

A guide to treatment choices for people with HIV



# Your treatment



The HIV and sexual health charity for life

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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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# The basics

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## Ten things to know about HIV and combination therapy

- 1** Being diagnosed 'HIV positive' doesn't necessarily mean that you are ill, or that you have AIDS, or that you are dying.
- 2** Many people with HIV are able to live long, healthy lives.
- 3** Combination therapy slows the spread of HIV in the body, prevents illnesses, and prolongs life.
- 4** Not everybody with HIV needs to take combination therapy straightaway. It's different for different people.
- 5** For combination therapy to work, you need to take the drugs at the right doses, at the right time.
- 6** Some people get unpleasant side effects from combination therapy.

- 7** HIV spreads by attacking the immune system, which defends the body from infections. When the immune system is weak, illnesses are more frequent.
- 8** Having AIDS is different from being infected with HIV. Somebody has AIDS when their immune system has been seriously damaged, and they have a serious illness.
- 9** Regular blood tests are important for everybody with HIV, whether they are taking combination therapy or not.
- 10** Treatment works best when people with HIV and doctors work together. Ask all the questions you need to, talk about any side effects or health problems you have, and make sure the doctor knows how you live your life. That way you're more likely to find a treatment that's right for you.

## HIV and the immune system

HIV stops the body's natural defence system from working properly.

### What's HIV?

A virus which attacks the immune system.

### What's the immune system?

The body's defence system, which protects us against infections and some cancers.

### What are opportunistic infections?

Infections that are usually harmless, but can cause illness when the immune system is weak.

### What is AIDS?

An advanced stage of HIV infection, when the immune system has been seriously damaged.

### Can damage to the immune system be reversed?

In many cases, yes, with combination therapy.

### What is combination therapy?

Drugs which stop HIV reproducing. This limits damage to the immune system, and so helps prevent illnesses.

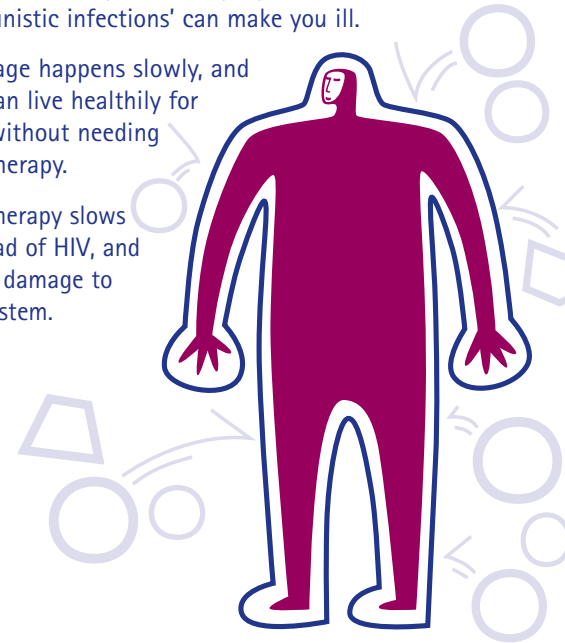
We all have an immune system, even before birth. It's made up of lots of cells that can move all around your body, to wherever they are needed to fight infections.

Everyday most of us will come into contact with some sort of virus, bacteria, fungus or other infection. The immune system usually recognises infections that it has dealt with before, so is able to fight the infection. But without an immune system, each one could make you seriously ill.

HIV spreads by taking over and attacking the immune system. When HIV has done a lot of damage to the immune system, everyday infections called 'opportunistic infections' can make you ill.

Still, this damage happens slowly, and most people can live healthily for several years without needing combination therapy.

Combination therapy slows down the spread of HIV, and so slows down damage to the immune system.

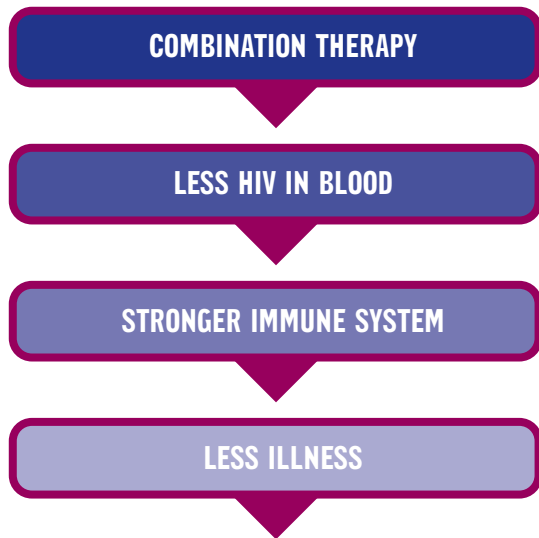


## What is combination therapy?

It's not a cure, but combination therapy can stop HIV from reproducing.

The drugs people normally take to treat HIV are called 'combination therapy' because people usually take three different drugs at the same time. Combination therapy is also called 'treatments', 'anti-HIV treatments' or 'HAART' (Highly Active Anti-Retroviral Therapy).

It works by stopping HIV from reproducing in your body, so that there is a lot less HIV inside your body. If there is less HIV, there is less damage to your immune system, and you are less likely to get ill.



Because of combination therapy, many people with HIV can expect to have a near-normal life expectancy.

But it isn't a cure – at the moment no drug can totally wipe out HIV from your body.

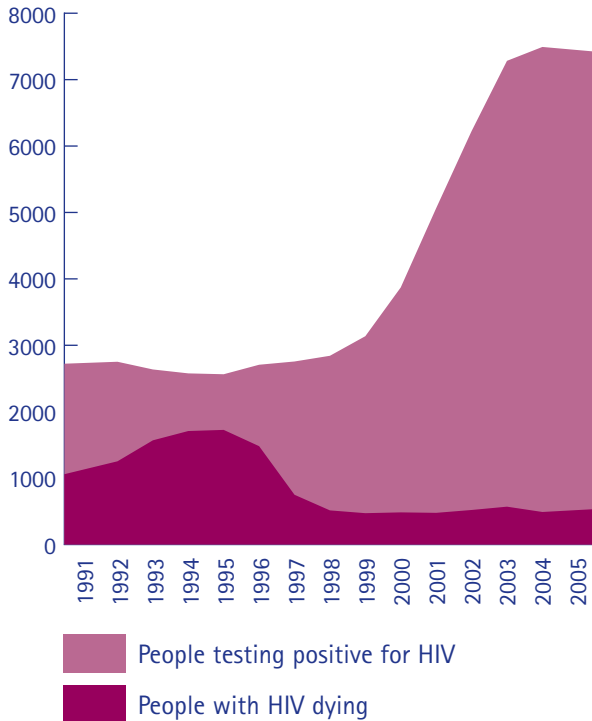
Most people take combination therapy once or twice a day, and usually take three or four different drugs. Sometimes two or three drugs may be combined in the same tablet. There may be anything from one to ten tablets to take each day.

The drugs you take are chosen from around 20 different medicines which are available. So you might not take the same drugs as other people you know.

Each anti-HIV drug belongs to a different “class” of drugs. Drug classes have very technical names, but these are some that you may hear about:

- nucleoside reverse transcriptase inhibitors (NRTIs or “nukes”)
- non-nucleoside reverse transcriptase inhibitors (NNRTIs or “non-nukes”)
- protease inhibitors (PIs)
- fusion inhibitors
- integrase inhibitors

The basic thing to know is that each one interferes with (or inhibits) a different part of HIV's lifecycle. Each one tries to stop HIV from reproducing in a different way. And a combination of drugs from different classes works better than one drug alone.



*Does combination therapy really work? Since it was introduced in 1996, the number of people with HIV dying has dropped and stayed low, even though more and more people have found out they have HIV. (Source: Health Protection Agency)*

## Two key blood tests

CD4 counts and viral loads give you important information about your health.

Even if you're not taking combination therapy, it's very important to have regular blood tests at the HIV clinic. These are normally taken every few months. The test results will help you and your doctor make decisions about your health.

The CD4 count is a measure of the strength of your immune system. When the immune system is strong, the CD4 count is higher.

- Someone who doesn't have HIV may have a CD4 count between 500 and 1200.
- If the count is between 200 and 500, there has been some damage to the immune system.
- If it is below 200, there has been more serious damage, and a greater risk of getting ill from opportunistic infections.

Viral load is a measure of the number of copies of HIV in a sample of blood. Viral load results aren't as easy as CD4 counts to understand, but the key thing to remember is the lower they are, the better.

Viral load results can vary dramatically between different people. Before starting treatment, viral load may be as high as 50,000 or 200,000. Successful combination therapy will make it drop rapidly, often to below 50. This may be called 'undetectable' viral load.

'Undetectable' doesn't mean that there is no HIV, just that there is not enough for the test to find and count.

With both tests, numbers can go up and down for all kinds of reasons. A single test result doesn't mean very much. You need to look at several test results together to see whether the trend is for them to go up, go down, or stay stable. It's also important to look at how quickly the results are changing.

You can ask your clinic for a print out of your test results, which can help you keep an eye on your progress.

See page 54 for information on other blood tests that you may take.

Aim for  
a **HIGH**  
CD4 count

Aim for  
a **LOW**  
viral load

# Starting treatment

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- 16 **What if I don't take treatments now?**
- 17 **Which drugs?**

## When to start combination therapy

CD4 counts are important. But so are your feelings, and you shouldn't rush into this decision.

There is no fixed time for everyone to start.

If you have your blood checked regularly at your HIV clinic, the test results will help you and your doctor make decisions about when to start. Several factors need to be considered together, but current guidelines suggest that most people should begin treatment when their CD4 count is between 200 and 350. (See page 9 for more about CD4).

**CD4 below 200** Treatment recommended

**CD4 between 200 and 350** Treatment should be considered

**CD4 above 350** Treatment not usually advised

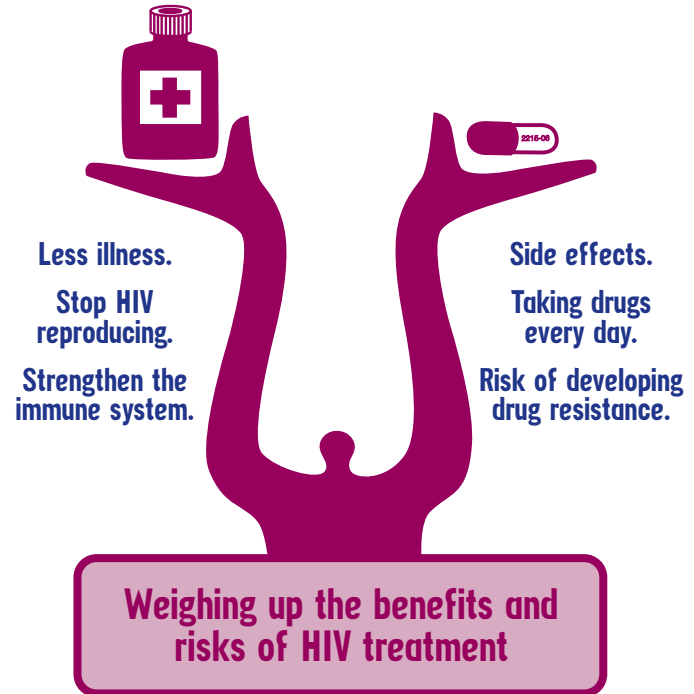
However guidelines could change in the future – some doctors believe that treatment should be started at a higher CD4 count.

The aim of therapy will be to see your CD4 count go up, and your viral load go down. Ideally, the viral load will drop to below 50.

But when you start also depends on your feelings – it's your own decision. Some people find starting combination therapy a difficult commitment to make.

Starting combination therapy can often mean that you have to alter how you live, when you wake up and go to sleep, what you eat and when you eat it.

Before starting combination therapy you should give yourself enough time to talk through all your options. As well as your doctor, you could speak to other people with HIV and workers at local HIV organisations. If there's a friend or family member who's supportive, they may also help you make your mind up.





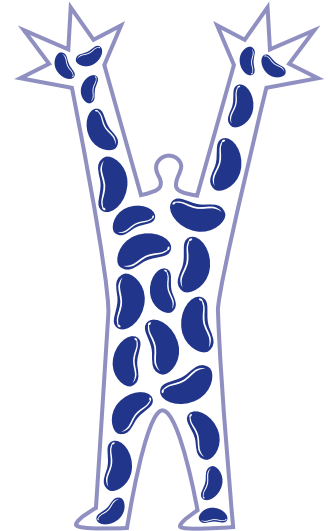
## Are you ready to start?

You should only start combination therapy when you're ready for it. You need to be sure that you'll be able to take it exactly as prescribed.

Here are some questions to ask yourself about fitting combination therapy into your life.

- Do I know enough about combination therapy, how it will affect me, and what benefits it can have for my health?
- Starting treatment will involve making changes to my life and routine. Can I concentrate on that at the moment?
- The first few weeks on a treatment are often the most difficult. Can I make my health a priority and give myself extra time to adjust? For example, could I take time off work?
- Have I found it difficult to take medicines in the past? If I had problems, what were the reasons for this? How can I avoid these problems in the future?

- If I have problems remembering to take my drugs on time, who could I talk to for support?
- Could I ask somebody to remind me - a friend or a housemate?
- Are there people who I wouldn't want to see me taking my drugs - people at work, people I live with, friends or family?
- What about people I might meet in the future - like a new partner? How will I deal with them knowing I'm taking anti-HIV drugs? Will this put pressure on me to tell them I'm HIV positive?



## What if I don't take treatments now?

Starting treatment is not usually a "now or never" decision.

Combination therapy isn't recommended for everyone, and may simply not be necessary for you now.

But even if your doctor thinks you should consider taking it, and you're not ready, you may be able to come back to this later.

Ask your doctor how much time you will have to consider the options being offered. The answer will probably depend on how your health is now, and how quickly it's changing.

If your health is fairly stable, it's unlikely to be a "now or never" decision. You may have a while to make up your mind.

But if your CD4 is already below 200 or you are ill with an infection, you may need to make a decision more quickly. Your doctor may advise you to start combination therapy urgently, in order to prevent serious illnesses and infections.

But the final decision will always be yours.

Whatever you decide, it's strongly recommended to stay in touch with your HIV clinic and continue to monitor your health by having regular blood tests.

## Which drugs?

There are expert guidelines on how treatment should be used.

BHIVA (British HIV Association) is the professional body for HIV doctors in the UK. They produce guidelines which recommend how HIV treatment should be used.

The guidelines are based on research and expert opinion. They are not a set of rules, but most doctors will normally follow them.

The guidelines recommend that you start with at least three anti-HIV drugs. Two will always be from the NRTI ("nuke") class of drugs.

In addition to these two, you might also take one drug from the NNRTI class.

Alternatively, as well as the two NRTIs you could use one from the protease inhibitor class and a small quantity of another drug called Norvir (Ritonavir).

Both NNRTIs and protease inhibitors are effective in reducing the amount of HIV in the body. NNRTIs are sometimes preferred because they have fewer long term side effects than protease inhibitors, and because it may be easier to take them as prescribed. But the disadvantage of NNRTIs is that resistance can develop more quickly.



Often two drugs are combined in one tablet, to reduce the number of pills you need to take. For example the two NRTIs may be put together.

You can get more information from two free booklets published by NAM (call 020 7840 0050 for copies):

- *HIV Therapy* describes BHIVA's guidelines.
- *Anti-HIV Drugs* gives information on all the available drugs.

### Resistance testing

When deciding which drugs to take, it can be very useful to have a 'resistance test'. This will help your doctor see if your virus may be resistant to the drugs which he or she is thinking about using. (See page 21 for more about resistance, and page 52 for the tests used).

Resistance tests are recommended by BHIVA guidelines for all people starting treatment, and are especially important when changing treatment. But they are expensive and not all hospitals use them as regularly as that. You may need to be persistent if you want to make sure that you get a resistance test.

# 3

## Adherence

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## What is adherence?

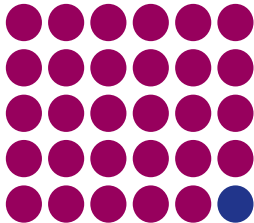
Anti-HIV drugs have to be taken exactly as prescribed.

Combination therapy works best when the drugs are taken exactly as prescribed. This is often called 'adherence', and it means taking the drugs:

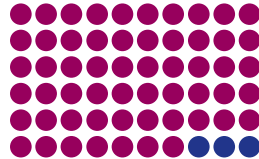
- **at the right times**
- **at the right dose**
- **strictly following any advice about food and drink**

Skipping even just a few doses will increase the risk of your treatments failing you. For anti-HIV drugs to be effective, you need to take them correctly a minimum of 95% of the time.

*With once a day drugs (every 24 hours), 95% adherence means having no more than one missed or late dose a month.*



*With twice a day drugs (every 12 hours), 95% adherence means having no more than three missed or late doses a month.*



If you're not able to take the drugs in this way the danger is that the virus will develop 'drug resistance'. This is explained on the next page.

## Why resistance matters

Drug resistance makes HIV treatment less effective.

Doctors often talk about "resistance". This means that the HIV you have is resistant to some anti-HIV drugs. In other words, the drugs don't work well any more.

Every time HIV makes a new copy of itself, it's slightly different. Often, these differences are not important. But sometimes, the new copy is stronger than the last one, and it is 'resistant' to the drugs you've been taking. This means that it will be able to reproduce again, even when you take the drugs.

If you're taking combination therapy, it's important to make sure that enough of the drugs are in your blood all the time to do their job properly. Missed or late doses could mean there are reduced levels of the drugs in your blood. This could allow the virus to make more copies of itself, including drug resistant copies.

Drug resistant HIV could lead to the treatment not working, and you not being able to use the same drug again in the future.

If you're able to take each dose of the combination therapy at the right time each day, then the development of drug resistant HIV is unlikely. That means the drugs will work for many years.

For more information, get **NAM's** free booklet *Resistance* (call **020 7840 0050** for a copy).

## A daily routine

It's worth planning how you could fit treatments into your life.

You'll need to develop a routine so that you remember to take the drugs at the same time each day. You may need to get some support if this means you need to make changes in your life.

It's worth thinking about how you could fit the treatment into your routine:

- **when you get up and go to bed**
- **your meal times and what you eat**
- **the times you're at home and the times you're at work**
- **where you could store your pills**
- **where you'd feel comfortable taking them**
- **how your routine is different at weekends**

If you talk to your doctor about all of this, he or she could help you choose a combination that fits your lifestyle.

Some of the drugs need to be taken either on an empty stomach, with a snack or with a substantial meal. For some drugs, this food should contain fat, but for others it must be low fat. So the food you like to eat will also make a difference.

## Questions to ask

Things to ask your doctor, nurse or pharmacist about your combination therapy.

- 1 How many pills will I need to take?
- 2 How many times a day will I need to take them?
- 3 How do the drugs need to be stored?
- 4 Are there any food restrictions with this combination?
- 5 Could the drugs react with any other medicines, herbal treatments or recreational drugs I might take?
- 6 What should I do if I forget to take my combination therapy?
- 7 What side effects might I get, and how could I minimise them?
- 8 Is an easier combination available?
- 9 Can you give me some written information about these drugs?
- 10 Who can give me help and advice if I do have problems?

### Once a day, or twice a day?

Some drugs are taken once a day, and others twice a day. For many, once a day treatment is the easiest and most convenient. But the disadvantage is that if you do forget a dose, the consequences are more serious than when you forget a twice daily drug. Drug levels will be low for longer, and more drug resistant virus may be produced.

## Sticking with it

Practical ways to remind yourself that it's time to take the pills.

- To get into the routine of pill-taking, you could practice for a few weeks before starting. Try having mints or vitamin tablets at the times you'll be taking your treatments. Learn from this and work with your healthcare team to come up with a schedule that is right for you.
- Keep your medication in a place where you will remember to take it.
- Try to link your pill taking times with other daily routines – getting up, meal times, taking the children to school, a particular radio or TV programme, or tea breaks at work.
- You can probably get pill containers or dosette boxes from your clinic. They have

compartments where you can divide up your tablets according to when they need to be taken. They can help if you forget which pills to take, or if you're not sure whether you've already taken your pills.



- Keep a note, a picture or some other reminder on the back of your front door to remind you to take medication with you before leaving home.
- Set an alarm on your mobile phone or watch to ring when your doses are due. But this can be indiscreet.
- Keep a diary or pill planner and tick off the dose once you've taken it.

If you are involved in decisions about treatment, you are more likely to be motivated to adhere well. Try to get information about HIV treatments and about the particular drugs you may take.

- If you use a computer at work, you can use the calendar or task programme to automatically send you reminders. You could use a code word to mean anti-HIV drugs.
- Plan for weekends, holidays or other times when you don't have your usual routine. Make extra efforts to remind yourself, and if appropriate, ask the people you're with to remind you.
- Keep a bottle of water in your bag, so you can take your treatment wherever you are.
- If you don't want people to see you taking your treatment, excuse yourself to go to the toilet or to make a phone call.
- Avoid running out of your medication by renewing your prescriptions in advance.

## Dealing with problems

If you do find it hard to take the pills on time, help is available.

If you do forget a dose of your combination therapy from time to time, try not to panic or feel guilty – we're all human!

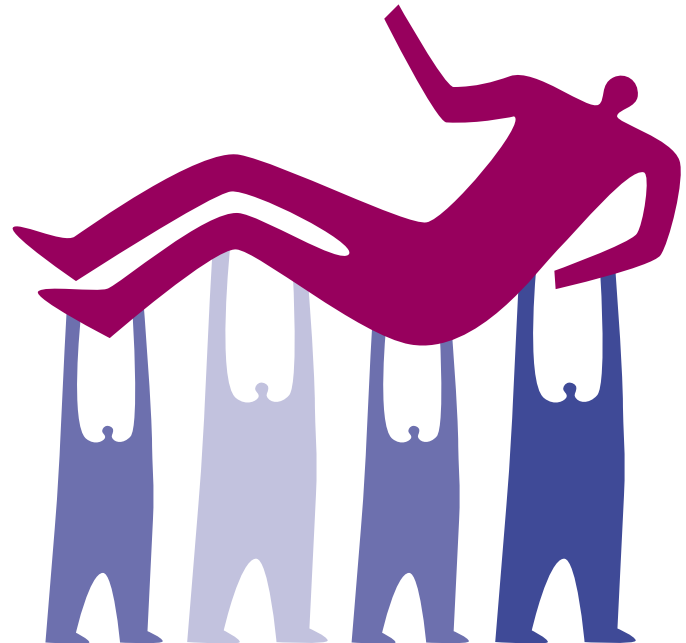
As a very general rule, if you realise you have missed a dose, take it as soon as you remember. But if you only realise when you're going to take your next dose, don't take a double dose.

If you often miss doses, have days off from treatment or frequently take the drugs at the wrong time, it may be better to talk to your doctor about trying a different combination.

Don't ignore problems. Try to find out why they're happening and find ways to overcome the difficulties. Try to work out if there's a pattern, like regularly forgetting your evening dose. This may help you to find answers to the problem.

If side effects put you off from taking the pills, remember that there are ways to minimise a lot of them (see pages 29–40). Make a note of side effects you get and make sure you mention them to your doctor.

Apart from your doctor, there will be other staff at your HIV treatment centre who can help you with adherence problems, including the nurses, pharmacists and dieticians (see page 52).



### Tips for storing your anti-HIV treatments

Make sure your medication is stored properly – cool, dry places away from sunlight are usually best. Places that can get damp like bathrooms or window ledges are best avoided.

The drug Ritonavir (Norvir) is one that should be kept in a fridge. This is for long term storage – you can keep a smaller supply in a cool, dry place for a few weeks.

Lots of people keep a spare supply at work, in the car, at their partner's house or in their bag in case they forget to take their pills with them when they're away from home or on a night out. But make sure that spare supplies are also kept in the right conditions.

# 4

## Side effects

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## Why don't I feel better?

HIV drugs aren't perfect, but side effects often go away after a while.

Most people who take anti-HIV drugs get some side effects at one time or another. You may wonder what the point is of taking medication that often makes you feel worse.

HIV is a very difficult virus to treat, and the drugs available aren't perfect.

As well as slowing the spread of HIV, the drugs may also interfere with your body in other ways. All additional or unintended effects are known as side effects.

Some of the most common are:

- **diarrhoea**
- **feeling sick**
- **feeling tired**

Many side effects are the result of the body getting used to a new drug. After a few weeks, as your body adjusts to a drug, side effects often go away or become easier to deal with. But this doesn't always happen, and it may be worth changing treatment if side effects continue to cause you problems.

Medicine packets contain information leaflets with long lists of possible side effects, including some that are quite uncommon. Don't assume that you will get every side effect mentioned. Not all people taking a drug will have the same side effects, and side effects can vary in their severity.

## Dealing with side effects

If clinic staff are aware of problems you're having, they may be able to help.

If your doctor knows that side effects are difficult for you, he or she may be able to do something to help. For example:

- **give you a treatment for the side-effect**
- **reduce the dose of your anti-HIV drug**
- **change your anti-HIV treatment**

But you shouldn't stop your treatment suddenly, or skip doses, without speaking to your doctor first. You could develop resistance to several drugs that way (see page 21). It's better, with your doctor, to plan how you can safely switch to a different treatment.

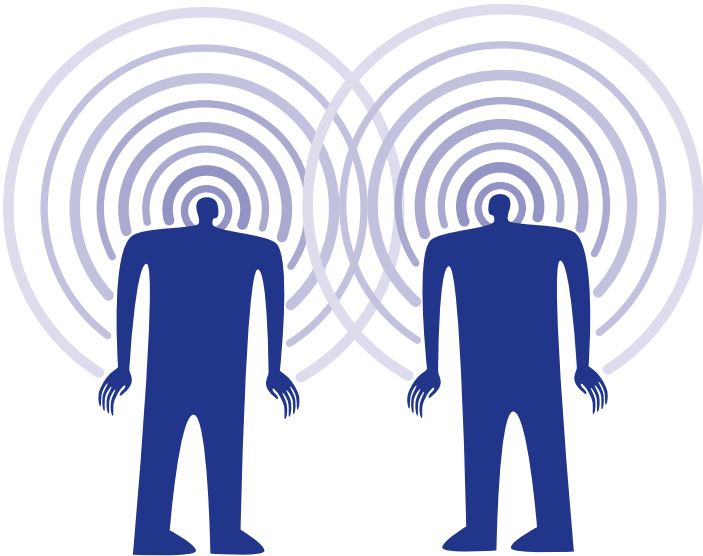
If side effects make life a misery, it's more difficult to take each drug dose at the right time. Your doctor will know this, and so he or she should be ready to listen to problems you have with side effects.

During a short meeting with the doctor, it may not always feel easy to talk about side effects, or describe how they are affecting your life. You may not be sure if problems are caused by the treatments themselves, or something else altogether.

It may help to keep a 'side effects diary' to write down, as accurately as possible, the problems you are having. Bring this with you when you come to the clinic, so they can understand how often you have problems, how long they last for, how severe they are, and how they affect your quality of life.

Doctors sometimes underestimate how much pain people are experiencing, because they think that their patients exaggerate pain. In fact, most people underestimate pain when talking to their doctor.

If you don't feel able to discuss these kind of problems with the doctor, there will be other clinic staff you can talk to. Nurse specialists and dietitians can often give good advice. The clinic staff are there to help, and should be interested in your well-being as a whole person. They are not there just to talk about HIV alone.



## Diarrhoea

- Lots of different anti-HIV drugs give some people diarrhoea. But infections and intolerance to some foods may also cause diarrhoea.
- Drugs like Immodium and Lomotil can help slow down the gut's movements, meaning you don't need to go to the toilet so often.
- If your diarrhoea is caused by the protease inhibitor Nelfinavir, calcium supplements may help.
- The body loses a lot of water through diarrhoea, so it's important to drink more. Even better than water are unsweetened teas, vegetable and fruit juices, and light vegetable or chicken soups. They all contain minerals that are lost with the water.
- A dietitian can give you good advice on foods to avoid, and foods to eat more of.
- Diarrhoea is unpleasant and can make it difficult to live a normal life. It can also lead to nutritional problems, and it's important that your doctor is aware of any problems.

## Feeling sick (nausea)

- Lots of different drugs can cause this problem, especially during the first few weeks of treatment.
- Anti-nausea drugs (also called anti-emetics) are often very effective.
- The problem may be reduced if you take your drugs with food, more frequently or at lower doses. Speak to your doctor first though.
- Some people find that ginger helps - either in tablets, as ginger tea, or in food.
- Nausea may be worse at mealtimes. Bland and cold food is usually better than hot, spicy, greasy or smelly food.
- Having several snacks and small meals in the day will be easier than a few large meals.
- If the problem doesn't go away, talk to your doctor about changing treatment.

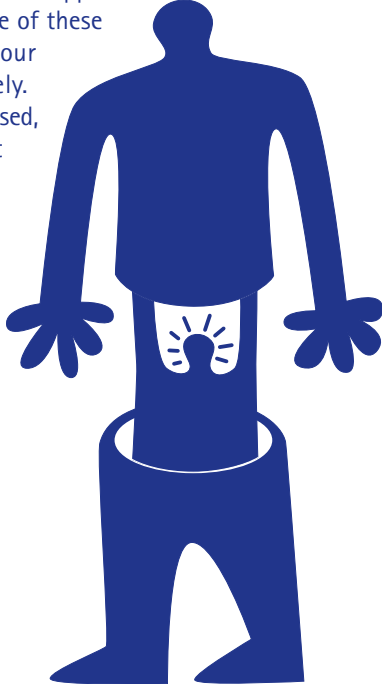


## Feeling tired (fatigue)

- Anti-HIV drugs are one cause of fatigue. Others include HIV itself, illnesses, poor diet, stress, depression, alcohol, recreational drugs and problems sleeping.
- Dealing with sleep problems or improving your diet could make a difference. See the Terrence Higgins Trust booklet *Your Body* for more information.
- Fatigue as a side effect may be linked to anaemia (low red blood cells). Treatments are available for this.
- It will help your doctor if you can accurately describe your fatigue. Give specific examples of things that make you tired, how often this happens, and how it compares to a few months ago.

## Skin rash

- Some people get mild rashes when they start a new drug. These may go away on their own, or your doctor may give you anti-histamine drugs.
- But sometimes severe rashes can be signs of a life-threatening allergic reaction to a drug. This can be the case with Abacavir (Ziagen, also found in the combined tablets Trizivir and Kivexa), and occasionally with Nevirapine (Viramune).
- It's hard to know how serious a rash is, so if a rash appears after starting one of these drugs, contact your clinic immediately. If the clinic is closed, contact Accident & Emergency.



## Peripheral neuropathy

- This means damage to the nerves, and affects the hands and feet. They may feel sensitive, numb or tingly.
- Neuropathy can range from being a minor nuisance to being extremely painful.
- It can be a side effect of the drugs that begin with 'd': ddC (Hivid), d4T (Zerit), ddI (Videx), but also 3TC (Epivir). There can be other causes too.
- If drugs are the cause, it's best to switch treatment without delay. If you continue to take the drugs, the nerve damage may become permanent.
- It may be possible to reduce the pain by wearing looser shoes, not walking too far, not standing for long, and soaking your feet in cool water.
- Acupuncture, and other complementary therapies, can help.

## Efavirenz side effects

- Some people taking the drug Efavirenz (Sustiva) get side effects that are not usually reported for other drugs.
- These include insomnia, drowsiness, vivid dreams, nightmares, dizziness, confusion, problems concentrating, abnormal thinking and mood swings.
- The side effects often go away after a few weeks, but if they don't it may be possible to change treatment.
- Taking Efavirenz about two hours before going to bed, and *not* with a high fat meal, may reduce the problem.

## Lipodystrophy: fat loss and fat gain

- This involves losing some fat from our face, legs, arms or buttocks, or gaining fat elsewhere.
- It can be a difficult side-effect to live with, as it can affect the way we see ourselves. We may worry that other people notice these changes.
- It can be a side effect of the drugs d4T (Zerit) and AZT (Retrovir, also found in the combined tablets Combivir and Trizivir), especially when they are combined with a drug from the protease inhibitor class.
- Exercise and a balanced diet may help.
- Fat loss to the face can be treated with injections of New Fill, which stimulates skin growth.

## Raised blood fats and blood sugars

- Visible problems of fat loss and fat gain often happen at the same time as increases in the amount of fat and sugar in our blood. They may be caused by protease inhibitors.
- Raised blood fats and sugars can increase the chance of having cardiovascular diseases such as heart disease, heart attack, stroke and high blood pressure.
- If you have these side effects, it's recommended to stop smoking, exercise regularly and eat a healthy diet to reduce the risk of cardiovascular disease.
- You may also take some tablets to further reduce the risk.



## Other side effects

- The most common side effects are described on the previous pages.
- Some people have also experienced other problems, including headaches, dry skin, stomach pains, hair loss, changes in taste or appetite, yellow eyes, yellow skin, sexual problems, muscular pain, sleep disturbance, and feeling depressed.
- Tell your doctor about *any* side effect that you experience.
- Your doctor will also carry out blood tests to check for side-effects affecting the liver, kidneys and other parts of the body.
- **HIV i-Base** publish a useful guide, *Avoiding and Managing Side Effects*. You can get a free copy through their web-site: [www.i-base.org.uk](http://www.i-base.org.uk)



## Specific circumstances

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## Changing treatment

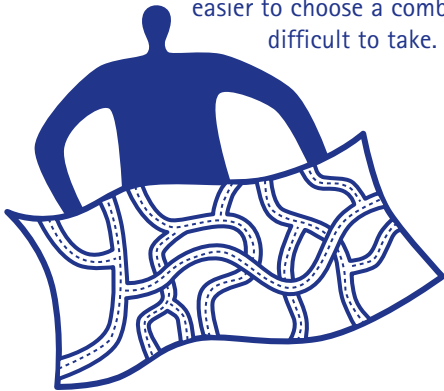
If you need to change, the new treatment should be chosen carefully.

There may be a problem with the drugs you're currently on:

- they're not keeping your viral load down
- your virus is resistant to them
- the side effects are too difficult to deal with
- the drugs have to be taken at times that don't suit you
- the rules about taking the drugs with or without food are hard to follow.

There's probably a better combination available. In other words, one that will suit you better, and give you better results. But to find the right one, you'll need to work closely with your doctor.

- ?** Now more than ever, it's essential that you talk honestly with your doctor about any problems you've had with taking the drugs at the right time.
- If your doctor understands your lifestyle, it'll be easier to choose a combination that's not too difficult to take. (See page 22-23).



At the same time, you can also insist that your doctor carries out a resistance test, to check which drugs will work best against the virus you have. BHIVA recommends that resistance tests are always carried before changing treatment. (See page 18).

Before you switch, make sure you know about the side effects that new drugs could have. There's no point changing treatment if the new drugs are even harder to take.

When changing drugs, you normally change all the drugs in the combination, not just one or two.

### Speak to your doctor first

If you're fed up with your treatment you may be tempted just to stop taking the pills. Perhaps the side effects make you feel awful, or the drugs might not seem to be working.

But there are serious risks to stopping treatment suddenly. Drug resistance could develop, making future treatment more difficult (see page 21).

If you speak to your doctor, he or she can advise you on how to stop the treatment in a safe way. For example you may need to stop taking one drug now, but continue with two others for another week. This may prevent drug resistance.

## Pregnancy

With good medical care, it's possible for women with HIV to give birth to healthy children.

HIV treatment can be used so you can have a safe pregnancy and birth. If you take all the necessary precautions, it's extremely unlikely that your baby will be HIV positive.

If you're thinking about having a baby, but aren't pregnant yet, it's worth speaking to your doctor first, so that he or she can check if you are in good enough health to have a baby safely. Your doctor can also tell you about how to get pregnant without putting your partner at risk of infection.

During pregnancy, it's usually important to take anti-HIV treatment, for two reasons:

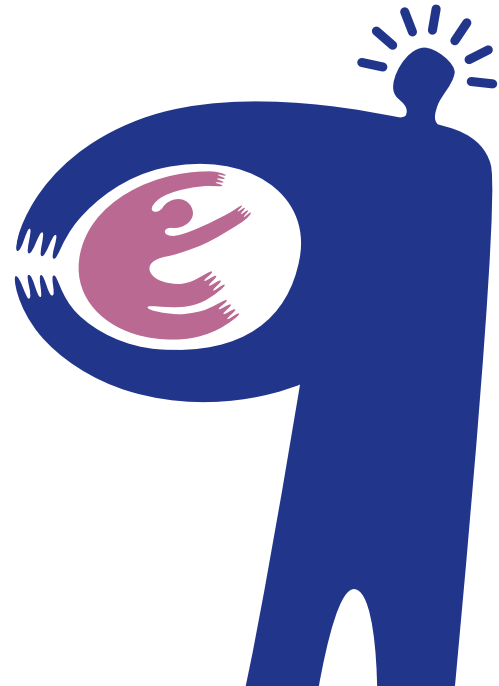
- **it will protect your baby from HIV**
- **you may also need treatment for your own health.**

A few anti-HIV drugs may not be safe for unborn babies. If you're already on treatment, ask your doctor about whether you need to change the drugs you take.

If your own health is good and you don't need to take anti-HIV treatment for yourself, it will still be recommended to take one or more anti-HIV drugs to protect the baby.

It's usually recommended to have a planned caesarean section, but if your health is very good, a vaginal delivery may be possible. All HIV positive mothers will be advised not to breastfeed their babies, as HIV can be passed on through breastmilk.

For more information, see *HIV, Pregnancy and Women's Health*, published by **HIV i-Base**. You can get a free copy through their web-site: [www.i-base.org.uk](http://www.i-base.org.uk)





## If you also have hepatitis

Liver infections can make HIV treatment more complex.

Hepatitis B and hepatitis C are infections which affect the liver. Some people with HIV also have hepatitis – this is known as “coinfection”. Blood tests are used to see if there is an infection. In its early stages, there may be no symptoms, but later on hepatitis can cause serious illness.

If you are coinfecting, you may need to see different doctors for hepatitis and HIV treatment. But your doctors should work closely together.

HIV makes hepatitis more serious. Compared to people who only have hepatitis, people who also have HIV are more likely to develop liver disease more quickly, and more severely.

Some anti-HIV drugs can harm the liver, so it's best to choose anti-HIV drugs which put less strain on the liver. Because alcohol can also damage the liver, it's also advisable to drink as little alcohol as you can.

Treatments are available for both infections, although not everyone will need them. Hepatitis B treatment may need to be taken on a long term basis. On the other hand, hepatitis C treatment usually only lasts 6 or 12 months, but its side effects can be severe. As anti-HIV drugs and anti-hepatitis C drugs can interact, doctors usually avoid giving both types of drugs at the same time.

For more information, see *HIV and Hepatitis*, a booklet published by **NAM (020 7840 0050)**.

## If you also have tuberculosis

Tuberculosis drugs need to be taken exactly as prescribed.

Tuberculosis (TB) is an infectious disease that can affect the lungs and other parts of the body. Some people are infected with both HIV and TB (“coinfection”), and TB is a common cause of serious illness for people with HIV.

TB infection can be either:

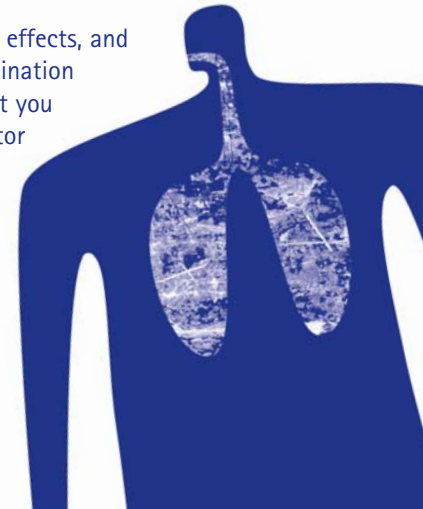
- **'latent' – at the moment, the immune system is able to control the infection, or**
- **'active' – the infection is causing illness.**

Active TB makes HIV worse – your CD4 count may go down, and your viral load may go up.

The good news is that drugs are available to treat active TB. It's often possible to be cured of TB, allowing much improved health in the future.

Anti-TB drugs can have side effects, and may interact with HIV combination therapy. So it's essential that you see both a specialist TB doctor and a specialist HIV doctor. They should work closely together.

TB is usually treated with several different drugs and there may a large number of pills to swallow.



Treatment usually lasts for 6–9 months, and may not be every single day.

But it's essential that every single dose is taken. After several weeks of treatment, you may start to feel a lot better, and might be tempted not to finish the whole course of treatment. If you stop early, you may still be infected with TB and you could get sick again later. See pages 19–27 of this booklet for more about taking medicines regularly.

For more information, see *HIV and TB*, a booklet published by **NAM (020 7840 0050)**.

### Keeping an eye on your health

**Screening:** your clinic can give you tests to check for hepatitis, tuberculosis and other infections.

**Vaccinations:** in order to prevent future infections, vaccinations against hepatitis B and the flu are available. These vaccinations are safe for people with HIV, but not all are – check with your doctor.

**Prophylaxis:** if your CD4 count is below 200, you may also take medicines each day to prevent specific infections.

# 6

## The HIV clinic

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## Getting the most from your doctor

An effective doctor–patient relationship is based on two-way communication.

HIV treatment is not always straightforward, and there are lots of choices to be made. If your doctor understands what's important to you and the way you live your life, you're more likely to get treatment that's suited to you.

HIV doctors are used to having patients who ask lots of tricky questions and get very involved in treatment decisions. Of course this is not everyone's style, and you may prefer to let your doctor take the lead.

Nonetheless, you can expect your doctor to:

- explain things clearly to you
- give you a range of options
- tell you about the risks and benefits of each option
- answer your questions in a way you understand
- pay attention to your concerns
- respect your confidentiality
- treat you as an individual, and
- offer you the best available treatments.

In return, it will help your doctor if you ask questions until you understand, tell him or her about your preferences, and are honest about problems you have taking medicines on time.



## Three ways to help

- 1 Come prepared.** Before your appointment, make a list of the issues and questions you want to discuss, so that you don't forget anything. You could even send this to the doctor beforehand.
- 2 Tell your doctor about any health problems you're having.** This includes illnesses, symptoms and side effects, as well as any difficulties you have taking your medicines. If the doctor doesn't know about problems, he or she can't do anything about them.
- 3 Get your blood tests done regularly.** They're vital for keeping an eye on your health. If you have them done a few weeks before your appointment, the results will be ready when you see the doctor.

Check-ups are usually every three to six months. Try to book your appointment in advance, and attend as planned. If you can't come, call the clinic in advance to fix a new date. If you turn up without an appointment, you may not be able to see your usual doctor.

If you see the same doctor regularly, you'll have a better chance of building up a good relationship.

Still, you won't necessarily feel completely comfortable with the first doctor you see. He or she may simply not be the right person for you. It's important to have a good relationship with your doctor, and if you're unhappy, you can simply ask to change to a different doctor at the same clinic.

## Who's who at the clinic

Apart from doctors, HIV clinics usually have a range of health professionals to help you.

Some of the other staff may be easier to see than your doctor, especially when you don't have an appointment. You might also find that there are particular members of staff who you feel particularly comfortable talking to.

**Staff nurses** do most of the routine examinations and tests, and will need to ask you questions about your health. They'll be able to answer many of your questions about HIV and treatments.

**Nurse specialists** have more in-depth knowledge. For example, they can advise you on dealing with drug side effects, and on fitting treatments into your lifestyle. At some clinics, if your health is stable, you might have your regular check-up with a nurse specialist, rather than a doctor. They may be able to put you in touch with a social worker, psychologist or other support service.

**Pharmacists** not only give you your drugs, but can advise you on dealing with any difficulties you have taking medicines – fitting them into your routine, dealing with food restrictions, dealing with side effects, storing the drugs, and travelling with them. If you have problems with the size, texture or taste of pills, the pharmacist may be able to suggest some changes. They can also tell you about drug interactions.

**Dietitians** can give you advice about food and nutrition – whether you need to lose weight, put on weight, or get more nutrients. They can also help if nausea, diarrhoea or illness make it difficult for you to eat properly, or if you have to take your treatment with certain types of food.

**Health advisers** can give you advice about safer sex, sexually transmitted infections and sexual problems.

**'Emergency' or 'walk-in' doctors** may be available if you have a problem between check-ups and need to see someone quickly. You may not be able to see your usual doctor.

### General practitioners (GPs or family doctors)

If you have health problems that are not connected with HIV, your clinic may ask you to get these treated by a GP. If you feel able to tell your GP that you have HIV, he or she will be able to check that medicines prescribed are safe to take with combination therapy. Your clinic may be able to recommend a GP who has experience of patients with HIV.

## Common lab tests

A guide to some of the most useful blood tests.

### Viral load

The number of copies of HIV in a sample of blood (see page 9).

### CD4 cell count

A measure of the strength of the immune system (see page 9).

### CD4 percentage

A different way of measuring CD4, which some say is more accurate. Higher percentages show a stronger immune system.

### Resistance tests

Check to see if drug resistance is a problem. There are two types of resistance tests. Genotype tests look at how your virus is different from the normal 'wild type' virus, and suggest which drugs might work. Phenotype tests add an anti-HIV drug to a sample of your virus, and show how sensitive or resistant your virus is to that drug. (see pages 18 and 21).



### Therapeutic drug monitoring

Shows what is the correct drug dose for you.

### Blood counts

Identify a range of health problems, including anaemia (a shortage of red blood cells).

### Tests to check for drug side effects

A wide range of tests are used to identify any problems with your liver, kidneys, blood sugars and blood fats.

### Sexually transmitted infections

The clinic may do routine tests for syphilis and hepatitis B, but might not check for other infections. If you're having sex, it's worth asking to have a complete check-up.

### Clinical Trials

You might be asked if you want to take part in a research trial. This could involve taking new drugs that haven't been fully tested before. They might be much better than the drugs currently available – or they could turn out to be less effective. **Remember that it's your choice whether to take part or not.**

## Getting more information and support

**Terrence Higgins Trust** provides information on a wide range of issues for people with HIV. THT Direct can give support and advice, and tell you about local services.

**THT Direct: 0845 12 21 200**  
[www.tht.org.uk](http://www.tht.org.uk)

**NAM** provides more detailed treatments information and publishes a free newsletter, *AIDS Treatment Update*.  
**020 7840 0050** (office number)  
[www.aidsmap.com](http://www.aidsmap.com)

**HIV i-Base** is another good source of treatment information. Their treatments phoneline is open Mondays to Wednesdays from 12pm to 4pm.  
**Treatments phoneline: 0808 800 6013**  
[www.i-base.org.uk](http://www.i-base.org.uk)

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

**THT DIRECT** > 0845 12 21 200  
[www.tht.org.uk](http://www.tht.org.uk)

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