

# HIV, mental health & emotional wellbeing



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Contact NAM to find out more about the scientific research and information used to produce this booklet.

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## This booklet provides information on emotional wellbeing and mental health for people living with HIV.

Emotional difficulties and problems with mental health can affect anybody (research suggests one in every six people in the UK has some sort of mental health problem), but living with a long-term illness like HIV can mean that you are more likely to experience mental health problems. There are things you can do to look after your emotional health, and help is available if you experience problems that you are not able to solve by yourself. Treatment for depression, anxiety and many other mental health problems can be very effective.

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## Emotional wellbeing, mental health and HIV

**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.

One reason for this may be HIV-related stigma, in other words the prejudices and negative attitudes that some people have about HIV. Stigma is one of the reasons that some people end up having quite negative feelings about themselves in relation to their HIV diagnosis.

"Stigma is one of the reasons some people end up having quite negative feelings about themselves in relation to having HIV."

It can be difficult for anybody, including people living with HIV, to avoid being exposed to the negative and inaccurate ideas and beliefs that have developed about HIV.

Also, some of the groups most affected by HIV in the UK (such as gay men, migrants and drug users) are more likely to have mental health problems, because of the stresses associated with being marginalised from mainstream society. Women are more likely to experience mental health difficulties than men.

Some anti-HIV drugs can affect your emotional and mental health (see page 31). If you have had mental health problems in the past, it is helpful to tell your HIV doctor this when you start discussing treatment options. That way, the most appropriate anti-HIV drugs for you can be prescribed.

## Dealing with problems

**Particular events such as receiving an HIV diagnosis, talking to others about having HIV, bereavement, the breakdown of a relationship, financial worries or work problems, or dealing with starting HIV treatment or its side effects, can result in feelings of deep unhappiness and emotional distress.**

This can include feeling 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.

If you are experiencing these kinds of emotional difficulties, learning to understand and cope with them is an important part of being able to deal with them.

“Learning to understand and cope with emotional difficulties is an important part of being able to deal with them.”

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 page 39 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.

## Professional support

**Everybody will have personal strategies for 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 medical doctor who is 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 ('talking therapies').

**Clinical psychologist** A clinical psychologist provides psychological therapies to reduce psychological distress and enhance or promote emotional wellbeing. They are also trained to do specialist assessments looking at the effect of illnesses on the brain. They will have postgraduate academic training, and usually work in a hospital or other health or social care 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.

**Community mental health nurse (CMHN)** Sometimes known as a community psychiatric nurse (or CPN), a CMHN is a registered nurse with specialist training in mental health. Some CMHNs are attached to GP surgeries or community mental health centres, while others work from psychiatric units.

**Psycho-therapist** This is a person who provides treatment for emotional problems through talking. They will have taken in-depth training in various forms of therapy, and may also have been trained as a psychologist, psychiatrist or social worker. There is some overlap in the roles of a psychologist and a psychotherapist.

**Counsellor** A person who offers counselling will talk to you about your difficulties with the purpose of finding new ways of managing them. These difficulties may be related to HIV such as a recent diagnosis, or they may be related to other major life events such as a job loss or the death of a parent. Counsellors are usually university graduates who have some postgraduate training in counselling, such as client-centred counselling. (See page 42 for help with finding a counsellor and contacts.)

**Community mental health teams (CMHT)** These teams help people with more complex mental health needs 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 (this is called 'liaison psychiatry').

**Psychological wellbeing practitioners** A type of NHS worker, who can provide support and care for people struggling with low mood and moderate anxiety. They are usually linked to primary care counselling services (often called Improving Access to Psychological Therapies, or IAPT) which are co-ordinated by your GP.

A document called *Standards for psychological support for adults living with HIV* describes how support should be provided to people living with HIV in the UK. The standards recognise the importance of providing timely and effective support for mental health and emotional wellbeing as part of good HIV care.

You can read the full version of the standards on the British HIV Association website (**[www.bhiva.org](http://www.bhiva.org)**).

A short version of the standards has been produced to help you find out more easily what psychological support you can get. Ask for a summary of the standards at your HIV clinic or support organisation, or you can read it online at **[bit.ly/2r1ogtf](http://bit.ly/2r1ogtf)**.

## Peer support

**Many people find it helpful to meet other people living with HIV. It may be good to talk to someone with personal experience of what it means to live with HIV who perhaps has been through similar things to you. The British HIV Association recommends that peer support should be available to all people living with HIV.**

At your HIV clinic, there may be a peer support worker who is living with HIV.

Several HIV organisations host groups for people to meet, talk, and provide peer support. Some people find it helpful to dip into a group when they're feeling under pressure or dealing with a particular problem. Others use them as a source of long-term support and feel they are part of a positive community.

## Mental health problems

### 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, uncertainty, 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.

It can be easy to assume the worst about life with HIV. It's possible that, before your diagnosis, no one told you that HIV treatment is now so effective that most people with HIV can expect to live as long as people who don't have HIV. Or that the medications also prevent the sexual transmission of HIV – if you take anti-HIV drugs and have an 'undetectable viral load', you won't pass HIV on to your sexual partners.

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, experiencing ill health, starting or changing treatment, talking about having HIV 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. In the end, many 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 normal and acceptable to have feelings that you find difficult. Although it can be easier said than done, don't feel bad about not feeling OK. Acknowledging and accepting 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 perfectly normal and acceptable to have feelings that you find difficult."

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 to understand or work through, psychological therapies can be helpful. Your HIV clinic should be able to help you find a suitable therapist if they don't offer such services themselves. (See page 42 for more help with finding a therapist.)

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

Trouble sleeping is a widely reported psychological disorder, both in the general population and among people living with HIV. Difficulty going to sleep or staying asleep can be the result of worry, stress or mental health problems, or the cause of them.

For many people, having a drink or occasionally using recreational drugs is a pleasurable part of life. However, alcohol and mind-altering 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, as well as making it harder to remember to take your HIV treatment.

"Setting goals for yourself can give you a sense of purpose."

Feeling isolated can be a source of distress, or can make feelings of distress worse. Finding ways of 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 can get support online if you prefer. You may also want to join non-HIV-related organisations, based on your interests, to meet other people and help you feel less alone.

Taking part in productive and enjoyable activities can help promote a feeling of wellbeing. For example, volunteering in your local community – perhaps with a charity or community group – can be a good way of meeting people, developing new skills and increasing self-esteem and confidence, as well as of helping others. You can find out more about volunteer work and see what types of opportunities are available, on the volunteering website **do-it.org**.

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.

Many people find practising mindfulness helps them with their day-to-day wellbeing. It is a technique you can learn that involves paying attention to the present moment, to your thoughts and feelings and the world around us, in the here and now. (See page 43.)

Others 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. Religious or cultural communities can be key networks of support and social interaction.

And some people also find that complementary therapies, such as acupuncture or massage, can relieve some of the symptoms of emotional distress. (See contacts on page 44 for more information on finding a complementary therapist.)

## 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. Anxiety can be a natural response to a new development in life when you are not familiar with it.

However, when anxiety becomes an ongoing issue that affects your 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 page 17), but can also happen by itself.

"Talking therapies can help provide the skills and practical techniques to understand the origins of anxiety and to manage it better."

Anxiety can be related to specific situations, such as being in crowded spaces, or travelling by public transport, or having an assessment, or it can happen without a particular trigger.

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. Relaxation techniques and mindfulness are also used sometimes to help people with anxiety.

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 levels of anxiety and depression. But no one treatment is the right one for everyone, and your medical 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.

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.

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## 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 characterised by being persistent and more severe than transient periods of sadness. It is thought that depression occurs much more frequently in people living with HIV than in the general population. Surveys of people living with HIV in the UK have shown that high numbers of HIV-positive people report experiencing depression and anxiety.

It is also worth remembering that some of the groups often affected by HIV – including gay men, ethnic minorities, women and transgender people – already have higher rates of depression than the general UK population. Some research suggests that people with HIV and hepatitis C co-infection also have high rates of depression.

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 some time after the birth, and be more severe and longer lasting.

Later in life, women going through the menopause are at greater risk of mood swings and of

depression. If this has an impact on your daily life, it's worth telling your doctor. The main aim of treatments for the menopause is to relieve symptoms and improve quality of life.

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 include thoughts of death, self-harm, or suicide.

Feeling depressed can also affect how you feel about HIV treatment and your ability to take your drugs as prescribed ('adherence'), so it's important that you and your doctor talk about how you feel. Other staff at your HIV clinic can also help you with adherence if you are finding it hard. You can find out more in NAM's booklet *Taking your HIV treatment*.

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## Treatment for depression

**It is important to get professional help if you think you are experiencing a number of these symptoms. Try talking to someone you trust – perhaps a friend, colleague, partner or family member – about how you feel and where you could get more support.**

You should not think that you are weak, unstable or 'mad'. In fact, it's a sign of strength that you are reaching out for some help to improve your situation.

Exercise can help with mild depression. It is something you can do yourself, but your GP may also be able to help by prescribing exercise and referring you to a programme at a local gym or health centre.

If depression is not treated, it will not go away permanently. The feelings may lessen, 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 page 39. 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 page 5). Your GP will also be able to help with diagnosis, treatment and referral to specialist services.

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 page 41 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.

### Drug treatment for depression **There are four main classes of antidepressant drugs:**

- ☐ SSRIs (selective serotonin re-uptake inhibitors)
- ☐ tricyclics
- ☐ SNRIs (serotonin and noradrenaline re-uptake inhibitors, also called serotonin and norepinephrine re-uptake inhibitors)
- ☐ MAOIs (monoamine oxidase 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 medications and generally doesn't cause many side effects. It's important the doctor prescribing the antidepressant knows about any other drugs you take, including your HIV treatment.

"It is recommended that you remain on antidepressants for at least six months after you feel better."

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.

The side effects of SSRI antidepressants often occur in the first few weeks of taking them. 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 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 for at least six months after you feel better.

It's important not to stop suddenly as withdrawal symptoms can be difficult to cope with. If you want to reduce your dosage of antidepressants, talk to your GP about gradually reducing the dose.

Antidepressants can be a vital tool in recovery from depression. But they are only one of the tools at your disposal. It's often helpful to combine antidepressants with a 'talking therapy'. There is evidence that talking therapies can be just as effective, or even more effective in some circumstances. Guidance in how to find a counsellor, psychotherapist or psychologist can be found on page 42.

## Addiction

**Addiction is defined as a high dependence on something, to the point where it could be harmful to you or to others. 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.

"For someone to deal with an addiction, they need to recognise the problem and want to stop."

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

It is generally agreed that, for someone to deal with an addiction, 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 page 39 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 to stop using alcohol or some drugs (such as GBL, or gamma-butyrolactone) safely. If you use these daily and would like to stop, talk to your healthcare team about how to go about this. (It can be dangerous in some situations to stop drinking or using the drug altogether without medical supervision.) Your HIV clinic staff can give advice or help; they won't judge you.

## Post-traumatic stress disorder

**Acute stress disorder (ASD) or post-traumatic stress disorder (PTSD) can sometimes be experienced by people with HIV. These types of anxiety disorders occur when a person has experienced a traumatic event and is unable to process the shock properly.**

The situations we find traumatic vary from person to person. There are many different harmful or life-threatening events that might cause someone to develop PTSD. These are just some examples:

- ☐ a serious injury, illness, or accident
- ☐ being abused or sexually assaulted
- ☐ multiple bereavements of friends, lovers or family

- being rejected because of stigma or prejudice
- war or political violence, including being forced to move to another country.

PTSD 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 for this condition, including psychological therapies. These can be a very successful way of managing the condition (see page 39 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.

### Cognitive impairment

**While some decline in memory and thinking skills is a normal part of getting older, more significant changes are called 'cognitive impairment'. Changes may include a shorter attention span, slowness in processing information, less fluency**

**in the use of language, a reduced ability to plan and organise everyday life, or lapses in memory.**

One form of cognitive impairment is linked to HIV infection. But people living with HIV can have cognitive impairment due to other causes. Some of the most important causes are:

- **Alcohol or drug-induced cognitive disorders.** Alcohol and recreational drugs can damage brain cells and disrupt body processes, with a long-term effect on cognitive function.
- **Depression, anxiety and other mental health problems.** Their symptoms can include lapses in memory, problems concentrating, a slowness in thinking, and it being harder to solve problems.
- **Vascular cognitive impairment,** caused by small vessel disease, stroke and other conditions that reduce blood flow to the brain, depriving brain cells of vital oxygen and nutrients. High blood pressure, diabetes, smoking and high cholesterol are risk factors for vascular cognitive impairment.
- **Alzheimer's disease,** in which abnormal structures called plaques and tangles damage and kill brain cells.
- **HIV-associated cognitive disorder** (sometimes called HIV-associated neurocognitive disorder or HAND). This occurs when HIV itself (or the response of the immune system to HIV) directly affects the brain and causes cognitive disorders. This form of cognitive impairment is more common in people

who had a low CD4 count before they began HIV treatment. Good adherence to effective HIV treatment lowers the risk of this type of cognitive impairment.

Changes to your lifestyle can reduce your risk of cognitive impairment and help prevent problems getting worse. Generally, things which are recommended in order to protect the health of your heart will also protect your cognitive abilities. Eat a healthy, balanced diet; exercise regularly; don't smoke; and lose weight if you are overweight. You should also limit your intake of alcohol and recreational drugs, and keep your brain active by continuing to be socially connected.

Treatment for cognitive impairment generally focuses on dealing with the lifestyle factors or medical conditions that appear to be contributing to it. You can also get help with managing the impact of cognitive impairment in your day-to-day life.

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## 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.

## Other mental health problems

**People living 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), personality disorders 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 page 22), 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 are already on when they are prescribing something new.

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## Mood and mental health side effects of HIV treatment

**Some anti-HIV drugs can affect your emotional and mental health. Some people have problems with depression, anxiety, sleeplessness, vivid dreams and dizziness. Most notably, this affects small numbers of people taking the following drugs:**

- efavirenz (*Sustiva*, also in the combination pill, *Atripla*)
- dolutegravir (*Tivicay*, also in the combination pills *Triumeq*, *Juluca* and *Dovato*)
- rilpivirine (*Edurant*, also in the combination pills *Eviplera*, *Odefsey* and *Juluca*)

The largest number of problems occur in people taking efavirenz. For this reason, the British HIV Association no longer recommends efavirenz as a 'preferred' drug to start HIV treatment with.

People with a history of mental health problems may be more likely to have difficulties if they start taking one of these drugs. It is important you tell staff at your HIV clinic if you've had depression or other problems in the past, before you start HIV treatment. In particular, if you do have previous experience of depression, efavirenz might not be a good choice for you.

Often the emotional troubles and sleep problems associated with these drugs lessen or go away

completely within a few weeks of starting this treatment. But for some people they become a long term side effect. In this case, there are likely to 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. 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). While the use of these drugs is now avoided, you may have taken them in the past and still be living with changes in body shape. If this has affected your self-confidence or self-esteem, ask at your clinic to see a counsellor or psychologist to discuss them.


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

## 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


**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 proper meals, with a good balance of different types of food. You can find out more in the booklet in this series, *Nutrition*.


 **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. You can get advice and help with sleep problems; talk to your GP or HIV clinic. Sometimes, changing your daily habits can help resolve sleep problems, but in some cases cognitive behavioural therapy or medication may be needed. There are specialist sleep centres for really serious, longstanding sleep problems. Your GP could refer you to one of these.

"Regular physical exercise can help you manage stress and can help with the symptoms of anxiety and mild depression."

 **Take some exercise that you enjoy.** Regular physical exercise can help you manage stress and can help with the symptoms of anxiety and mild depression. It will also help you sleep soundly at night. Exercising with someone else may make it more enjoyable as well as increasing 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.

 **Keep regular contact with friends, family members and neighbours** who are important to you. Other people can help you stay active, keep you grounded and help you deal with practical problems. Strengthening your social connections may also help prevent cognitive impairment.

 **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 to avoid these substances.

☐ **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 to ask for a helping hand or encouragement. In fact, it's a sign of strength that you can recognise that you need some help.

☐ **Allow yourself some pleasures in life.** It can be difficult to give yourself time for pleasurable activities when you are going through a difficult time. Sometimes you need to replenish your energy by finding space for the good things in life. We can't always do this by ourselves, so reach out to others to help you.

**Be kind to yourself** ☐ Don't hate yourself for being who you are.

☐ Don't judge yourself harshly.

☐ Remember that difficult feelings and thoughts will pass.

☐ 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.

**And if you are finding things hard** ☐ Ask for help – there will be somebody who can help you. (See page 39 for contacts.)

## Supporting somebody with emotional or mental health problems

**As a family member, partner or friend, you 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 and physical 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 recovery can take time and is likely to involve both good and bad periods.

☐ **Involve the other person** in 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.

☐ **It's not selfish to also take care of yourself.** Sometimes saying "no" can be more helpful, in the longer term, to you and the person you are trying to help.

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.

## 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 practices 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 the booklet. The following counselling, mental health and information 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 Infoline: 0300 123 3393.  
Monday to Friday 9am-6pm. Text: 86463.  
There is also a Mind Legal Line, for legal information and advice: 0300 466 6463.  
**[www.mind.org.uk](http://www.mind.org.uk)**

**Rethink Mental Illness** A national mental health charity, providing information and advice on mental health topics, and running services and support groups across England.  
Advice line: 0300 5000 927.  
Monday to Friday 9.30am-4pm.  
**[www.rethink.org](http://www.rethink.org)**

**SANE** Mental health charity providing emotional support, guidance and information.  
SANEline: 0300 304 7000.  
Open every day 4.30-10.30pm.  
**[www.sane.org.uk](http://www.sane.org.uk)**

**Samaritans** Confidential emotional support 24 hours a day.  
Helpline: 116 123, open every day.  
**[www.samaritans.org](http://www.samaritans.org)**

**NHS Moodzone** Practical advice, interactive tools, videos and audio guides to help you feel mentally and emotionally better.  
**[www.nhs.uk](http://www.nhs.uk)**

**The Royal College of Psychiatrists** Provides information on mental health problems, treatments and other topics on its website.  
**[www.rcpsych.ac.uk/mental-health](http://www.rcpsych.ac.uk/mental-health)**

## Who to contact if you need urgent support

### If you feel like harming or hurting yourself or other people:

Call the Samaritans on 116 123  
(open 24 hours a day, 365 days a year)

### If you have already harmed yourself and need immediate help:

#### Call 999

Go to your nearest Accident and Emergency department (A&E). You can search for your local department on the NHS website.

### For non-emergency situations:

Call your GP and ask for an appointment as soon as possible.

Call the NHS on 111 (open 24 hours a day, 365 days a year). They will help you find support services and the help you need.

### Mental health services

If you are already receiving support from mental health services, you should have a care plan. This will include details of who you should contact in a crisis.

If you can't find your care plan, contact your Community Mental Health Team (CMHT) and ask for your care co-ordinator or the person on duty.

If you can't get in touch with your team (if it's evening, or a weekend or bank holiday), contact the NHS on 111 to get the details of your local crisis team.

## To find a counsellor or therapist

**A good way to find a counsellor or therapist is to ask at your HIV clinic, another HIV organisation or GP surgery** about their services or contacts they may have. Alternatively, you could find someone through personal recommendation.

In England, the NHS's Improving Access to Psychological Therapies (IAPT) initiative provides free therapies on the NHS, including cognitive behavioural therapy (CBT), counselling and guided self-help. You can refer yourself or ask your GP to refer you. IAPT services are offered in different ways, for example one-to-one, as an online course, or in a group. Find a service in your area at: **bit.ly/2xRZI63**.

You can also find a counsellor or therapist through a nationally recognised organisation. Many counsellors and psychotherapists are registered with the British Association for Counselling and Psychotherapy (BACP) or the United Kingdom Council for Psychotherapy (UKCP). You can find their members at **www.bacp.co.uk** and **www.psychotherapy.org.uk**.

There is information on both websites about choosing a therapist and the different types of talking therapies.

Most psychologists in the UK are members of The British Psychological Society (BPS). To search for a psychologist, visit **[www.bps.org.uk](http://www.bps.org.uk)**.

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 an HIV organisation, mental health charities, your HIV clinic 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.

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### To practice mindfulness

You can find an online mindfulness course and details of mindfulness teachers in your area at **[www.bemindful.co.uk](http://www.bemindful.co.uk)**.

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### To find a complementary therapist

**Many people find that complementary therapies, such as acupuncture or massage, can be beneficial** in reducing physical discomfort or stress. 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](http://www.complementary.assoc.org.uk)**.

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### HIV organisations

Here are the details of just some of the organisations which support people living with HIV. To find out about organisations in your local area, call THT Direct (**0808 802 1221**) or ask at your HIV clinic.

**Body & Soul** Body & Soul is a charity providing support for children, teenagers and families living with, or affected by, HIV. The charity offers therapies, groups, advice and advocacy and activity programmes for children and teenagers.

020 7923 6880  
**[www.bodyandsoulcharity.org](http://www.bodyandsoulcharity.org)**

**George House Trust** George House Trust provides a wide range of HIV support, advice and advocacy services for people living with HIV in the northwest of England. Services include counselling, peer mentoring, financial advice, and one-to-one and group services.

0161 274 4499  
[www.ght.org.uk](http://www.ght.org.uk)

**Living Well** Living Well is a not-for-profit social enterprise. It provides counselling, wellbeing groups, peer support services and therapies for people living with HIV in a number of London boroughs.

020 3137 3373  
[www.livingwellic.com](http://www.livingwellic.com)

**Metro** Metro is an equality and diversity charity that provides health, community and youth services across London and the southeast of England. Metro's HIV services include support groups, an advice helpline, counselling and workshops.

020 8305 5000  
[www.metrocentreonline.org](http://www.metrocentreonline.org)

**NAZ** NAZ provides sexual health and HIV prevention and support services to Black Asian Minority Ethnic (BAME) communities in London. NAZ offers peer support groups and a counselling service for mental and sexual health and wellbeing.

020 8741 1879  
[www.naz.org.uk](http://www.naz.org.uk)

**Positive East** A community-based HIV charity, providing a range of services for people living with HIV or affected by HIV in London. Positive East offers information and advice, peer and group support, a health and wellbeing programme, and counselling.

020 7791 2855  
[www.positiveeast.org.uk](http://www.positiveeast.org.uk)

**Positively UK** Positively UK provides peer-led support, advocacy and information to people living with HIV to manage any aspect of their diagnoses, care and life with HIV. Positively UK runs a range of groups for women, heterosexual men and women and gay men.

020 7713 0444  
[www.positivelyuk.org](http://www.positivelyuk.org)

**Terrence Higgins Trust** Terrence Higgins Trust (THT) offers a wide range of support and advocacy services in England, Scotland and Wales. THT provides information for people newly diagnosed with HIV, advice on benefits, immigration and debt, counselling, groups, complementary therapies, and online counselling and advice.

THT also offers a support, advice and information helpline, THT Direct.

THT Direct: 0808 802 1221.  
 Open Monday to Friday, 10am-8pm.  
[www.tht.org.uk](http://www.tht.org.uk)

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## Summary

- People with HIV are at some risk of experiencing 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 mood changes. These may be temporary and can be dealt with.

## HIV helplines

### THT Direct 0808 802 1221

Open Monday to Friday, 10am-8pm.  
Support, advice and information from the Terrence Higgins Trust.

### HIV i-Base 0808 800 6013

Open Monday to Wednesday, 12pm-4pm.  
For advice on any aspect of HIV treatment.

### Positively UK 020 7713 0444

Open Monday to Friday, 10am-4pm.  
Contact Positively UK about any aspect of your diagnosis, care and living with HIV.

## More from NAM

NAM's website is full of useful information resources and the latest news on HIV and related topics: **[www.aidsmap.com](http://www.aidsmap.com)**

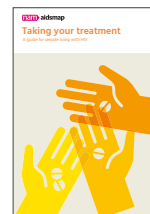
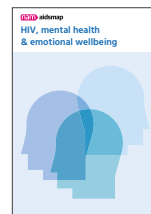
Subscribe to our bulletins and news feeds, and connect with us on social media:

**[www.aidsmap.com/about-us/connect-us](http://www.aidsmap.com/about-us/connect-us)**

All of NAM's booklets and resources for members of our Patient Information Scheme on the clinic portal: **[clinic.nam.org.uk](http://clinic.nam.org.uk)**

## NAM's booklets

NAM's booklets are available from HIV clinics which are members of our Patient Information Scheme. Ask for our booklets at your clinic.



### Other booklets in the series:

- ☐ A long life with HIV
- ☐ Anti-HIV drugs
- ☐ CD4, viral load & other tests
- ☐ HIV & children
- ☐ HIV & hepatitis
- ☐ HIV & sex
- ☐ HIV, stigma & discrimination
- ☐ HIV & women
- ☐ Nutrition
- ☐ Side effects

NAM values all feedback which helps us to improve our resources. If you have any comments or feedback about any of our resources, please email us at **[info@nam.org.uk](mailto:info@nam.org.uk)**.

The information in this booklet isn't intended to replace discussion with your doctor about your treatment and care, but it may help you to think about any questions you'd like to ask your healthcare team.

## **NAM**

Unit 19, St Marks Studios  
14 Chillingworth Road  
London N7 8QJ

**T** +44 (0) 20 3727 0123

**W** [www.aidsmap.com](http://www.aidsmap.com)

**E** [info@nam.org.uk](mailto:info@nam.org.uk)

Registered charity no. 1011220

## **About NAM**

NAM is a charity that works to change lives by sharing information about HIV & AIDS. We believe that independent, clear, accurate information is vital to those living with HIV.

## **Please help us**

If you would like to support our work and help us to continue to provide resources like this one, please donate today at [www.aidsmap.com/#donate](http://www.aidsmap.com/#donate) or call us on 020 3727 0123.

**This booklet can be viewed in large print as a PDF file on the NAM clinic portal.**  
**Ask your clinic about how to access the portal.**