



www.aidsmap.com

information series for hiv-positive people

hiv & mental health



acknowledgments

Written Michael Carter

Produced by NAM

First edition 2005

NAM is a charity that publishes information for people affected by HIV and those working with them. We believe information helps people to make decisions about, and be in control of, their lives, health and treatment options.

Thanks for the assistance of:

Dr José Catalan
Consultant psychiatrist, Chelsea and Westminster Hospital,
London

Geoff Warburton
UKCP registered
psychotherapist

Susan Cole
UK Coalition of People Living
with HIV and AIDS

Funders:

NAM is grateful to the funders of this booklet series:

Department of Health, NHS South West London HIV & GUM Commissioning Consortium, Derek Butler Trust and Healthsure Charitable Trust.

hiv & mental health

This booklet provides information on mental health for people with HIV. Problems with mental health can affect anybody, but it seems that HIV-positive people are more likely to experience a range of mental health problems. Treatment for depression and many other mental health problems work well in HIV-positive people.

A summary is provided on page 20 and a glossary on page 21.

Mental health is an issue for people with HIV

- An explanation of some job titles

1

HIV-related mental disorders

- Dementia
- Mania

4

Depression, anxiety and emotional distress

- Depression
- Anxiety
- Emotional Distress

7

contents

Mental health problems as a side-effect of anti-HIV and other medicines	14
Looking after your mental health	16
■ Supporting somebody with mental health problems	
Where to go for mental health advice and support	19
Summary	20
Glossary	21

1 Mental health is an issue for people with HIV

Good mental health is important to everybody.

If you have a serious, and potentially fatal physical illness such as HIV, issues such as emotional distress, anxiety and depression may seem to be a secondary health concern.

In fact good mental health is an integral part of good overall health for people with HIV. For example, it is worth noting that HIV-positive people with mental health problems seem to have lower levels of adherence to their anti-HIV medication.

Thanks to the success of anti-HIV drugs, many people with HIV are living longer lives. That doesn't mean that mental health

is no longer important for people with HIV. Far from it. If you are living with a long-term illness then issues such as uncertainty about the future, treatment side-effects, pain, fear of future disease progression and even everyday life events can still cause emotional strain and have mental health implications.

It therefore makes good sense for people with HIV to have information about the ways in which HIV can affect their mental health and about common mental health issues such as depression, anxiety and emotional distress.

An explanation of some job titles

Everybody will have personal strategies for dealing with their mental health needs.

But just as people develop physical illness and need to see a health professional, many people experience emotional issues or problems with their mental health for which they need professional help.

This can be a frightening or confusing experience.

It may help to understand some of the commonly used job titles and types of treatment commonly used in mental health.

- **Psychiatrist** A psychiatrist is a medical doctor who has specialised in the diagnosis and drug treatment of mental health issues. As well as being able to prescribe you medicines (for example antidepressants), a psychiatrist will also be skilled in a range of psychotherapies.
- **Clinical psychologist** A clinical psychologist provides psychological therapies for the treatment of mental health problems. They will have extensive academic training, usually having an advanced postgraduate degree and work in a hospital or other medical setting. Psychological therapies are based on talking and working with

people to understand the causes and triggers of mental health problems and on developing practical strategies to deal with them. One example is cognitive behavioural therapy (often abbreviated as CBT).

- **Mental health nurses** Nurses who have undertaken specialist training in the provision of services, support and care to people with mental health issues. Many are very skilled in the diagnosis and treatment of problems, and some are also able to prescribe medicines.
- **Psychotherapist** A person who provides treatment for emotional or mental

health problems through talking. This person will be highly qualified and may or may not be a doctor. There is some overlap in the roles of a psychologist and a psychotherapist.

- **Counsellor** A counsellor can provide short-term support and an opportunity to talk through emotional issues, for example after receiving an HIV diagnosis. Counselling is fairly unregulated in the UK, so it makes good sense to check for qualifications.

Dementia

Before effective anti-HIV treatment became available (often called highly active antiretroviral therapy, or HAART for short, the abbreviation that will be used throughout this booklet) it was calculated that between approximately 2%-7% of people with very weak immune systems due to advanced HIV infection would develop dementia. Survival was, and remains, very poor for HIV-positive people with dementia.

Thanks to the success of anti-HIV treatment, new cases of dementia are now very rarely seen, and only in people who have not been taking HAART.

The symptoms of dementia in people with HIV resemble those seen in older people with senile dementia and include:

- Difficulty in thinking or understanding, including forgetfulness, loss of memory, severe problems concentrating, confusion, and problems planning and organising.
- Behavioural changes including feelings of isolation, a loss of interest, and childish behaviour.
- Problems with movement and coordination, such as loss of balance or strength from the limbs.

It is important to remember that there can be many other causes of the symptoms listed above, not only dementia. It is important to see your HIV doctor to find out what the cause is if you experience any of these symptoms.

Tests can assess subtle changes in memory, concentration, and the way the brain processes information. These can be as simple as an ability to memorise and recall lists. A sample of cerebrospinal fluid can also be checked to look for cell abnormalities and the presence of HIV. Scans can also help diagnose dementia.

Even before HAART became available in the late 1990s, the number of new cases

of dementia seen in HIV-positive people was already falling.

Any HAART combination that keeps your CD4 cell count above 200 will protect you from developing dementia.

People with dementia often require special care. There used to be special residential facilities providing care for HIV-positive people with dementia, but because the condition is now so rare these have now closed. If round-the-clock care is needed this is likely to be provided either in a person's home or a general residential care home.

Mania

Manic episodes – uncontrolled impulses, or bursts of energy or rage – are occasionally seen in people with very advanced HIV infection with very weak immune systems (a CD4 cell count below 50). It is thought that they were due to damage to the brain caused by HIV. Thanks to HAART cases are now extremely rare.

7 Depression, anxiety and emotional distress

Depression

People often say that they are 'depressed' when they are feeling down. Often what they are experiencing is a natural fluctuation in mood, or an appropriate reaction to a distressing event or situation.

Depression is an illness, and doctors often talk about 'clinical depression' or 'major depression' because of this. It is thought that depression occurs much more frequently in people with HIV than in the general population. In a recent survey of people with HIV in the UK, two thirds of respondents said that they had experienced depression at least once in the year before. It is also worth remembering that gay men and Africans, the two groups most

affected by HIV in this country, already have higher rates of depression than the general UK population.

HIV doctors are very used to seeing people with depression, and many of the large HIV clinics have specialist mental health teams including psychiatrists, psychologists and mental health nurses.

Causes of depression can vary between people. Illness, unbearable stress and social problems often cause depression to develop, and it has been suggested that some people may be genetically more prone to depression than others. In many cases, however, there might be no identifiable cause for the depression.

Depression is characterised by the presence of some or all of the following symptoms for some or all of the time for a period of weeks or even months:

- Low mood.
- Apathy.
- Poor concentration.
- Irritability.
- Difficulty sleeping.
- Waking up early.
- Oversleeping constantly.
- Inability to relax.
- Changes in eating habit, such as loss of appetite or overeating.
- Weight loss or weight gain.

- Lack of pleasure from usually enjoyable activities.
- Feelings of low self-worth.
- Inappropriate and excessive feelings of guilt.
- Thoughts of death, self-harm, or suicide.

If you think you have symptoms of depression it is important to get help. Try talking to your partner, a friend or a family member about how you feel. If you think you need professional help, contact one of the organisations listed at the back of this booklet and on page 19. Your GP or HIV doctor will also be able to help. Nobody will think that you are weak, unstable or 'mad' if you ask for help because you think you might be depressed.

Seek help immediately if you are thinking of harming or killing yourself.

If you have depression, your doctor may recommend that you take a type of medicines called antidepressants. These drugs relieve the symptoms of depression by correcting chemical imbalances in the brain. They can take between four and twelve weeks to have an effect, and like all medicines, can have side-effects.

There are three main classes of antidepressant drugs called tricyclics, MAOIs and SSRIs. If your doctor prescribes an antidepressant, it is most likely that it will be from the SSRI (selective serotonin re-uptake inhibitor)

class. Drugs in this class, which include fluoxetine (*Prozac*TM) have fewer side-effects and interactions with other medications. In particular, the antidepressant *Cipramil*TM (citalopram) is often used because it has few interactions with anti-HIV drugs.

Make sure that you tell your HIV doctor and pharmacist if you have been prescribed an antidepressant.

SSRI antidepressants do however have side-effects, particularly in the first few weeks. Side-effects at this time can be particularly difficult to cope with because antidepressants often need to be taken for several weeks before they start to relieve the symptoms of depression.

The herbal antidepressant St John's wort interacts with protease inhibitors and NNRTIs leading to low levels of the anti-HIV drugs in the blood, risking the development of drug resistant HIV. For this reason you must not take St John's wort if you are taking a protease inhibitor or an NNRTI.

The amount of time you stay on antidepressants will vary on your individual circumstances. You may well start to feel a lot better a few weeks after you start taking them, but it is generally recommended that you remain on antidepressants for at least three months if you are taking them to treat your first

depressive illness, or longer if a recurrence in your depression has occurred.

To prevent withdrawal symptoms occurring, you may have to reduce the dose of the antidepressant you are taking over a period of weeks before you stop taking it completely.

There is good evidence that antidepressants work better if accompanied by talking therapies designed to help you understand and control your depression. Cognitive behavioural therapy is one example. It usually involves a short course of sessions with a psychologist where you will have an opportunity to explore the origins and

warning signs of your depression, and learn skills to control it.

There is some evidence that manic depression (a combination of uncontrollably high moods followed by depression) is slightly more common in people with HIV, possibly associated with the onset of illness related to HIV or the commencement of anti-HIV treatment. Drugs can help correct chemical imbalances in the brain associated with these mood swings, and CBT can help provide the skills to recognise the warning signs and triggers for mood swings.

Anxiety

Anxiety is a feeling of panic or apprehension. It can be a very appropriate and useful reaction in certain circumstances when it is the body's natural response to a threat or challenge. However, many people have long-term problems with anxiety which interferes with their ability to get on with their daily life.

Symptoms of anxiety can include sweating, rapid heart rate, agitation, nervousness, headache, and panic attacks. It often occurs along with symptoms of depression, and can also happen by itself.

Post-traumatic stress disorder is sometimes experienced by people with HIV. This occurs when a person has experienced a traumatic event which the memory is unable to process properly. This can cause flashbacks, nightmares, and nervousness.

If your anxiety is caused by practical problems, then getting practical advice about how to approach these difficulties may well provide a solution. Counselling may also prove useful, and a short course of cognitive behavioural therapy with a psychologist can help provide the skills to understand the origins of anxiety and to control it.

Anxiety which occurs alongside depression is often successfully treated by antidepressants.

Massage, acupuncture, other complementary therapies and exercise can all relieve the symptoms of anxiety.

Drugs such as benzodiazepines, including *Valium*TM, used to be widely prescribed for the treatment of long-term anxiety. Their use is now restricted because they are addictive. However, they are still used to treat short-term periods of anxiety without any risk of addiction.

Emotional distress

Particular events, such as being diagnosed with HIV, the breakdown of a relationship, bereavement, being ill, dealing with side-effects, or work problems can cause feelings of deep unhappiness and emotional distress.

Feelings can include denial, anger, and sadness and these can last for weeks or months before there is an acceptance of the new situation. This is often referred to as a 'grieving process'.

Support from friends and family can be very helpful at this time. Professional help is also available. Your HIV clinic may be

able to arrange a short-term course of counselling, and some HIV support agencies also offer similar services. Trained staff at specialist helplines may also be supportive.

Complementary therapies, such as acupuncture and massage can help relieve the symptoms of emotional distress.

If you find that your feelings are more than you can cope with or are interfering with your ability to get on with your daily life, make sure that you mention this to a member of your healthcare team. Help is available.

Mental health problems as a side-effect of anti-HIV and other medicines

14

The NNRTI efavirenz (*Sustiva*TM) has been associated with depression and sleep problems, including sleeplessness, and vivid dreams. Some doctors think that the depression that some people develop when taking efavirenz is actually a recurrence of early depressive symptoms, and it has also been suggested that people with a history of depression may be more likely to become depressed again when they start taking efavirenz.

If you are taking efavirenz and experience depression or sleep problems and have other treatment options available to you, then it may be possible to switch to

another treatment that does not cause these side-effects.

Anti-HIV drugs can also indirectly cause mental health problems by causing side-effects. Lipodystrophy can cause a loss of self-confidence and self-esteem, and one US study found that many people taking anti-HIV drugs would be willing to see their life-expectancy shorten by two years rather than develop the side-effect.

For more information on lipodystrophy see the booklet, *Lipodystrophy* in this series.

Interferon and pegylated interferon treatments for hepatitis C virus, which

many people with HIV are coinfecting with, can cause depression. If you need to take these drugs your doctor may also prescribe you antidepressants, particularly if you have a prior history of depression. For more information see the booklet *HIV and hepatitis* in this series.

Looking after your mental health

There is a lot you can do to look after your own mental health.

Take care of yourself

- Make sure you get enough to eat, and try and take pleasure from food.
- Getting a good night's sleep is very important to both your physical and mental health, and not getting enough sleep can trigger emotional and mental health problems.
- Take some exercise that you enjoy.
- Drinking too much alcohol and recreational drug use can also contribute to emotional and mental health problems.

- Try and deal with work, relationship, money or housing problems as soon as possible.

- Allow yourself some pleasures from life.

Be kind to yourself

- Don't hate yourself for being who you are.
- Don't judge yourself harshly.
- Set yourself achievable goals and standards, reward yourself if you achieve these, and don't punish yourself if you do not.

Talk to somebody

- Don't bottle up worries or concerns.
- Don't isolate yourself.
- Join in with activities.
- Try something new.

If you find things too much

- Ask for help – there will be somebody who can help you.

Supporting somebody with mental health problems

Family members, partners and friends can be a very valuable source of support for people experiencing mental health problems.

But to effectively provide this, you need to make sure that you are looking after yourself and not neglecting your own mental health needs.

Providing support

- Accept that mental health is as important as physical health and that your partner, family member or friend cannot just 'snap out' of their mental health problems.

- Talk to your partner, family member or friend about what they're going through.
- Take an interest in their physical and mental health.
- Provide encouragement to seek help and treatment and to remain on it.
- Understand that mental health problems can be debilitating and that recovery can take time and is likely to involve both good and bad periods.
- Ask before making plans – accept that activities which you think may be pleasurable can seem overwhelming to a person who has mental health problems.

Provide for your own needs

- Make sure you take care of your physical and mental health.
- Make sure you talk to people about how providing support is affecting you.
- Be honest with yourself about the level of support you can provide.
- Seek help if you find you cannot cope.

Where to go for mental health advice and support

A good place to start would be your HIV clinic. Your HIV doctor should take your mental health as seriously as your physical health. Many of the larger HIV clinics have expert HIV mental health teams.

Information on HIV helplines which can provide information and support are listed at the back of this booklet. The following counselling and mental health organisations may also be useful.

PACE

PACE provides counselling for gay men and lesbians for issues including HIV.

tel: 020 7700 1323

web: www.pacehealth.org.uk

Saneline

UK mental health charity

tel: Helpline 0845 767 8000

web: www.sane.org.uk

Mind

UK mental health charity

tel: Mind Info Line 0845 766 0163

web: www.mind.org.uk

Samaritans

Confidential emotional support 24 hours a day

tel: 08457 90 90 90

- Mental health is important for people with HIV.
- People with HIV seem to be more likely to experience a range of mental health problems, including depression.
- HIV infection can cause dementia and mania, but these problems are now very rare thanks to HAART.
- Treatment is available if you have depression.
- Some anti-HIV drugs can have side-effects which include mental health problems.
- There are things you can do to look after your mental health.
- Help is available if you are having mental health problems.

21 Glossary

adherence The act of taking a treatment exactly as described.

AIDS Acquired Immune Deficiency Syndrome. A collection of specific illnesses and conditions which occur because the body's immune system has been damaged by HIV.

CD4 A molecule on the surface of some cells onto which HIV can bind. The CD4 cell count roughly reflects the state of the immune system.

dementia Changes in mental function, co-ordination and personality resulting from direct effects of HIV infection in the brain.

HAART Highly Active Antiretroviral Therapy, a term used to describe anti-HIV combination therapy with three or more drugs.

HIV Human immunodeficiency virus, the virus which causes AIDS.

immune system The body's mechanism for fighting infections and eradicating dysfunctional cells.

NNRTI Non nucleoside reverse transcriptase inhibitor, the family of antiretrovirals which includes efavirenz and nevirapine.

NRTI Nucleoside analogue reverse transcriptase inhibitor, the family of antiretrovirals which includes AZT, ddI, 3TC, ddC, abacavir and FTC.

side-effect Unwanted result or consequence of a treatment.

Notes

nam

free monthly newsletter

AIDS Treatment Update, NAM's free newsletter, gives you regular and up-to-date information on the latest developments in HIV treatments, and is accompanied each month by a one page factsheet providing basic information on key treatment topics.

Issues regularly covered include:

- starting and changing treatment
- dealing with side effects
- medical monitoring
- feedback from major conferences

To order:

- use the form overleaf
- call 020 7840 0050
- email info@nam.org.uk

Order form

AIDS Treatment Update

Please set up my free subscription to AIDS Treatment Update**

Please tick the format you require:

paper

email (pdf)

audio tape*

name

address

postcode

email (if applicable)

signature

Please send me information about NAM's full range of publications on HIV and AIDS

Please tick this box if you would not like to receive information about NAM's fundraising.

Return this order form to:

NAM

Freepost LON17995

London

SW9 6BR

phone 020 7840 0050

fax 020 7735 5351

email info@nam.org.uk

website www.aidsmap.com

* (available to people with visual impairment)

** (NAM is unable to provide free subscriptions to professionals or organisations - please contact us for prices)

HIV & AIDS Helplines

National Sexual Health Helpline

telephone 0800 567123

opening hours daily, 24 hours

Terrence Higgins Trust Helpline

telephone 0845 1221 200

opening hours Monday-Friday, 10am-10pm
Saturday & Sunday, 12noon-6pm

HIV i-Base Treatment Phonenumber

telephone 0808 800 6013

opening hours Monday-Wednesday,
12pm-4pm

The booklet series includes: ■ adherence ■ anti-hiv drugs ■ clinical trials ■ glossary
■ hiv & children ■ hiv & hepatitis ■ hiv & sex ■ hiv & tb ■ hiv & women ■ hiv therapy
■ lipodystrophy ■ hiv & mental health ■ nutrition ■ resistance ■ viral load & CD4

More from NAM

NAM Information Forums

Monthly, free meetings offering an opportunity to hear the latest news, views and research around HIV treatments. Held in the evening at a central London location. Call NAM for details.

NAM information series for HIV-positive people

This booklet is part of an easy-to-read series available free from NAM to people personally affected by HIV. Call NAM for your copies.



contact details

NAM

Lincoln House
1 Brixton Road
London
SW9 6DE
UK

tel +44 (0) 20 7840 0050

fax +44 (0) 20 7735 5351

email info@nam.org.uk

website www.aidsmap.com

First Edition 2005

© NAM

All rights reserved

design Alexander Boxill

photography Creatas

print Lithosphere

This booklet can be viewed in large print as a pdf file using Acrobat Reader.

Call NAM on +44 (0) 20 7840 0050.

www.aidsmap.com

Visit NAM's website for

- an introduction to HIV and AIDS
- online access to other booklets in this series
- NAM Factsheets - one page plain language guides to over 90 HIV-related topics
- contact details for over 3200 AIDS service organisations in the UK and worldwide
- a searchable database of HIV treatments information
- a complete list of HIV treatment centres in the UK