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hiv, mental health & emotional wellbeing

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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.

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hiv, mental health & emotional wellbeing

This booklet provides information on emotional wellbeing and mental health for people with HIV. Emotional difficulties and problems with mental health can affect anybody (research suggests one in every four people in the UK will experience some sort of mental health problem at some point), but living with a long-term illness like HIV can mean that you are more likely to encounter them. There is a lot of help available if you do experience such problems. Treatment for depression, anxiety and many other mental health problems can be very effective.

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Emotional wellbeing, mental health and HIV

1

Emotional wellbeing and mental health are important for everyone. Going through difficult times is part of life, but from time to time these can be especially hard to deal with. Furthermore, some people also experience mental health problems, such as depression or anxiety – where emotions such as being in a low mood, feeling helpless or hopeless about the future, experiencing grief – carry on for some time, or return again and again, and start to interfere with quality of life.

Being diagnosed and living with a serious illness like HIV is likely to have a big emotional impact, and people with HIV, as a group, have higher rates of mental health problems than those seen in the general population.

If you are experiencing emotional difficulties or mental health problems, learning to understand and cope with them is an important part of being able to deal with them.

2 Emotional wellbeing

Particular events such as receiving an HIV diagnosis, bereavement, the breakdown of a relationship, financial worries, or dealing with starting HIV treatment or its side-effects, can result in feelings of unhappiness and emotional distress. This can include emotions such as anger, guilt, fear, sadness and loneliness – which are difficult to manage and may interfere with your ability to get on with daily life.

Support from family and friends can be very helpful at these times, as can support such as that provided by helplines, peer support and counselling (see p. 32 for contacts). These services offer you the chance to talk through issues, find sources of practical help and receive emotional support. Many HIV clinics have specialist mental health teams and some

HIV support agencies can offer short courses of counselling. Or you may be referred to more specialist services if necessary.

If you have a GP, they will be able to make an assessment of your mental health, can prescribe medication (such as antidepressants) and arrange referrals to other services, such as counselling or community-based mental health services, with either the NHS or a voluntary organisation.

Some people also find that complementary therapies, such as acupuncture or massage, can relieve some of the symptoms of emotional distress. (See contacts on p. 34 for more information on finding a complementary therapist.)

Mental health problems can affect anybody, but it seems that people with HIV may be more likely than the general population to experience them. The groups most affected by HIV in the UK (gay men, refugees, migrants and drug users) are also more likely to have mental health problems, because of the stresses associated with being marginalised from much of mainstream society. Experiencing HIV-related stigma can be stressful in itself.

Advanced HIV infection is known to cause serious mental health problems. As they are linked to having a very low CD4 count, these are now very rare due to the availability of effective treatment. More common are feelings of acute emotional

distress that often accompany difficult life events and mental health problems such as depression and anxiety.

In addition, some anti-HIV drugs can cause psychological problems. If you have had mental health problems in the past, it is helpful to tell your HIV consultant this when you start discussing treatment options. That way, the most appropriate anti-HIV drugs for you can be prescribed.

4 Professional support

Everybody will have their own way of dealing with their emotional and mental health needs. However, just as people develop physical illness and need to see a health professional, many people may benefit from, or need, professional help for emotional issues or problems with their mental health at some point in their lives.

In order to make this as easy and comfortable an experience as possible, it may help to understand some of the commonly used job titles and types of treatment often used in mental health.

- **Psychiatrist** A psychiatrist is a doctor who has specialised in the diagnosis and drug treatment of mental health issues.

As well as being able to prescribe medicines (for example antidepressants), some psychiatrists will also be skilled in a range of psychotherapies (a type of psychological or 'talking therapy').

- **Clinical psychologist** A clinical psychologist provides psychological therapies for the treatment of mental health problems. They are also trained to do specialist assessments looking at the effect of illnesses on the brain. They will have academic training, 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 of such a therapy is cognitive behavioural therapy (often abbreviated as CBT), but there are many others.

- **Mental health nurse** A nurse who has undertaken specialist training in the provision of services, support and care to people with mental health issues. Many are trained to diagnose and treat mental health problems with medication and psychological therapies. They also offer advice and support to people with long-term mental health conditions.
- **Community mental health nurse (CMHN)** Sometimes known as a community psychiatric nurse (or CPN), a

CMHN is also a registered nurse with specialist training in mental health. Some CMHNs are based in GP surgeries or community mental health centres, while others work from psychiatric units.

- **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. (See p. 34 for help with finding a counsellor and contacts.)

- **Community mental health team (CMHT)** These teams help people with more complex mental health needs to live independently, but with support, instead of being admitted to hospital. These teams will include mental health professionals such as those listed above, as well as local authority social services staff. You will need to have a GP to use a CMHT, even if your HIV clinic makes a referral on your behalf. They do not generally accept self-referrals, but your GP can tell you more about this.

Most mental health teams only see people who live in the area covered by the team. Some hospitals and HIV clinics can bring in psychiatric services to provide mental health care and support for their patients when it's needed.

- **Psychological wellbeing practitioner** A new type of NHS worker, who can provide support and care for people suffering from mild to moderate anxiety and depression. They are linked to existing services; your GP can refer you to them or you may be able to refer yourself.

Emotional distress

Life involves emotional stresses and strains. Being diagnosed with HIV, and living with it, will at times cause such stresses, and some aspects of your life will become more complicated – and possibly stressful – because of HIV.

Finding out that you have HIV can lead to a wide range of feelings. It is common to feel fear (including fear of dying), worry, concern about what other people will think, guilt, shame, embarrassment, anger and sadness after a diagnosis. Some people feel numb, and others feel a sense of relief that they have finally found out about their status.

You may question how your life will be living with HIV; it can be easy to assume the worst.

However, the feelings people have about HIV can change over time, so your initial response to finding out that you have HIV is unlikely to last. Many people find that they gradually come to terms with having HIV, although some aspects of being HIV-positive can still make them feel anxious or distressed.

Attending regular medical appointments, illness, starting or changing treatment, disclosing your status or starting a new relationship can all be sources of anxiety or cause emotional distress. Sometimes these can involve a revisiting or reconsideration of feelings about life with HIV. And most people with HIV will find that their emotional wellbeing is affected by life with the virus from time to time, no matter how successful

an adjustment they have made to their diagnosis.

Remember that it's perfectly acceptable to have feelings that you find difficult. Although it can be easier said than done, don't feel bad about feeling bad. Acknowledging your feelings is an important first step to working them out. Even though it can be hard to feel this way, experiencing emotions like anger, anxiety and fear are often normal responses to events during your life, including some of the adjustments you may have to make because of HIV.

It's also important to know that there's a lot you can do to look after your emotional wellbeing.

Talking about your experiences and feelings with a loved one, friend or another person with HIV can be a big help. When you are finding your thoughts and feelings difficult, or hard to understand or to work through, psychological therapies can also be helpful. Your HIV clinic should be able to help you find a suitable therapist if they don't offer such services themselves. (See p. 34 for more help with finding a therapist.)

Looking after the basic requirements of good health – such as getting enough sleep, eating properly and managing stress – provides an important foundation for your emotional wellbeing. So if you are having problems with these for any reason, it may be good sense to ask for professional help.

For many people, having a drink or occasionally using recreational drugs is a pleasurable part of life. However, alcohol and drugs are also used by many people for short-term relief when they are experiencing difficult feelings. They might offer temporary relief, but in the long run relying on them is likely to make your feelings harder to deal with. Prolonged and excessive drinking and drug-taking can also damage your physical health and affect how your body absorbs anti-HIV drugs.

Taking part in productive and enjoyable activities can help promote a feeling of wellbeing. Having interests that you find engaging and rewarding (in any way) are important. Setting goals for yourself can give

you a sense of purpose. It's most helpful if these goals are realistic and can be achieved by taking small, measurable steps.

Feeling isolated can be a source of distress, or can make feelings of distress worse. Interacting with other people in ways that you are comfortable with is important to good emotional wellbeing. Many HIV support organisations offer one-to-one and group peer support. You may also want to join organisations based on your interests, to meet other people and help you feel less alone.

Some people find that faith or spirituality are important sources of comfort and stimulation. Prayer, meditation or quiet reflection can be helpful for reducing stress

and loneliness. And religious or cultural communities can be key networks of support and social interaction.

Anxiety

Anxiety is a feeling of apprehension or dread that bad things may happen, causing both physical and psychological effects. It's not always a bad thing: it can be a very appropriate and useful reaction. As the body's natural response to a threat or challenge, it can help you react quickly to a situation.

Life with HIV can at times involve worry and uncertainty and anxiety may be a natural response to a new development in life.

However, when anxiety becomes a long-term problem that affects quality of life or restricts your choices, psychological support may be needed.

Symptoms of anxiety can include sweating, breathlessness, a racing heartbeat, agitation, nervousness and headache. Sometimes, people can think they are having a heart attack. People may worry constantly, feel strongly that they cannot cope, be irritable, weepy, unable to relax or to concentrate, and inclined to think that the worst will happen. Anxiety often occurs along with symptoms of depression (see next page), but can also happen by itself.

If your anxiety is caused by specific problems – concerns about money, housing or taking

HIV treatment, for example – getting practical advice about how to approach these difficulties may well provide a solution. There are techniques you can learn to help control anxiety and talking to family and friends can help.

Psychological therapies may also prove useful. Having some form of talking therapy, such as cognitive behavioural therapy, can help provide the skills and practical techniques to understand the origins of anxiety and to manage it better.

Anxiety can occur with depression, so it can be treated by antidepressants and other medication. It may be that you will be offered talking therapy, as this is now the preferred

method of professional help for mild to moderate anxiety and depression. But no one treatment is the right one for everyone, and your doctor should discuss the different options with you.

Massage, acupuncture, other complementary therapies and exercise can sometimes relieve some of the symptoms of anxiety. Cigarettes, stimulants (such as coffee) and depressants (such as alcohol) may seem to be helpful but usually increase the symptoms of anxiety, so it helps to avoid them. Eating a healthy diet and getting plenty of sleep can also make a big difference to your ability to cope with stress.

Drugs such as benzodiazepines, including *Valium*, used to be widely prescribed for the

treatment of long-term anxiety. Their use is now restricted because they are addictive and are less effective the longer they are used. However, they are still used to treat short-term periods of extreme anxiety and panic with little risk of addiction. Your GP can advise you about this sort of medication, although psychological therapy should generally prevent you needing medication. Remember, if your GP does prescribe these drugs, consider telling them about any HIV treatment you are on, or talk to someone at your HIV clinic, to avoid interactions between the drugs.

Depression

People often say that they are 'depressed' when they are feeling down or sad. Often this

is probably a natural fluctuation in mood, or an appropriate reaction to a distressing event or situation – everyone will experience this at times.

However, depression is a recognised mental disorder and is treatable. Mental health professionals often talk about 'clinical depression' or 'major depression' when they are referring to this condition. It is thought that depression occurs much more frequently in people with HIV than in the general population. Surveys of people with HIV in the UK have shown that high numbers of HIV-positive people report experiencing depression and anxiety.

There is also evidence 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. Some research suggests that people who are co-infected with hepatitis C also have high rates of depression (the treatment for hepatitis C can also cause depression; see p. 27).

One of the most common signs of depression is feeling fatigue, tiredness and low energy. However, this fatigue or tiredness might be associated with some sort of physical condition, such as low testosterone levels or hypothyroidism. It's essential you ask for a thorough physical check-up if you are struggling with low energy.

Some women who are pregnant or have recently given birth can be more prone to depressive symptoms – this generally starts very soon after the baby's birth and only lasts a short time but it can also start during pregnancy or sometime after the birth, and be more severe and longer lasting. Paying attention to a woman's emotional state is an important part of health care during and after pregnancy and childbirth.

Causes of depression vary, but can involve biological, psychological and social factors. Illness, stress and social problems often cause depression to develop. For example, the physical effects of HIV disease progression itself can trigger depression. Experiencing a number of significant losses in life in a short

period of time can also trigger a depressive episode. It has also been suggested that some people may be vulnerable to developing depression and other mood disorders simply because of their genetic make-up. In many cases, however, there might be no obvious or identifiable cause for the depression.

Whatever the causes may be, depression can become very entrenched. It can even become dangerous if a person becomes suicidal. So paying attention to the signs of depression and doing something about it can be life saving.

Depression is characterised by the presence of some or all of the following symptoms, for some or all of the time, and for a period of weeks or even months (rather than for a few

hours or days): low mood, crying spells, apathy, irritability and difficulties with concentrating. Symptoms can also include constant fatigue, sleeping problems (difficulty in falling or staying asleep, or oversleeping constantly), and changes in eating habits (loss of appetite or an inability to control overeating).

A key feature of depression is the loss of pleasure in activities that are usually meaningful and enjoyable. Reduced sex drive, social withdrawal and isolation are also signs. Feelings of low self-worth and inappropriate or excessive feelings of guilt are also symptoms of depression which can also include thoughts of death, self-harm, or suicide.

It is important to get professional help if you think you are experiencing a number of these symptoms. Try talking to your partner, a good friend or a family member about how you feel. You should not think that you are weak, unstable or 'mad' if you ask for help because you think you might be depressed. In fact, it's a sign of strength that you are reaching out for some help to improve your situation.

If depression is not treated, it will not go away permanently. The feelings may get less, so that you feel better, but it's likely that you will have another episode of depression in the future. Psychological treatments for depression are very effective and can reduce the chance of depression recurring.

If you think you need professional help, contact one of the organisations listed at the back of this booklet and on pages 32-35. Your GP or HIV doctor will also be able to help. HIV doctors are very used to working with people who are experiencing depression. Many of the large HIV clinics have specialist mental health teams including psychiatrists, psychologists and mental health nurses (see p. 4).

Seek help immediately if you are thinking of harming or killing yourself. Your GP should be able to arrange some immediate help during working hours. You can go to your local accident and emergency department at any time of day or night, where you will be able to see a mental health specialist for assessment and help. (See p. 32 for other sources of help.)

If you suffer from depression, your doctor may recommend that you take antidepressant medication. These drugs relieve the symptoms of depression by correcting chemical imbalances in the brain. They do not cure depression but they help you with the symptoms so you can get into a better state to start helping yourself.

Treatment for depression

There are three main classes of antidepressant drugs:

- tricyclics
- MAOIs (monoamine oxidase inhibitors)
- SSRIs (selective serotonin re-uptake inhibitors).

If your doctor prescribes an antidepressant, it is most likely that it will be from the SSRI class. Drugs in this class, which includes fluoxetine (*Prozac*), have fewer side-effects and interactions with other medications. In particular, the antidepressant citalopram (*Cipramil*) is often used because it has few interactions with anti-HIV drugs and generally doesn't cause many side-effects. It's important the doctor prescribing the antidepressant knows about any other drugs you take, including anti-HIV drugs.

If your GP suggests that medication may be helpful to help improve your mood, it is a good idea to inform them if you are on HIV medication, to ensure that one drug does not reduce the absorption of the other. If this is

difficult, make sure you inform your HIV consultant of any medication your GP has prescribed in case your HIV medication needs to be reviewed.

Antidepressants can take between two and twelve weeks to have a significant and lasting effect, and your dose may need to be increased for the drug to be effective. Like all medicines, they can have side-effects, although not everyone will experience them.

SSRI antidepressants have some side-effects, particularly in the first few weeks. Side-effects at this time can be particularly difficult to cope with because of the time the medication can take to relieve the symptoms of depression. Make sure you discuss any

concerns about side-effects with your doctor.

The herbal antidepressant St John's wort interacts with anti-HIV drugs in the protease inhibitor (PI) and non-nucleoside reverse transcriptase inhibitor (NNRTI) classes, leading to low levels of the anti-HIV drugs in the blood and 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 length of time you need to take antidepressants will vary with your individual circumstances. You may start to feel a lot better a few weeks after you start taking them, but it is highly recommended that you remain on antidepressants until you have

finished your course of treatment, as you may become worse again if you stop too soon (this is usually at least six months if you are taking them to treat your first depressive illness, or longer if this is not your first episode of depression).

If you feel strongly about reducing your dosage of antidepressants, talk to your GP so the reduction in dose can be medically managed in case it causes side-effects.

Antidepressants can be a vital tool in recovery from depression. But they are only one of the tools at your disposal. There is growing clinical evidence that psychological or 'talking therapies' can be just as effective, or even more effective in some circumstances. Guidance on

how to find a counsellor, psychotherapist or psychologist can be found on p. 34.

Addiction

Addiction is defined as a high dependence on something, to the point where it could be harmful to you. It could be to a substance – food, alcohol or other recreational drugs – or to a behaviour – such as shopping, gambling or sex.

When the need for the substance or behaviour starts affecting normal life – perhaps causing someone to become secretive or to arrange their lives around meeting this need – people may be regarded as having an addiction, or to be dependent on the behaviour or substance.

There is no single reason why someone

develops a dependency, but some people deal with stress or difficulties by turning to mood-altering substances and behaviours. These might seem to solve their immediate problems, but in fact the problem still exists and the dependency is preventing them from dealing with the problem. In the long run, this can cause more problems, and may lead to someone's life becoming out of control.

It is possible to have either a physiological or a psychological addiction to something, or for both to exist together.

It is generally agreed that, for someone to address an addiction successfully, they need to recognise the problem and want to stop. There are a number of treatments that work well for

addiction – generally psychological therapies. However, sometimes these will need to be combined with medication, especially if an addictive substance has changed the body's physiology, such as opiates. (See p. 32 for more information on how to find help.)

Try to cut back on your drug and alcohol use slowly and gradually. Monitoring how much you use will help you judge how you are doing on reducing or giving up these substances. You may need medical help and support to stop using alcohol or drugs safely. If you use these daily, particularly alcohol or GBL (gamma-butyrolactone), and would like to stop, talk to your healthcare team about how to go about this. Your HIV clinic staff can give advice or help without judging.

Post-traumatic stress disorder

Acute stress disorder (ASD) or post-traumatic stress disorder (PTSD) can sometimes be experienced by people with HIV. These disorders occur when a person has experienced a traumatic event – something outside normal life experiences – and is unable to process the shock properly. This can cause flashbacks, nightmares, a powerful sense of dread, nervousness and an avoidance of reminders of the event. Memories of the event can also be affected and people often say they have difficulty concentrating as they are easily distracted by worries.

There are a number of treatments available, including psychological therapies. These can be a very successful way of managing these conditions (see p. 34 for contacts).

It is important to remember that many, if not most, people who experience some kind of traumatic event manage to get through the difficulties associated with it. That is, they manage to adjust to the event and get on with life. However, it is generally recognised that the symptoms associated with PTSD can become a significant problem and can start to interfere with daily life if they continue.

Dementia

Before effective HIV treatment (often called highly active antiretroviral therapy, or HAART) became available, it was calculated that approximately 2 to 7% of people with very weak immune systems due to advanced HIV infection would develop dementia. Survival rates were, and remain, very poor for HIV-positive people with HIV-related dementia.

Even before potent HIV therapy became available in the late 1990s, the number of new cases of dementia seen in HIV-positive people was already falling.

Any potent HIV therapy combination that keeps your CD4 cell count above 200 will protect you from developing dementia or milder damage to concentration, memory and decision-making abilities. People with CD4 counts under 50 are at most risk of HIV-related dementia, although not everyone with such a low CD4 count will develop it.

Thanks to the success of HIV treatment, new cases of dementia are now very rarely seen, and these are only in people who have

not been taking potent anti-HIV drugs.

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

- Difficulties in thinking or understanding, including forgetfulness, loss of memory, severe problems concentrating, confusion and problems planning and organising.
- Behavioural changes including withdrawing from other people, agitation, a loss of interest, and childish behaviour.
- Problems with movement and co-ordination, 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. See your HIV doctor to find out what the cause is if you experience any of these symptoms and are troubled by them. It may be that you are feeling stressed and that you have too much on your mind.

Sometimes changes can be due to a condition called minor cognitive motor disorder or HIV-associated mild neurocognitive disorder. The symptoms of these conditions are much more subtle. Severe anxiety or depression can also result in similar memory or physical changes. Try not to panic if you notice these changes, but do let clinic staff know so that you can be

referred to a specialist (usually a clinical psychologist) who can assess whether these changes are due to brain changes or mood problems.

Tests can be done to assess any 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 in the nervous system. Scans can also help diagnose these sorts of problems. You may be referred to a psychologist or neuropsychologist for these tests.

There has been some concern that older HIV-positive people – those aged 50 and above – may have an increased risk of mild brain impairment, involving symptoms such as forgetfulness. The evidence is far from conclusive, but untreated depression, fatigue, drug or alcohol abuse, and poor sleep patterns can also result in similar symptoms. In many cases, these subtle brain changes won't have a noticeable impact on everyday life.

People with severe dementia often require special care. There used to be several dedicated residential facilities providing care for HIV-positive people with dementia, but because the condition is now so rare these have largely 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. However, the Mildmay Hospital in London still provides specialist care for people with HIV-related dementia and related problems. HIV clinics can provide referrals.

Mania

Manic episodes – uncontrolled impulses, irrational thinking, unusual behaviour 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 are due to damage to the brain caused by HIV. Thanks to potent HIV treatment, cases are now extremely rare.

24 Treatments for mental health problems

People with HIV may also experience other mental health problems unrelated to their HIV diagnosis, such as attention deficit hyperactivity disorder (ADHD), schizophrenia, obsessive-compulsive disorder (OCD) and bipolar disorder (formerly known as manic depression). There are medical treatments available for these conditions, including drugs such as antipsychotics, anticonvulsants and mood stabilisers such as lithium. Psychological therapies and support groups will also help.

As with treatment for depression (see p.16), there may be interactions between these drugs and some anti-HIV drugs. These will need to be taken into account in choosing a treatment regimen for both your HIV and a

mental health condition. It's important your healthcare team knows about any drugs you're already on when they're prescribing something new.

Some anti-HIV drugs can affect your emotional and mental health. Most notably, the non-nucleoside reverse transcriptase inhibitor (NNRTI) efavirenz (*Sustiva*, also in the combination pill, *Atripla*) has been associated with depression and sleeplessness, as well as vivid dreams.

Some doctors think that the depression that some people develop when taking efavirenz is actually a recurrence of pre-existing depressive symptoms; people with a history of depression may be more likely to become depressed again when they start taking efavirenz. It is important you tell staff at your HIV clinic if you have a history of depression before you start HIV treatment.

Often the emotional troubles and sleep problems associated with efavirenz lessen or go away completely within a few weeks of starting this treatment. But for some people they become a long-term side-effect.

Research suggests that such side-effects are more likely to happen if you have a particular gene that creates higher levels of efavirenz in the blood. It's possible to test blood levels of efavirenz and, if these are too high, it might be possible to reduce your dose. But you shouldn't try and do this by yourself. You should talk to your HIV clinic about these or any other side-effects that are causing you concern.

If you find that you cannot cope with the problems efavirenz can cause, it's good to

know that there may be other equally effective treatment options available to you. Ask your clinic staff for advice on these.

Anti-HIV drugs can also affect your emotional wellbeing by causing side-effects such as pain, nausea and vomiting, or diarrhoea. But most side-effects are generally mild and lessen or go away over time. Furthermore, it's nearly always possible to do something about side-effects. There are now over 20 anti-HIV drugs available, and it's often possible to change to a drug that doesn't cause the side-effect you find problematic.

Some older anti-HIV drugs can cause changes in body shape through fat loss or fat gain (a

condition called lipodystrophy). Although the use of these drugs is now avoided as much as possible, changes in body shape can lead to loss of self-confidence and self-esteem. If you have these feelings, ask at your clinic to see a counsellor or psychologist to discuss them. You can also raise this issue with your HIV doctor to find out what can be done to stop, or reverse, these body shape changes.

You can find out more about side-effects and how to avoid or deal with them in the booklet in this series, *Side-effects*.

Some drugs used to treat other infections that are common in people with HIV can also cause mental health problems.

Interferon and pegylated interferon treatments for hepatitis C virus, which many people with HIV are co-infected with, can cause emotional distress and depression.

If you need to take these drugs your doctor may also arrange some psychological therapy or prescribe you antidepressants, particularly if you have a prior history of depression. It is important that you discuss this with your healthcare team if this is the case. For more information see the booklet *HIV & hepatitis* in this series.

28 Looking after your emotional and mental health

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

Take care of yourself:

- Make sure you get enough to eat. Try to take pleasure in eating well. Sitting down and eating a meal with someone else can help you cope with stress and improve the quality of your life. Eating on the move may be necessary once in a while. But do try to slow down and eat properly.
- Get a good night's sleep. This is very important to both your physical and mental health, and not getting enough sleep can trigger emotional and mental health problems. Also, try not to sleep too much: this can make you feel tired and reduce motivation to do anything else. Often, the less you do, the less you feel like doing.
- Take some exercise that you enjoy. Regular physical exercise can help you manage stress and will also help you sleep soundly at night. Exercising with someone else may make it more enjoyable and increase your social contact.
- Make use of hobbies or other activities you enjoy to keep yourself busy and occupied. You could also think about developing new interests.
- Drinking too much alcohol and excessive use of recreational drugs can contribute to emotional and mental health problems, as well as damaging your physical health and interfering with your HIV treatment.

- Try and deal with work, relationship, family, money or housing problems as soon as you notice them. Avoiding them can simply increase your levels of stress.
 - Everyone needs to take responsibility for dealing with their problems. However, sometimes this may involve asking for some help. It's not a sign of weakness – in fact it's a sign of strength that you can recognise that you need some help.
 - Allow yourself some pleasures in life. Focusing on your troubles and worries all the time doesn't always solve your problems. Sometimes you need to replenish your energy by enjoying the good things in 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 are finding things hard; ask for help – there will be somebody who can help you. (See p. 32 for contacts.)

30 Supporting somebody with emotional or mental health problems

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

But to provide this effectively, 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 just 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 at first to a person who is struggling. Even though you may know that it will be good for them to start doing something, you may need to be patient as well as persistent.

Provide for your own needs

- Make sure you take care of your own physical and mental health.
- Make sure you talk to people about your experiences of providing support and how it is affecting you.
- Be honest with yourself about the level of support you can provide.
- Seek help if you find you cannot cope.
- Don't help others at the expense of helping yourself. Sometimes saying "no" can be more helpful, in the longer term, to you and the person you are trying to help.

32 Where to go for emotional and 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.

GPs can also provide help and support with mental health problems. Many GP surgeries now have some form of counselling available. They can also refer you on to specialist services if necessary.

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.

Mind

A national mental health charity, with local branches, providing information and advice on a wide range of mental health problems and treatments.

Mind Info Line 0845 766 0163

www.mind.org.uk

The Royal College of Psychiatry

This is the professional and educational body for psychiatrists. It produces information leaflets on a range of mental health problems and treatments.

www.rcpsych.ac.uk

PACE

PACE provides counselling for gay men and lesbians in London on issues including HIV.
020 7700 1323
www.pacehealth.org.uk

Positively Women

Positively Women is a national charity providing support for women living with HIV. Women living with HIV answer their helpline. PW will ring you back free of charge.
020 7713 0222

Shaka Services

Shaka Services provides confidential counselling and emotional support on HIV and related issues for people from African and Caribbean communities living with or

affected by HIV/AIDS in London.
020 7735 6744
www.shakaservices.org.uk

Saneline

Mental health charity providing support and information by telephone and email.
Helpline 0845 767 8000
www.sane.org.uk

THT Direct

The gateway to Terrence Higgins Trust's services.
0845 12 21 200
www.tht.org.uk

Samaritans

Confidential emotional support 24 hours a day.
08457 90 90 90

NHS Choices

You can find out more about looking after your mental health, and getting help with mental health problems, or problems with alcohol or drugs, at www.nhs.uk.

To find a counsellor or therapist:

The best way to find a supportive counsellor or therapist is often through personal recommendation. Alternatively, you can ask at your clinic, another HIV organisation or GP surgery about their services or contacts they may have.

You can also find a counsellor or therapist through a nationally recognised organisation.

Many counsellors are registered with the British Association for Counselling and Psychotherapy (BACP) and psychotherapists with the United Kingdom Council for Psychotherapy (UKCP). Click the 'find a therapist' buttons at www.bacp.co.uk or www.psychotherapy.org.uk.

Most psychologists in the UK are members of the British Psychological Society (BPS). To search for a psychologist, call the BPS on 0116 254 9568 or visit www.bps.org.uk and click the 'find a psychologist' button.

Counsellors or therapists who are not registered with one of these bodies may still be well-trained and very experienced, but it's

a good idea to check their qualifications and see if they belong to a professional body.

Alternatively, you can ask at your clinic, another HIV organisation, mental health charities or your GP about local therapy services or specialist services for issues such as addiction or postnatal depression. Again, always make sure these therapists belong to a nationally recognised organisation and/or that they have a licence to practise.

The NHS's 'Improving Access to Psychological Therapies' initiative also provides online cognitive behavioural therapy. You can get a prescription for this service from your GP.

To find a complementary therapist:

Finally, many people find that complementary therapies, such as acupuncture or massage, can be very beneficial in reducing physical discomfort or stress. Again, always search for a practitioner via a reputable agency such as the Complementary Therapists Association (CThA), which is recognised by the Department of Health (www.complementary.assoc.org.uk).

36 Summary

- Emotional and mental health are important issues for people with HIV.
- People with HIV seem to be more likely to experience a range of emotional and mental health problems, including distress, unhappiness, anxiety and depression.
- There are things you can do to look after your emotional and mental health.
- Help is available if you are having emotional or mental health problems.
- Treatment and support services are available if you suffer from mental health problems.
- Some anti-HIV drugs can have side-effects which include mental health problems. These may be temporary and can be dealt with.
- HIV infection can cause dementia and other conditions, but these problems are now very rare thanks to HIV therapy.

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HIV Treatment Update

NAM's regular newsletter keeps you up to date with the latest news and developments about HIV, to help you talk to your doctor, and make decisions about your health and treatment.



HIV Weekly

NAM's weekly email round-up of the latest HIV news. Sign up today for straightforward news reporting and easy-to-read summaries of the latest HIV research.



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Please complete this form and send to NAM, FREEPOST LON17995 London, SW9 6BR

Under the terms of the Data Protection Act you may advise us at any time if you do not wish to receive further mailings from NAM

What did you think of this booklet?

NAM wants to make sure this booklet is useful to you. We would be grateful if you could take a minute to provide us with some valuable feedback. The questionnaire is anonymous and confidential.

As a result of reading this resource have you learnt anything about HIV, your health and treatment?

- I have learnt nothing new
- I have learnt something but it's not particularly useful to me
- I have learnt something that is useful to me
- I have learnt something that seems vitally important to me

Please tell us in your own words what you have learnt:

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As a result of reading this resource I am more likely to: (tick all that apply)

- Discuss my treatment and care with my healthcare team
- Feel more confident talking to my healthcare team
- Feel better equipped to take decisions regarding my treatment and care
- Feel more informed about HIV treatment and living well with HIV
- Find other information and support, if I need it
- None of the above

Please tell us if there is anything else you are more likely to do or feel as a result of reading this booklet:

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Please tear off this page and post it to: NAM, FREEPOST LON17995 London, SW9 6BR.

We would like to ask you a few more questions. You don't have to answer these, but if you do, it will help us make sure our information is relevant and useful to our readers.

Please circle the description that best describes you

- I am: male / female / transgender
- I live: in London / in the UK but outside London / outside the UK (please specify)
- My ethnic background is: White / Black-Caribbean / Black-African / Black – other /
Indian or Pakistani or Bangladeshi / other Asian or oriental / other or mixed
- My HIV status is: unknown / negative / positive
- (If positive) I think I got HIV as a result of: sex between men and women / sex between men / injecting drugs /
from blood or blood products / mother-to-child transmission /
other / don't know / rather not say
- I work: in the HIV field / not in the HIV field / I do not work at the moment
- I got this booklet from: nurse / doctor / clinic / THT's HIV Health Support Service /
support group / friend / family member / NAM /
other (please specify)

**Thank you very much for taking the time to fill in this questionnaire.
NAM really values your feedback. It helps make the information we provide better.**

If you have any other comments on the content of this booklet please email info@nam.org.uk

HIV helplines

THT Direct

from the Terrence Higgins Trust

telephone 0845 1221 200

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

African AIDS Helpline

telephone 0800 0967 500

opening hours Monday-Friday, 10am-6pm

HIV i-Base Treatment Phonenumber

telephone 0808 800 6013

opening hours Monday-Wednesday, 12pm-4pm

NAM information series for HIV-positive people

The booklet series includes: ■ adherence & resistance ■ anti-hiv drugs ■ CD4, viral load & other tests
■ clinical trials ■ hiv & children ■ hiv & hepatitis ■ hiv & sex ■ hiv & stigma
■ hiv & women ■ hiv therapy ■ hiv & tb ■ nutrition ■ side-effects

More from NAM

NAM Information Forums

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.**

HIV Health Support Service

NAM supports THT in providing one-to-one and group skills sessions on health and treatments to people living with HIV. **Call THT Direct for details.**



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Call NAM on 020 7840 0050.

Donate to NAM

Every year NAM provides information resources, like this booklet, to thousands of people living with HIV, completely free of charge. To do this we really do rely on the generosity of people like you to help us continue our vital work. You can make a difference today.

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