

A guide to emotional well-being for people with HIV

Your feelings

Terrence
HIGGINS
TRUST



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This booklet is part of a range of publications produced by Terrence Higgins Trust to support you in living well with HIV. Most of these publications are designed to be suitable for you whatever your race, nationality, gender or sexuality.

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When we are told that we have HIV, most of us experience some of a wide range of feelings.

Common feelings include fear, worry, loneliness, shame, embarrassment, sadness, blame, dirtiness, hopelessness, anger at ourselves, anger at others and guilt. Some of us just feel numb, and some of us carry on as if nothing has happened. Some of us even feel relieved.

Strong, unpleasant feelings usually fade away over time. But if we have problems with our health, if people treat us differently, or if we have difficulties with sex, we can again experience a wide range of negative feelings.

And there may be other worries and concerns in our lives. For example, difficulties with people we're close to or more practical problems like housing can be very upsetting. There may also be unresolved problems and baggage from the past.

In all these situations, we may become distressed, thinking we shouldn't feel like this. We can become worried about being worried, depressed about feeling depressed, worried about being so depressed, guilty about feeling angry, ashamed about feeling scared and so on.

There isn't a right or wrong way to feel. Different people experience different things differently. The way you feel can be part of coming to terms with what's going on in your life.

This booklet

Research suggests that although anybody can have difficulties with their feelings and emotional well-being, people with HIV are more likely to experience these difficulties. But there are simple, everyday things we can do to look after our emotional well-being.

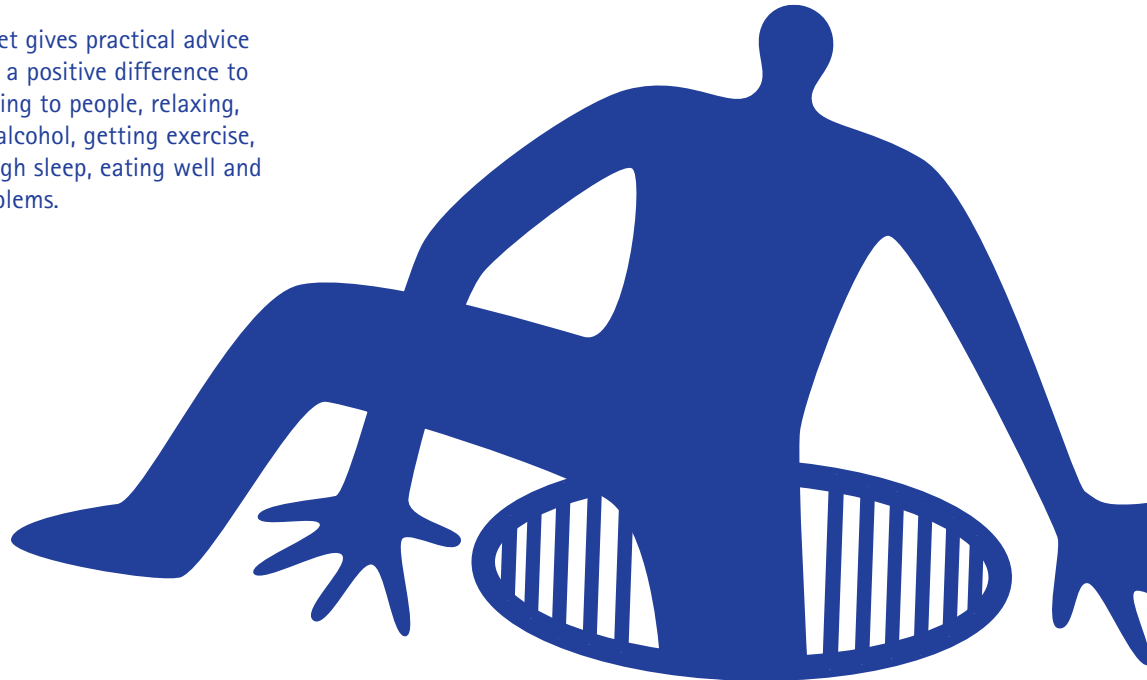
This booklet can be read from cover to cover, or you might find it more helpful to dip in and out of sections that seem relevant.

Part 1: 'Keeping ourselves well'

The first part of this booklet gives practical advice on things which can make a positive difference to how we feel. It covers talking to people, relaxing, not over-using drugs and alcohol, getting exercise, doing things, getting enough sleep, eating well and dealing with practical problems.

Part 2: 'When things are not going well'

The second section talks in more detail about difficult feelings that people with HIV sometimes experience. It focuses in particular on feeling down, feeling anxious, and dealing with the side-effects of the anti-HIV drug Efavirenz. It suggests things you can do yourself, as well as the medication and 'talking treatments' that professionals can offer.



No two people's lives are the same, and there are all kinds of reasons why different people can have difficult feelings.

Just a few of the problems that sometimes affect people with HIV are listed opposite.

This booklet doesn't give specific information for each of those situations. But it does give general advice about looking after yourself and coping with emotional challenges.

You may still need to get detailed information and advice about practical problems. See page 31 for more on this.

putting your life on hold
 feeling isolated
 fears for the future
 problems with drink or drugs
 being sick work
 privacy & confidentiality
 family difficulties
 other people's attitudes
 somewhere decent to live
 immigration worries
 worries about children
 feeling different
 not having enough money
 relationship problems
 side effects
 friendships
 finding a partner
 feeling tired
 problems with benefits
 problems with sex
 treatment decisions
 losing self-confidence

You may find this booklet useful if...

You're feeling OK now and want to stay that way (see part 1)



You're not feeling quite as good as you could do (see part 1)



You're getting strong, unpleasant feelings of being down or anxious (see part 2)



You're worried about someone who may be feeling down or anxious (see part 2)



You're taking Efavirenz and are concerned about its side-effects (see page 50)



You want to know where to get more help, support or information (see page 54)



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Keeping yourself well

We all have our emotional ups and downs. It may seem surprising but simple things like getting some exercise or talking to people can make a difference. They can help us maintain our emotional well-being and prevent us from being overwhelmed by negative feelings.

Talking to people

Having contact with other people is usually good for us. Research has shown that people who talk regularly to friends, relatives and acquaintances live longer and have fewer problems with their physical and mental health.

Just having people around us seems to be good, but it may be even better if we're with people we can talk to about how we're feeling. Talking about our feelings and problems can often make us feel better.

It can help us to work out ways of dealing with problems

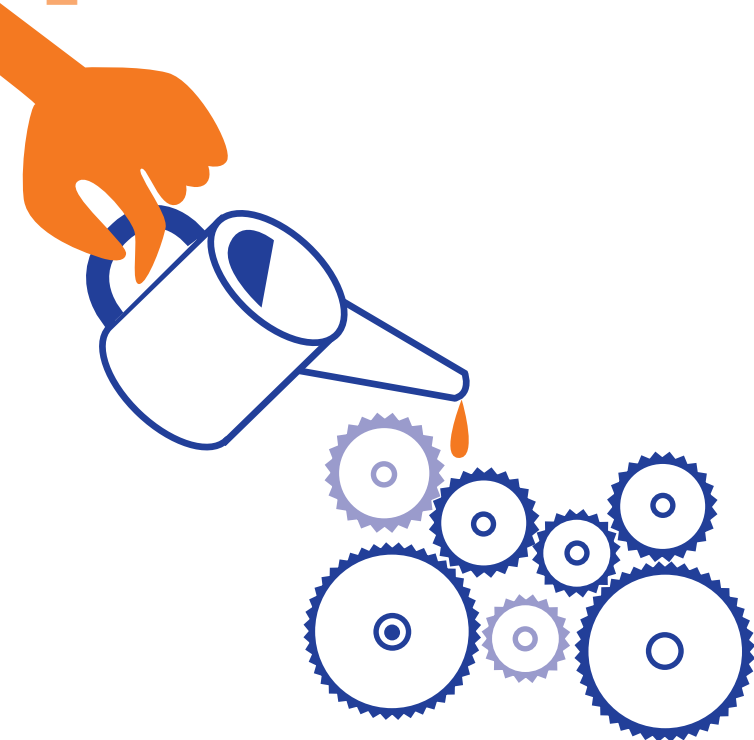
It can help us to better understand what's going on

It can help us to keep things in proportion

It gives us a chance to get things off our chest; we may feel 'lighter' afterwards

It can strengthen friendships and make us feel closer to other people

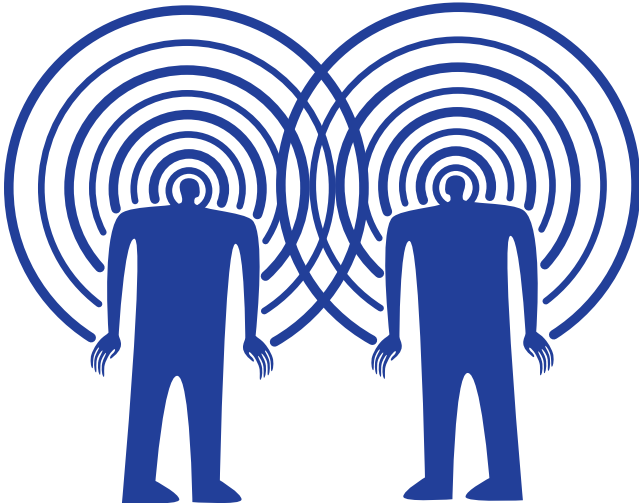
It can also give us the opportunity to get practical or emotional support from the people we talk to. But this won't always happen - some people you talk to may react negatively or inappropriately. But there may be other people you can approach, because you are confident that they will be calm, supportive and trustworthy.



Some people prefer to talk only with other people who've been through very similar experiences to them. But most of us can empathise with or have an understanding of a wide range of feelings. It may be more important to find people who are able to listen than people who've had a similar life to you.

You may have friends, colleagues or family members who you feel close to and are able to discuss sensitive issues with. But some of us don't always feel comfortable talking about personal issues with the people we know, or it may feel that we have nobody to talk to.

It can happen that we start to feel isolated or cut off from other people. There can be lots of reasons for this – upheavals or changes in our lives, losing people close to us, being treated as 'different' by others, or actually feeling different ourselves.



Or we may always have had difficulty relating to other people, and the people we meet seem to find it difficult to relate to us too. There can be lots of reasons for this, including finding it difficult to trust people and having poor social skills.

Support is available from your clinic, helplines and HIV support organisations

If you don't feel you can talk about a problem with someone you know, support will be available from a helpline, your clinic, or an HIV support organisation. You may be able to talk to a counsellor or another professional, or make contact with other people with HIV.

If something in particular is troubling you, it may take several attempts before you find the courage to talk to someone about it. But if you feel you could benefit, it's probably worth trying again.

If you do find it difficult to make friends, it may be worth joining a club, a group, a class or a voluntary organisation to do something that you enjoy or that interests you. Whether it's playing a sport, learning a new skill, helping people in difficulty, or going to cultural events together, it can be easier to relate to others through the medium of a shared interest.

If you really are out of practice at meeting people, it's advisable to take small steps at first, and not launch head-first into an intense involvement with one person. Make the most of every opportunity for social contact, however small: talk to neighbours and people in shops. Don't ignore a fellow passenger who tries to start a conversation with you. Ask questions and be curious.

If you're having difficulty relating to other people, these services may be useful:

Assertiveness or social skills training:
this usually takes place in a group, and teaches us how to value ourselves, and better communicate with other people.

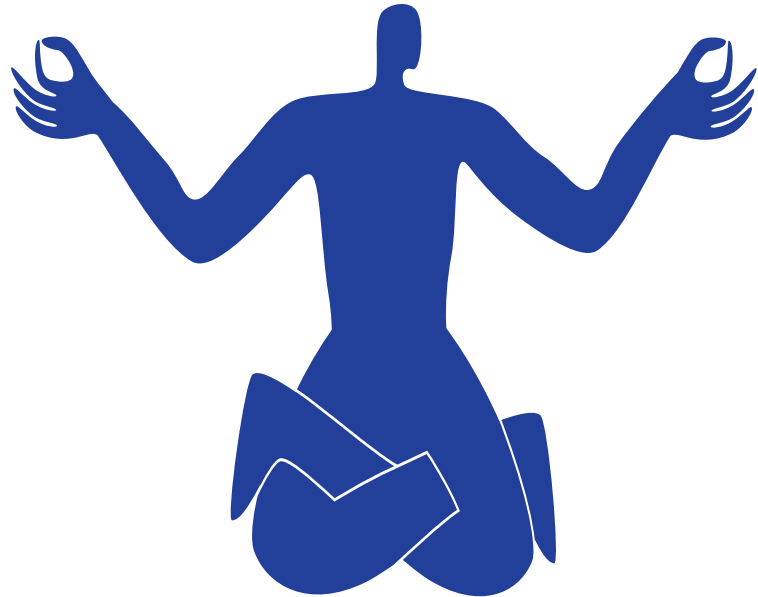
Counselling and therapy:
this happens one-to-one, and we talk through our experiences to find a way forward.

Staff at HIV clinics and HIV organisations should be able to tell you where these services are available.

Relaxation

Our bodies and minds need time to switch off and recover from the pressures and concerns of everyday life. There are lots of ways to do this. Taking time to soak in a warm bath, listening to music, or going for a walk can all help us wind down and relax.

It's essential for emotional well-being to strike a balance between activity, rest and play. Try to notice pleasurable things around you, however small. Allow yourself moments of distraction – gaze out of the window, and enjoy the view.



It's essential to strike
a balance between
activity, rest and play.

From time to time in the day, just stop for a while, let your shoulders drop, breathe in slowly and then gently sigh your breath out through your mouth.

It can be even more useful to use relaxation techniques which help the body slow down and relax (in other words, not be tense). The techniques start with the body but have an effect on the mind too. They can be particularly useful when we feel worried or find things stressful.

Examples of these techniques are:

- Breathing exercises
- Exercises to tense and then relax your muscles
- Meditation
- Yoga
- Tai Chi
- Massage
- Aromatherapy
- Reflexology

Some techniques are simple to learn and then practice at home – you can learn from books, CDs, DVDs or classes. You may find it easier to practice regularly by taking part in a class. You should be able to get details of classes from an HIV organisation, library or leisure centre. For some of the other techniques, like massage, you'll need a practitioner to work with.

You can get more information from a booklet called *The Mind guide to relaxation*, published by the mental health charity **Mind** (www.mind.org.uk **0845 766 0163**).

Different techniques work for different people. In all of them, the point is to help you forget your daily concerns. If this doesn't happen, or if intrusive thoughts come to you, it's not worth worrying or getting frustrated. Just try something else and see if it works better for you.

A very few people can find the feelings created by a relaxation technique unexpectedly distressing. If this happens to you and you're in a class, let the teacher know. If you're on your own, it's worth going to talk to a doctor, a counsellor or an HIV worker about it.

The benefits of relaxation exercises will increase if you use the techniques regularly.

Leisure activities won't make you feel relaxed in the same way as these techniques, but can contribute to our well-being. Reading a book or watching a favourite TV programme can help us forget our worries for a while and give us the chance to think about something else.

Drink and drugs

Having a good time with friends and being sociable can be good for us. Many of us drink alcohol in situations like these, and drinking in moderation isn't usually a problem.

However if we drink or use recreational drugs too much, it can sometimes cause problems with our emotional well-being, or make them worse. Hangovers and come-downs can give us feelings of being down, tense or short-tempered. If we are already having problems with feelings like these, it can be even harder to find a way out of them, and can make the feelings worse.

Stimulant drugs like cocaine, ecstasy, speed and crystal meth can also cause or worsen feelings of worry and anxiousness. Caffeine, energy drinks (like Red Bull) and the drug khat can also have similar, but milder effects.

We may use alcohol or drugs to help us forget, or to stop us thinking about things, or to 'drown our sorrows'. This often works in the short-term. But problems and feelings don't just go away when they are blanked out or ignored for a while. Also, too much drink or drugs will probably bring their own problems.

We may use alcohol or drugs to help us forget or to stop us thinking about things

People talk about using drink or drugs 'in moderation'. So how much is too much? You're probably having too much if:

- **You've told yourself that you're going to cut down, but haven't managed to.**
- **Your friends are worried about your drinking or drug taking.**
- **It's affecting your day to day life: your work, friendships and relationships.**
- **It's making you behave in ways you later regret.**
- **It's affecting your health.**

Exercise

Exercise can be the last thing we feel like doing when we are tired, worried or down. It may feel difficult just to leave the house, never mind swim ten lengths. However exercise can make us feel relaxed and energised. It can help us sleep better, and has benefits for people experiencing fatigue, anxiety and depression. It can also help prevent these problems occurring in the first place.

The benefits of exercise for fitness and our physical health are well known. And when we have fewer problems with our health, we tend to feel better emotionally.

Physical activity stimulates the body into releasing endorphins, serotonin and other natural chemicals that make us feel good. It's thought that aerobic exercise like walking, swimming or cycling is particularly good if we suffer from feelings of anxiety, and that any regular exercise can help reduce feelings of depression.

You don't have to join a gym. A minimum of ten minutes a day of continuous walking, swimming, cycling, dancing or taking part in exercise classes should give you some benefit. For maximum benefit to your physical health, increase the daily dose to 20 or 30 minutes.



When we don't feel so good about ourselves, or have poor self-image, exercise can sometimes help us feel better about our bodies. Taking part in an activity or learning to do something new may also give us a sense of achievement.

There's more information about exercise in *Your Body*, another booklet from Terrence Higgins Trust.

Doing things

Sometimes we can get out of the habit of doing things that are important to us or give us satisfaction.

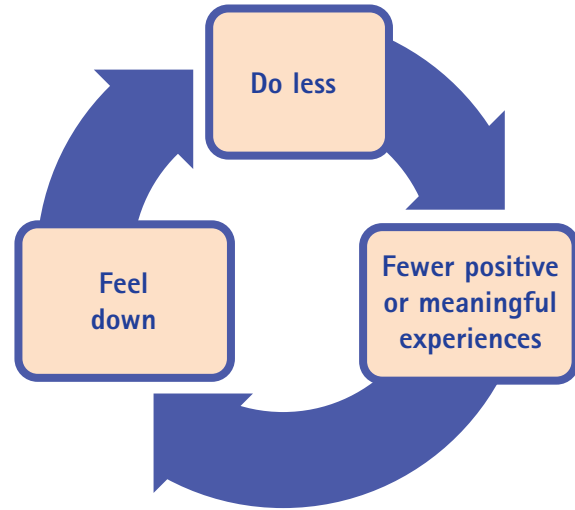
For one person, this might be going to the gym and meeting friends for a drink. For someone else it could be visiting relatives and going to church. For a third person, it could be playing a sport and doing voluntary work.

It can happen that we take part less and less in leisure activities, or we lose touch with friends and relatives.

This can be a particular problem if we have problems with money, or if we're feeling isolated. For many people, work keeps them busy and brings them into contact with other people. When we're not working, our days can feel quite unstructured, and the amount of time to fill can seem overwhelming.

Or it may be that we're working, but often get tired, and so don't feel able to do very much after work.

It's worth arranging things to do during the week and pushing yourself to do them whether you feel like it or not



There's a danger of getting into a vicious circle of feeling down, and so not feeling like doing anything.

The less we do, the fewer positive or meaningful experiences we have, and that makes us feel even more down.

We can think that we won't enjoy anything. It's worth remembering things you've enjoyed doing in the past, arranging times to do them during the week, and pushing yourself to do them whether you feel like it or not.

Spirituality

For many of us, faith and spirituality are extremely important.

Of course, this isn't the case for everyone. Some organised religions have been hostile to gay men and other groups affected by HIV. In some churches, synagogues, mosques or other faith communities it can be very difficult to be open about living with HIV. Also, some religious leaders have made totally false claims about "curing" HIV through prayer.

But some of us find comfort in faith and spirituality. We may have our own, private spirituality that helps us make sense of the world. Or we may join with others at a church, synagogue, mosque or other place of worship.

You may be able to get support and encouragement from others at your place of worship. There may be a priest, minister or other religious leader who you feel able to talk to.

For many, prayer is particularly important, although it can take many different forms. For some it may be about making private requests to a higher power, or taking part in a ritual with other believers. For others it may be a moment of contemplation or meditation.

Prayer can be a time for quiet reflection, during which we are free from our day to day distractions. This moment of stillness may help us to develop understanding and awareness.

It may help us to express difficult feelings and thoughts, and we may feel that we've been able to share our difficulties with someone else. We may become aware of possible solutions to problems we are facing.

Many find that prayer helps them find hope, calm, strength and courage.



Getting enough sleep

Sleep is very important to our emotional well-being. If we have several nights without sleep, we may find that we:

- are always tired and nod off during the day
- find it hard to concentrate or make decisions
- start to feel down or anxious

If you do have trouble sleeping, the following information may help.

Doctors think it's better for adults to get seven or eight hours of sleep a night, rather than napping during the day. Older people may need less sleep. And it's not necessarily a problem to sleep less than this - if you do, and are not tired during the day, you're probably getting enough.

When you can't sleep, it's probably not a good idea to lie in bed worrying about it. It's better to get out of bed and do something relaxing - read, put on some quiet music or listen to the radio until you feel tired enough to go to bed again.

If something is troubling you and there is nothing you can do about it right away, it may help to write it down and tell yourself that you will deal with it tomorrow.

The following may make a difference to the quality of your sleep:

Getting regular exercise, especially in the late afternoon or early evening.

Taking time to relax before going to bed.

Having a bedtime routine that helps you unwind.

Only going to bed when you are sleepy.

Getting up at the same time every day, whether you are still tired or not.

Not taking long naps during the day - they will affect your natural rhythm.

Being in a comfortable bedroom - not too hot, cold, noisy or light.

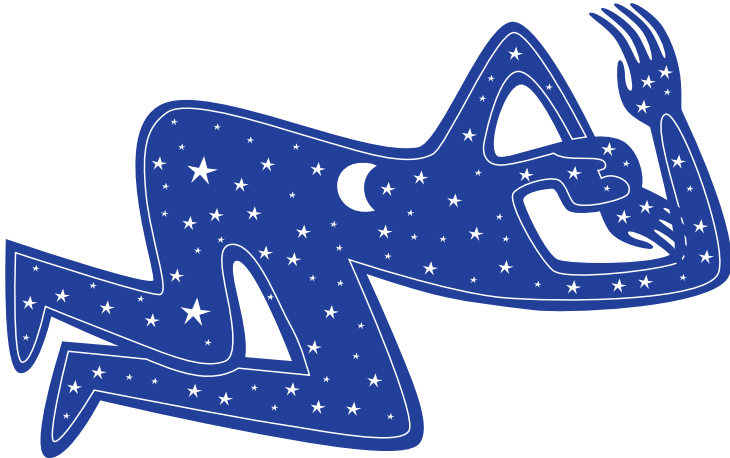
Having a comfortable bed and mattress - not too hard or soft.

If you can, only use your bed for sleep - don't watch TV, talk on the phone or eat there.

Food and drink we've had in the evening makes a difference too:

- A large or late meal will be difficult to digest.
- Alcohol can help us fall asleep, but we're more likely to wake up in the middle of the night.
- Caffeine stays in the body for several hours and reduces the quality of sleep. It's found in tea, coffee, and cola. Milky or herbal drinks are more likely to be caffeine free.
- Nicotine is also a stimulant that stays in the body. Cigarettes (and replacement patches or gum) can affect your sleep.
- Stimulant drugs such as cocaine, ecstasy and speed affect sleep too.

A few people find that sleeping problems are a side-effect of their anti-HIV medication. You may want to speak to your HIV doctor about this.



Problems with sleep and with disturbing dreams are more common with Efavirenz than with any other anti-HIV drug - see page 50 of this booklet for more information.

Sleeping tablets used to be prescribed a lot but we now know that some of them can be addictive and can leave you tired and irritable the next day. They may lose their effect after some time, and should only be used for a few nights at a time. They are only available on prescription.

It can take several weeks to develop new sleep habits. These guidelines can help improve your sleep, but it may take time.

Food and diet

How can food affect our feelings?

- The food we eat affects our physical health which can influence our mood.
- The brain, like any other part of the body, needs enough of the right sort of food to grow and work well.
- Changes in blood sugar levels are associated with changes in mood and energy and are affected by what we eat.
- There is some evidence that low levels of vitamins, minerals and essential fatty acids are linked to mental health problems. (A balanced diet should give you enough vitamins and minerals. Fatty acids are found particularly in oily fish, but also in linseed, flaxseed, rapeseed and walnut oils.)
- Some people have reactions to artificial colourings and flavourings in food.
- If we're depressed, we can lose our appetite, meaning we don't get all the nutrients our bodies need. This can make us feel tired and run down, making us even more miserable.



The basis of health eating is to:

Base your meals on carbohydrates like bread, breakfast cereals, pasta, rice, potatoes, yam, plantain, maize, and millet. Try to choose wholegrain varieties if you can.

Eat lots of fruit and vegetables. These can be fresh, frozen, canned or juiced.

Eat moderate amounts of meat, fish, eggs and other protein-rich foods.

Eat moderate amounts of dairy products like milk, cheese and yoghurt.

Cut down on salt, sugar and saturated fat.

Eat regularly and don't skip breakfast.

It's recommended to drink around 1.2 litres (just over 2 pints) of water a day. That's about six to eight wine glasses of water each day.

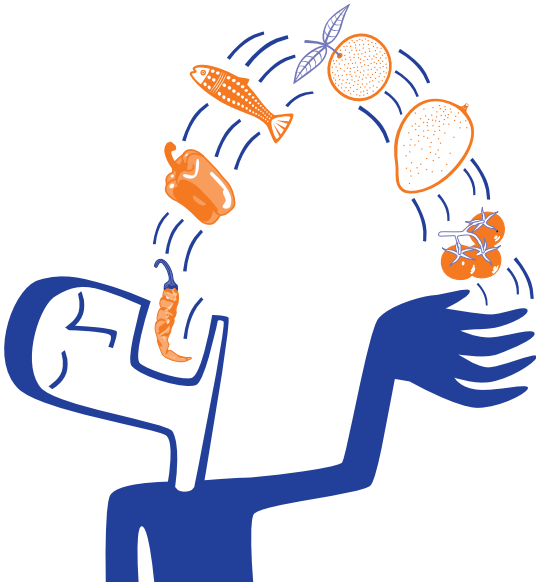
Good food doesn't always come cheap. But cooking foods from basic ingredients usually costs less than buying ready meals, especially if you shop in local markets and larger supermarkets. Nutritious but cheaper foods include eggs, beans and pulses, as well as carbohydrates like bread, pasta and rice. Also, fruit, vegetables and fish in frozen or canned form are less expensive than fresh.

We're advised to eat five portions of fruit and vegetables a day. This may not be as hard as it seems, especially if you know that a 'portion' is equivalent to:

- **three heaped tablespoonfuls of vegetable, or**
- **a fruit the size of an apple.**

So if you can imagine in one day eating some carrots, frozen peas, some lettuce, an orange and a glass of 100% fruit juice, then it may be possible to reach the target.

For more specific advice about healthy eating, you can ask to see a dietitian at your HIV clinic. You can also find more detailed information in *Your Body*, another booklet from Terrence Higgins Trust.



Dealing with practical problems

Often our emotional difficulties are a normal reaction to a situation we're in. As mentioned on page 4, there are all kinds of practical problems that can make us unhappy.

The best way to make ourselves feel better is probably to find a way to change that situation. Depending on what's wrong, this might mean changing the treatments we're on, so that we have fewer side effects. Or it could be that we manage to sort out money, housing or immigration problems. Alternatively, the problem may be being isolated, and we find a way to meet new people.

There may be something we could do ourselves to change the situation. Or we might need to ask someone else for some practical help.

To know if the situation can be changed, we usually need to get information. But just doing this may seem daunting. We might prefer not to know what's really going on, we may be scared that our worst fears will be confirmed, or we may be worried that things will be too complicated.

Getting information might involve discussing personal matters with strangers, talking to people we don't like, or contacting people in authority.

However if we're clear about the problem we're facing, we can make better sense of what's going on, we may discover solutions, and we may stop worrying about things unnecessarily.

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 family difficulties

Who can you turn to? THT Direct can tell you about local services that will be able to give you information and advice on a wide variety of issues. You can call THT Direct on 0845 122 1200.

If you are worried about HIV and your health, a good place to start might be your doctor, one of the nurses at the clinic, or a local HIV support agency. There are also plenty of easy-to-understand leaflets and websites out there.

The information we get will often suggest the choices we have for solving our problems. But we may need more than just information.

Choices may be easier to make when we've talked things through with people we trust. We may need to give ourselves enough time to think about how we want to live our lives, and to consider the implications of all the different options. Understanding what is going on can help us feel more in control.



Research shows that, on the whole, people with HIV experience less distress if they:

Get information to help them sort out problems.



Make careful choices based on this information.



Talk about their difficult feelings.

Unfortunately information won't always bring good news. We might realise that we can't do anything about the situation that's troubling us, or that it's unlikely to change. For example, we might find out that a better treatment isn't available, or that we're not eligible for the housing we want.

In situations like these, we probably need to find a way to cope with the situation, or adapt to it, with the minimum distress.

Just talking to someone we can trust about how we feel or what is worrying us can help. (See page 9). Talking to people about how we feel doesn't always make the feelings go away, but can help us cope with them better.

Experiencing strong negative feelings as well as positive ones is part of having a full emotional life. However if difficult feelings go on for a long time, it may be a good idea to get some professional help. The next part of this booklet looks at dealing with difficult feelings in more detail.



When things are not going well

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When things are not going well

Despite our best efforts to look after our emotional well-being, there may be times when difficult feelings start to interfere with our everyday life.

It may be difficult to enjoy the things we usually do, and we may need to get extra help to deal with the situation.

This section gives practical advice for times when we feel down or feel anxious. These are some of the problems most commonly reported by people with HIV.

It also describes the side-effects some of us have with the anti-HIV drug Efavirenz.

But there are other, less common problems that we might experience. It might be difficult to understand what's going on, or even to realise that there is a problem. It could be friends or family who tell us that we seem to be behaving differently or acting oddly. If this is the case, it's probably worth taking note of what they say.

If anything seems to be wrong, it's probably a good idea to start by talking the situation over with your GP or HIV doctor.

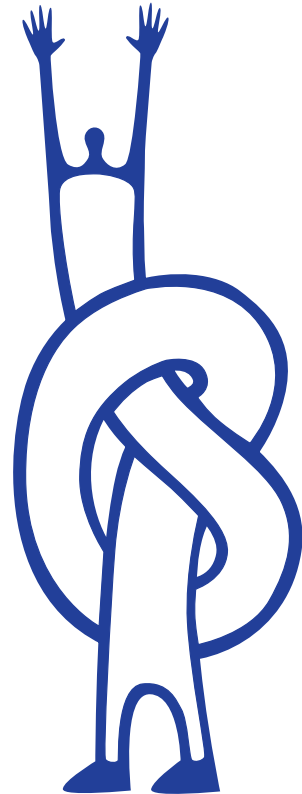
Feeling down

We all feel fed up, miserable or sad at times. These feelings don't usually last longer than a week or two, and they don't interfere too much with our lives. Sometimes there's a reason, or sometimes they just come out of the blue. We usually cope with them ourselves. We may talk to somebody we're close to, but otherwise don't need any help.

However when these feelings don't go away so quickly, and are so bad that they interfere with our everyday life, it's usually a good idea to get some professional help.

Feelings like this may be stronger and more unpleasant than the short periods of unhappiness that we all have from time to time. They may go on for much longer. They can last for months rather than days or weeks.

Doctors call this 'depression' when we have several of these feelings for more than a few weeks. It's a very common problem for the general population (1 in 6 people have it at some time in their life), but people with HIV are much more likely to experience it.



You may be experiencing some of the following things:

- Feeling sad, guilty, upset, numb or despairing a lot of the time
-
- Losing interest and enjoyment in things
-
- Losing interest in sex
-
- Finding it difficult to concentrate and remember things
-
- Finding it difficult to relate to other people
-
- Feeling very tired
-
- Feeling restless and agitated
-
- Losing appetite and weight
-
- Losing self-confidence
-
- Feeling useless or inadequate
-
- Feeling hopeless about the future
-
- Expecting the worst and having negative or gloomy thoughts
-
- Thinking about killing yourself

There will sometimes be an obvious reason for feeling down. It could be a disappointment or a frustration or perhaps the loss of someone or something important.

These events may 'turn on' our feelings of sadness or unhappiness. Normally those feelings would go away after a time, but when we're depressed, it's as if the off switch is broken and we can't turn the feelings off.

At other times it isn't clear why we feel down. We're just 'in a mood', 'feel low' or 'have the blues'. We really don't know why.

Whether there's a cause or not, there are simple things we can do to help ourselves.

It's a very common problem for the general population, but people with HIV are more likely to experience it

Things we can do to help ourselves

Get more exercise (see page 18).

Do something (see page 20).

Break down tasks. When we're avoiding things we have to do, it may help to break them down into smaller stages, and tackle them one by one. For example, if there are lots of jobs around the house, you could try starting with one small area one day, and move on to another the next.

Talk to other people (see page 9).

Eat well (see page 28).

Concerned about harming yourself?

Sometimes we can have thoughts about harming or killing ourselves.

If this is the case you are strongly advised to talk to someone about it. You could speak to a worker in an HIV organisation, your GP, your HIV doctor, or the Samaritans (0845 790 90 90).

If you're worried that you may actually harm or kill yourself, you are strongly advised to go immediately to the Accident & Emergency (Casualty) Department at your local hospital, or to your family doctor. If you already have contact with psychiatric services, contact them.

Don't use more drink or drugs (see page 16).

Deal with practical problems. If you think you know what's keeping you low, tackle the cause. (See page 31.)

Challenge negative thinking. Many people find that self-help leaflets or books are useful in overcoming the negative thoughts that can cause depression. Or you could see a professional who uses a CBT (cognitive behavioural therapy) approach (see below).

How professionals can help

If you're feeling down or depressed, it may be helpful to talk to your HIV doctor or family doctor about it. You could also speak to a worker at an HIV organisation. Your doctor may treat you, or you may be referred on to a psychologist, psychiatrist, psychiatric nurse or counsellor.

They may suggest a 'talking treatment', or anti-depressant medication, or both.

What are talking treatments?

Sometimes it's hard to express our real feelings, even to close friends. Talking things through with a trained professional can be easier. It can be a relief to have another person's undivided attention for a while and get things off our chest.

Different professionals use different types of techniques, and may use a combination of two or more. But the most important thing is that you feel comfortable with the person you see, and you feel that it is helping.

The full range of treatments will not always be on offer in every area, but these are some of the most frequently used techniques:

Cognitive behavioural therapies (CBT) help us to look at and change the thoughts and behaviours that make us depressed, so that we can look more realistically at ourselves and at life.

Person-centred counselling helps us to be clearer about how we feel about life and other people, and how we can change things.

Psycho-dynamic counselling can help us see how our past experiences may be affecting our life today, and help us take control of our life.

Group therapies involve working with other people to address our problems, and can help us change the way we are with other people.

Talking treatments usually take time to work. Some therapists may see you weekly; others every two or three weeks. Sessions usually last about an hour, and you may need to continue with a treatment for several weeks, a few months, or maybe longer.

What are anti-depressants?

If your low feelings are severe or go on for a long time, your doctor may suggest that you take anti-depressants. They're not tranquillizers, although they may help you to feel less anxious and agitated. They can help us to cope and feel better, so that we can start to enjoy life and deal with problems again.

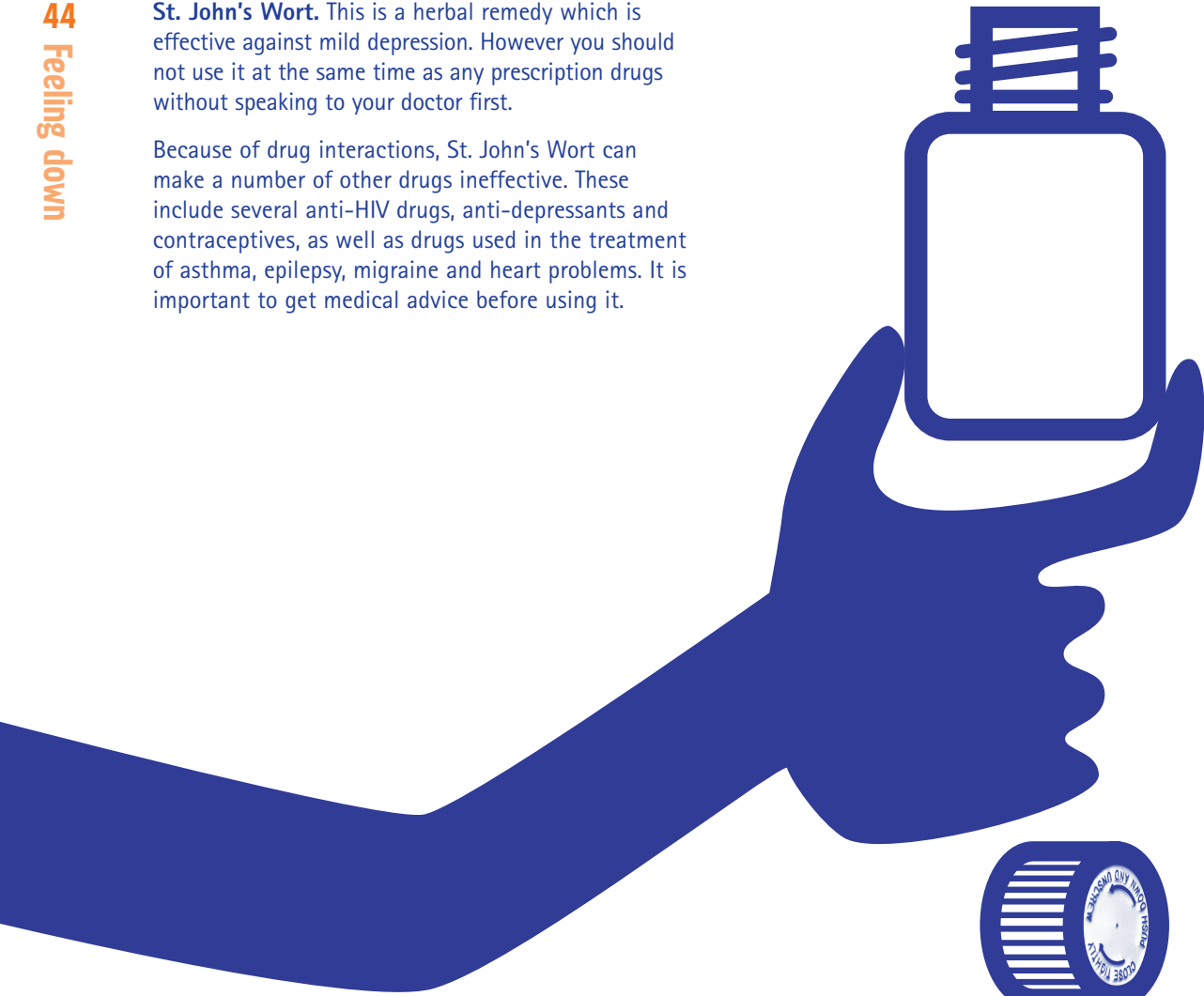
It's important to know that you won't feel their effect straightaway. People often don't notice any improvement in their mood for two or three weeks. But other things may change more quickly. For instance, people often notice that they are sleeping better and feeling less anxious in the first few days.

Once you're beginning to feel better, you can plan, with your doctor, to gradually reduce the dose and then stop taking them. This is usually after at least six months. There are several different types of anti-depressants, and they are not all equally effective with everyone. If you've been taking them for a month and they don't seem to be working as they should, it's probably a good idea to talk again to the person who prescribed them.

Like most drugs, some anti-depressants have side-effects. The person prescribing them should tell you about side-effects, and there will also be an information leaflet with the drugs themselves.

St. John's Wort. This is a herbal remedy which is effective against mild depression. However you should not use it at the same time as any prescription drugs without speaking to your doctor first.

Because of drug interactions, St. John's Wort can make a number of other drugs ineffective. These include several anti-HIV drugs, anti-depressants and contraceptives, as well as drugs used in the treatment of asthma, epilepsy, migraine and heart problems. It is important to get medical advice before using it.



Feeling anxious

We all have worries, are afraid of certain things and get tense sometimes. Feelings of anxiety and fear are normal reactions to difficult or threatening situations. But anxiety can become a problem when we worry so much that it interferes with our life.

Some people worry constantly about the same thing and others worry over anything and everything. In either case, the worries can seem to be out of proportion.

Anxiety of this severe kind can mean feeling overcome with panic, restlessness, or breathlessness. It can involve feeling unable to control disturbing or upsetting thoughts.

We may be concerned about things that other people think are not so important. We may be afraid of what might happen to us, and feel powerless to stop something bad happening. It may get so bad that the world seems threatening, making us feel vulnerable.

When we think about the things that worry us, we may have physical changes, such as sweating, palpitations (a pounding heart) or rapid breathing. These changes are caused by an increase in adrenaline, the hormone which is released by our bodies to help us deal with danger.

We may find ways to avoid situations that make us feel bad. In the short term that makes us feel safer, but avoidance can become a habit and may make the situation worse. We narrow down the things we do or limit the places we go, stopping us from living life as we'd like to.

"I worry about everything; I get tense and wound up, and end up having a go at people for no good reason"

"Even though we always use condoms and follow all the rules, I'm constantly worrying about infecting my partner"

"Although my blood results are good, every time I feel a bit ill I get really upset and think I'll need to go to hospital"

Things we can do to help ourselves

- Use relaxation techniques (see page 13).
- Get more exercise (see page 18).
- Talk to someone (see page 9).
- Don't over use drink or drugs, especially stimulants (see page 16).
- Eat well (see page 28).
- Get enough sleep (see page 24).

How professionals can help

If you think you are worrying too much, it may be helpful to talk to a professional about it. You could start with your HIV doctor, family doctor or a worker at an HIV organisation. Your doctor may treat you, or you may be referred on to a psychologist, psychiatrist, psychiatric nurse or counsellor. They may suggest a 'talking therapy' such as CBT, or drug treatment, or both.

Cognitive behavioural therapies (CBT) are based on the idea that anxiety happens because we have negative thoughts about ourselves and the world. During cognitive therapy, we learn how to challenge negative thoughts and replace them with more realistic thoughts.

Other talking therapies can help us understand where our fears come from, or why we are so bothered by these fears. They can help us get our fears better in perspective.

Relaxation techniques (see page 13) can teach us how to release the tension in our bodies and to relax our muscles. Although self-help books and tapes can be useful, many people find it easier to learn in a class or with a therapist.

For long term treatment, many people find that **anti-depressant drugs** help with feelings like tension, irritability and worry. They won't start working for at least three weeks, and you'll probably need to take them for at least six months. You may get some side effects.

Several different types of drugs can be used to help reduce feelings of anxiety for short periods only. They aren't usually prescribed for any more than a month because we can become dependent on them. They may be given to us when our anxiety suddenly gets worse. These are the two most common types:

Hydroxyzine is a type of antihistamine (a drug normally used for allergies). It can help with problems like worry, tension and fear. But it can also make us drowsy.

Benzodiazepines are tranquillizers. They can help with physical symptoms like palpitations and breathlessness, as well as feelings of worry. There are several side effects though - drowsiness, memory problems and dizziness. People often get addicted to them, or find that their anxiety comes back as soon as they stop taking the drug.

Efavirenz side effects

Efavirenz is an anti-HIV drug, also known as Sustiva. It is very commonly prescribed, and many people find that Efavirenz keeps their virus under control. However some other people have found the drug's side effects so unpleasant that they have stopped taking it and switched to different treatment.

Side effects like nightmares, dizziness and mood alteration that affect our mental well-being have not been reported for other anti-HIV drugs.

The most common side effects are:

Insomnia and drowsiness

Dizziness

Vivid dreams and nightmares

Confusion

Problems concentrating

Abnormal thinking

Mood swings



A lot of people who take the drug get some of the side effects during the first weeks or months of treatment. For most of us, they are mild and easy to manage. If you know what to expect before you start, they should be easier to deal with and less alarming.



Of course these kinds of problems are not always caused by Efavirenz. For example, we may have nightmares for other reasons, or for no reason at all.

A few people experience these problems very intensely. Some other people have experienced feelings of paranoia, aggression or severe depression, or have thought about harming themselves. But scientists are not sure if these problems are really caused by Efavirenz – there may be another explanation.

Nonetheless, if you have these kinds of feelings, you are advised to contact your clinic as soon as possible to talk about changing treatment.

Things we can do to help ourselves

Take Efavirenz before you go to bed. That way the feelings of dizziness and anxiety will be most intense when you are asleep. It may be best to take the drug about two hours before going to bed.

Follow the advice on sleeping habits on page 24.

Don't take it with a high fat meal. This unnecessarily increases the amount of the drug in the blood, and makes the side effects worse.

Start treatment when you aren't busy with other things. You'll probably get the most severe side effects during the first two weeks - if you work, you may want to arrange to take some time off.

Don't drive or operate machinery if you get these side effects.



How professionals can help

People who've experienced depression, anxiety and other mental health problems in the past are more likely to have difficulties with Efavirenz. Make sure you tell your doctor about any problems you've had in the past.

It's worth telling your doctor about any side effects you experience. It may help to keep a 'side effects diary' to write down, as accurately as possible, the problems you are having.

If you are unhappy about the way the drug is making you feel, your doctor should be able to switch you to a different treatment.

Because of genetic differences, some people may need lower doses than others. This is sometimes the case for people of African origin. Your doctor may be able to use a technique called TDM (Therapeutic Drug Monitoring) to check that the dose of the drug is not too strong for you.

It may also be possible to take drugs to reduce anxiety or help you sleep.

Getting more help, support and information

We hope this booklet hasn't given the impression that living with HIV is always and inevitably distressing. Most of us living with HIV cope very well with the emotional challenges we face.

Occasional feelings of anxiety or being down happen to everybody, and we can usually get through them. It's how we recognise and cope with these feelings that is most important.

Getting support is usually important. We can turn to local support groups and HIV organisations, as well as our GPs and HIV clinic staff.

There are also several specialised helplines we can contact:

THT Direct
0845 12 21 200

Details of local counselling services and support groups, as well as information, advice and support on all aspects of HIV and sexual health.

10am – 10pm Mon – Fri
12 noon – 6pm Sat – Sun

Mind Infoline
0845 766 0163

Confidential help and information on mental health issues and services.

9.15am – 5.15pm Mon – Fri

Saneline
0845 767 8000

Confidential support and information on mental health issues and services.

1pm – 11pm Mon – Sun

Samaritans
08457 90 90 90

Confidential emotional support for people who are experiencing feelings of distress or despair, including those which may lead to suicide.

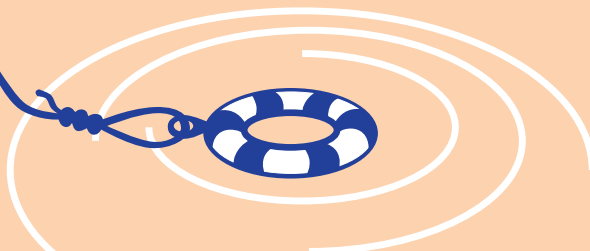
24 hours a day

If you'd like to get more detailed written information about the issues discussed in this booklet, try these websites:

Mind
www.mind.org.uk

Royal College of Psychiatrists
www.rcpsych.ac.uk

Terrence Higgins Trust
www.tht.org.uk



For details of local services, information,
advice and support, contact us:

THT DIRECT  0845 12 21 200

www.tht.org.uk

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The HIV and sexual health charity for life

Website: www.tht.org.uk **THT Direct:** 0845 12 21 200

Registered office: 314-320 Gray's Inn Road, London WC1X 8DP

Tel: 020 7812 1600 **Email:** info@tht.org.uk

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