or watch a movie because they cannot follow the plot or they lose track of the conversation when speaking with others. Memory for day-to-day events also becomes a problem so that the affected person has to use a diary or rely on a friend or loved one to prompt them to do things. Their personality changes so that they become apathetic not caring to keep up with friends or perform their hobbies or interests. Motor function also becomes impaired leading to clumsiness so that the person may bump into objects and drop things more easily. These complaints usually develop slowly over several weeks to months.

Once these complaints become obvious, it is important to seek medical attention so that other causes can be addressed and treated as required. Sometimes other infections can cause these same symptoms and sometimes depression can lead to very similar complaints. To address these alternatives, a brain scan as well as blood tests and a lumbar puncture should be performed.

If you are caring for someone with ADC, you may begin to notice behaviours, which are uncharacteristic or inappropriate given the situation. For example: People may appear to regress in their behaviour or appear childish. A person may have a tantrum in a shopping centre, when refused certain products. At times, coping with such behaviours can be difficult and stressful. However, remember that the behaviour is usually not deliberate, the person may be having difficulty controlling their behaviour and they are probably quite frightened. They often need your reassurance, even though it may not appear that way.

Trying to make sense of the environment can become increasingly difficult and as the ADC progresses simple tasks such as bathing, dressing and eating can become major hurdles to overcome. They are frequently confronted with failure, so maintaining their dignity is most important.

While there are common features in the progression of ADC, each individual's response is unique. This information sheet is a general guideline outlining useful strategies for a range of common experiences. If you find that you need more specific assistance then it is recommended that you contact your local health worker.

### **Some causes of difficult behaviour:**

1. Stress caused by the excessive demands of a situation;
2. Frustration caused by mis-communication;
3. Another underlying illness, such as an opportunistic infection.

## **Things that you can do:**

### **1. Try to minimise stress:**

.A calm, unstressed environment where there is a clear, familiar routine can help avoid excessive reactions.

- Speak clearly and use simple sentences, allowing time for response. (Don't interrupt response). Give limited choices in order to avoid confusion.
- Try to talk in a place which is free from distractions. (eg. turn TV off when discussing daily activities). Try to focus on familiar skills which are within their capabilities.
- Break a task down into simple steps that are not overwhelming. (If possible, encourage the person to help break the task down into steps - this helps to maximise their input and independence).

### **2. Modifying the environment:**

- Be aware of situations that lead to difficult behaviours such as aggression and try to avoid them.
- Try to do difficult and frustrating tasks when the person is at their best and not tired. .Use a diary to help monitor when good and difficult times are likely to occur.
- Use pictures or labels on objects that will assist in identification and location. (These are useful as prompts, too, especially in the bathroom during performance of ADL's).
- Try to avoid frustration by adapting the environment to cope with the difficult behaviour . .Simplify the environment. (eg. reduce excess "clutter").
- Try to remember that a difficult behaviour may intensify when there is a major change in lifestyle.

### **3. Distraction:**

- If there are a few moments before an outburst when you notice the person appears agitated you may be able to prevent the over reaction by calming the person down early.
- First, try to respond to the feelings of anger by soothing, comforting and reassuring the person gently. Then try to defuse the situation by distracting them and finally, praise success.
- Alternatively, you could try calmly ignoring the outburst and busying yourself with something else.

## **Here are some suggestions for communicating with people with ADC:**

- Talk to the person normally and treat them as an adult.
- Speak clearly. Be patient, calm and understanding.
- Don't talk about the person as if they are not there.
- Face the person directly and speak clearly. Repeat yourself if the person does not understand.
- Give instructions one at a time. Make them short and clear.
- Use pictures as cues eg. bathroom.
- Touch is often reassuring.
- .Don't rush the person, allow them time before you offer to help eg. dressing.
- Try not to confuse the person by over loading them with too much information.
- Sit, stand or kneel so that you make level eye contact.
- Ask, don't give orders. Try and give the person a choice of 2 options.
- Don't whisper.
- Listen carefully to what the person is saying. If they appear to be experiencing difficulties in communicating, clues can often be obtained from their non-verbal behaviour and emotional tone.
- Try to stay calm and patient.
- Look at the person directly before you start talking to them.
- Find a place to talk that is free of distractions.

### **Aggression:**

- Sometimes the person with dementia may become very violent for a short time. They may become verbally abusive, cause damage to property or become physically violent.
- Try to stay calm and not show fear or alarm, try not to raise your voice.
- Try to understand that even if the aggression is directed at you, it is not a personal attack.
- Never put your own safety at risk: if the behaviour escalates out of control, remove yourself from the situation, call your doctor or the police and contact your local mental health crisis team.
- Never try to restrain the person.
- Try not to argue with the person when they become upset because at times it may be difficult for them to rationalise or be logical -there is no point in trying to reason. Save your energy and concentrate on trying to remain calm.
- Try not to engage in a way that escalates the behaviour. (eg. arguing or reasoning with the person).
- Try not to be punitive towards the person.
- Remember that you are dealing with an illness rather than the person.

### **Looking after yourself:**

- Sudden over-reactions may leave you upset and a little shaky. It is essential that you seek support for yourself from a supportive family member, a friend, an understanding professional or a support group and that you get a break from the constancy of the task -mention that respite care is available.
- Identify the areas of support that you need and learn about the services in your area.
- Allow yourself to get help with other tasks such as cleaning so that you can have some respite.
- Remember that your own feeling of distress, frustration, guilt, exhaustion and exasperation are quite normal.
- Seek professional help yourself if you feel yourself increasingly incapable of coping.

This information is drawn from a series of **Fact Sheets** produced by the AIDS Dementia and HIV Psychiatry Team (ADAHPT). A component of the AIDS Dementia and HIV Psychiatry Service (ADAHPS), which is a new joint Statewide tertiary service of South Eastern and Central Sydney Area Health Services for people with AIDS Dementia and HIV-related psychiatric conditions.