

Taking your HIV treatment



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This is an interactive booklet.

All page numbers, either on the contents page or mentioned within the booklet, are clickable. You can also click on the names of resources and organisations to go to the relevant web pages.

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

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

This booklet provides basic information about how HIV treatment works, what taking it involves and how to manage it in your life.

You'll get the most benefit from your treatment if you take each dose at the right time, in the right way (often described as 'adherence'). The booklet gives some advice to help you to do this and explains what can happen if doses are missed, including drug resistance.

This booklet is not intended to replace discussion with your doctor, nurse or pharmacist. But it can be a starting point for those discussions.

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The aim of HIV treatment

HIV is a virus that attacks the body's defence against infection and illness – the immune system. If you are living with HIV, you can take drugs to reduce the amount of HIV in your body.

By taking these anti-HIV drugs, you can slow down or prevent damage to your immune system. By protecting your immune system earlier, you can help prevent health problems occurring now and in the future. These drugs are not a cure, but they can keep the virus under control, helping you stay well and lead a longer and healthier life.

Anti-HIV medications are known as antiretroviral drugs, or antiretroviral therapy (ART).

HIV mainly affects cells in the immune system called CD4 cells. Over many years of untreated HIV infection, the number of CD4 cells drops gradually and the immune system is weakened. Without treatment, the immune system becomes unable to fight infections leading to a condition called AIDS (Acquired Immune Deficiency Syndrome).

Antiretroviral drugs work by interrupting this process. In people who are diagnosed in good time, AIDS is now extremely rare.

Someone living with HIV who isn't taking HIV treatment may have thousands, or even millions, of HIV particles ('copies') in every millilitre of blood, which are replicating all the time. The aim of treatment is to reduce the amount of HIV (known as the 'viral load') to very low levels; when this level reaches below 50 copies per millilitre, this is called an 'undetectable' viral load.



"Once your viral load has become undetectable, your immune system should slowly begin to recover."

To give you the best chance of reducing the amount of HIV in your blood to an undetectable level, your doctor will usually recommend that you take an effective combination of antiretroviral drugs. This is usually three drugs ('triple therapy') but some newer combinations use two drugs only.

Once your viral load has become undetectable, your immune system should slowly begin to recover. In addition to keeping you well and preventing damage to your immune system, taking treatment and having an undetectable viral load also prevents HIV from being passed on to someone else during sex.

Regular check-ups

Regular appointments with your doctor will be used to monitor your health, especially the results of blood tests.

Even if you decide not to start treatment yet, it's important to come in for all of these check-ups.

If you've recently tested positive or have recently started treatment, these appointments may initially be quite frequent. When things are more stable, a check-up every six months is normal.



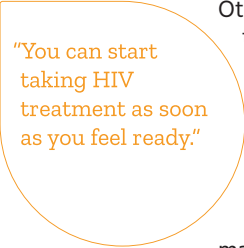
When to start treatment

The sooner you start to take HIV treatment, the sooner you can benefit from it. HIV treatment guidelines, both in the UK and elsewhere in the world, recommend that all people with HIV should take HIV treatment, regardless of their CD4 count.

You can start taking HIV treatment as soon as you feel ready.

In 2015 a large, well-conducted study demonstrated that there are advantages to starting treatment as soon as possible, even with high CD4 cell counts. The study clearly demonstrated that starting HIV treatment earlier is beneficial and reduces the risk of most serious illnesses. While people sometimes worry about the side effects of anti-HIV drugs, the study also showed that people who began HIV treatment earlier had a better quality of life than people who waited.

Another important benefit of starting treatment is that it usually suppresses the amount of HIV in your body fluids to an 'undetectable' level. Having an undetectable viral load means that there is not enough HIV in your body fluids to pass HIV on during sex. In other words, you are not infectious.



"You can start taking HIV treatment as soon as you feel ready."

Other research has shown that with HIV treatment, many people living with HIV can have a relatively normal lifespan.

If your CD4 cell count is below 200, it is especially important that you begin HIV treatment as soon as possible.

The lower your CD4 cell count, the greater the risk of infections and HIV making you ill.

Similarly, if you have caught HIV very recently – within the past three months – your doctor is likely to encourage you to start treatment without delay. This is because some people can become seriously ill soon after infection. Starting treatment very soon after infection reduces the chances of illness. It also gives you the best chance of having a normal immune system while living with HIV.

While the medical case for starting treatment as soon as possible is clear cut for most people, the decision to start treatment rests with the person living with HIV. Before starting treatment, it's important that you understand how it works and what it involves. You may need a little time before you feel ready to start.

Why taking your HIV treatment properly is important

To allow HIV treatment to work properly, it's important that you take your HIV medication as prescribed.

This is often called 'adherence', and it means taking the drugs at the right times, at the right dose, and following any advice about food restrictions. Adherence is the most important factor under your control in the success of your HIV treatment.

Not taking your HIV treatment properly could mean that:

- The levels of the drugs in your blood are not high enough to effectively fight against HIV. If this happens, your HIV will be able to replicate.
- Your viral load will increase and your CD4 cell count (an important indicator of the health of your immune system) will fall. This situation increases your chances of becoming ill because of HIV.

- Your HIV develops resistance to one or more anti-HIV drugs. The strains of HIV that reproduce when you're taking HIV treatment may be resistant to the drugs you are taking. Resistance can mean that your HIV treatment won't work effectively (see page 58).
- Your HIV may also become resistant to drugs similar to those you are currently taking (that is, in the same 'class' of drugs). This is called cross-resistance and the risk varies between different classes of HIV drugs.
- Your viral load will increase to a level at which you may pass HIV on to a sexual partner (if condoms or pre-exposure prophylaxis – PrEP – are not being used).
- You would then need to change your HIV treatment. This new treatment might be more difficult to take than the combination you were taking before. It might have more, or new, side effects.

Preparing to start HIV treatment

There are now over 20 anti-HIV medications available, and a number of recommended options for people starting HIV treatment (see page 24).

This means that you and your doctor will usually be able to find a combination that best suits your circumstances and lifestyle.

Your doctor should consider your medical history, potential side effects, and possible interactions with other medicines and drugs. Taking your individual needs and preferences into account can help ensure that you start on a drug combination that is right for you.

"Your doctor can help ensure that you start on a drug combination that is right for you."

For example:

- Some tablets need to be taken with food, which works best for people who eat around the same time each day.
- If you don't have a daily routine, do shift work or often travel away from home, this could affect your choice of medications.
- If you have any concerns about privacy and storing medication, either at home or at work, your doctor can take this into account.

It's a good idea to think about how taking medication will fit in with your work, family and social life. Discuss your day-to-day life with your doctor, nurse or pharmacist to help establish the best times to take your anti-HIV drugs and to identify any concerns before you start treatment.

How many pills and doses will I need to take?

Initial HIV treatment for most people consists of between one and three pills, once a day.

Medicines from the four main classes of anti-HIV drugs (nucleoside/nucleotide reverse transcriptase inhibitors or NRTIs; non-nucleoside reverse transcriptase inhibitors or NNRTIs; integrase inhibitors; and protease inhibitors) are available in forms that need to be taken just once a day. There are also some HIV treatments in which several medications are combined into a single pill that is taken once a day.

While research has shown equally high levels of adherence in people taking once- and twice-daily treatment, if you have a preference for one of these, it is best to discuss it with your doctor.

Some people have difficulty swallowing pills, taking large numbers of pills or remembering to take more than one dose a day. If this is the case for you, choosing the simplest combination, with the fewest pills or doses, is likely to boost your chance of taking your treatment properly.

The NAM booklet *Anti-HIV drugs* and the online tool *My drugs chart* provide information about the dosing requirements of each of the most commonly used anti-HIV medications.

What else is going on in your life?

A wide range of factors can have an influence on how well you adhere to your HIV treatment. These differ between people, can change over time and aren't always directly related to your health.

What's happening in other areas of your life can affect your ability to take your treatment properly. Feeling isolated or alone, or having worries about money, housing or work can make it harder to take your HIV treatment properly. These concerns may seem more pressing and important than looking after your health.

Emotional distress and mental health problems, such as depression, have also been linked to people not taking HIV treatment properly. Drug use or problems with alcohol can also lead to low levels of adherence to HIV treatment.

If you are affected by any of these issues, it's worth talking to your doctor or another member of your healthcare team about them. They will often be able to provide extra information, help or support.

You may find NAM's online tool *Get set for HIV treatment* a helpful way to think through the issues that might affect your ability to start and stick to treatment.

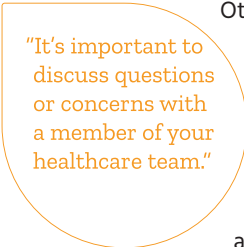
Being involved in decisions about your treatment

You are more likely to take your HIV treatment correctly if you are involved in the decisions about when to start treatment and about which drugs to start treatment with.

If you have questions or concerns about how effective HIV treatment is or its possible side effects, it's important to discuss them with a member of your healthcare team.

Your doctor should take time to talk through with you why you need to start or change HIV treatment. You can expect your doctor to explain things clearly, give you a range of options, pay attention to your concerns and answer your questions in a way you understand.

You can ask for written information to take away and read about any treatment you are considering. It's a good idea to ask questions if you are unclear about anything and to keep on asking questions until you understand. You may find it helpful to write down any questions you have before you go to your appointment, as it is easy to forget them once you are in a consultation.



"It's important to discuss questions or concerns with a member of your healthcare team."

Other members of the healthcare team at your clinic, particularly specialist HIV pharmacists, health advisers and nurses are good sources of information and support when starting or changing treatment. Some clinics can arrange for you to have 'peer support' (support and advice from someone else living with HIV) and all clinics will be able to tell you about support groups in your area if you think you would like to try one.

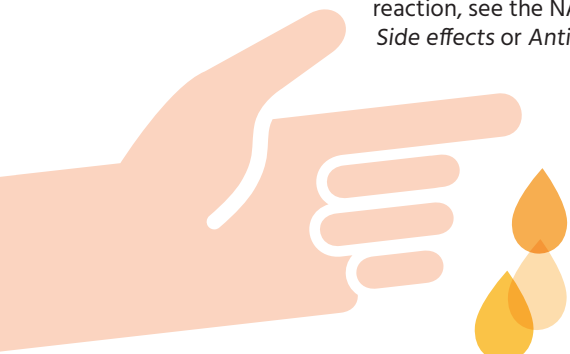
You can find out about some other reliable sources of information at the end of this booklet (see page 68).

Blood tests before starting or changing HIV treatment

Before you start taking HIV treatment, or if you need to switch to a new combination, you should have a number of blood tests.

To help make sure that you start with an effective combination of anti-HIV medications, you should have a blood test to see if your HIV has resistance to any antiretroviral drugs. This is because it is possible for a strain of HIV that has already developed resistance to some drugs to be passed on to someone who has not taken those drugs.

Your clinic will usually also do a genetic test (called HLA-B*5701) to see if you are more likely to develop an allergic (hypersensitivity) reaction to the anti-HIV medication abacavir (*Ziagen*, also in the combination pills *Kivexa* and *Trizivir*). For more information on this hypersensitivity reaction, see the NAM booklets *Side effects* or *Anti-HIV drugs*.



Your clinic will also test you for hepatitis B and C, and run tests to look at your blood sugars, as well as the health of your liver and kidneys. The results of these tests will help you and your doctor decide the best treatment for you, and when you should start.

Viral load and CD4 tests will tell you about the health of your immune system and if your treatment is working effectively.

When you start or change a drug combination, a viral load test will be done within the first month, to check that the treatment is working. After this, testing is generally performed every three to six months, although it may be more often to begin with and then less frequently once you are stable on treatment and doing well.

If you need to change HIV treatment because your viral load becomes detectable again (see page 64), your choice of new medications should be guided by having another resistance test at this stage to see which drugs will work for you.

"Once you are on HIV treatment, you will continue to have tests to assess any effects of the drugs on your system."

If you need to change treatment because your current HIV treatment isn't controlling your viral load, it's important that you do this in good time to reduce the risk of resistance. How quickly you need to do this will depend on which anti-HIV drugs you are taking; your healthcare team will discuss this with you.

Even if you have resistance to several drugs, the range of anti-HIV drugs available now means there will still be options for you. An undetectable viral load is a realistic objective for nearly everyone, including people who have taken a lot of different treatments in the past and have drug-resistant virus. You can find out more about drug resistance and resistance testing later in this booklet (see page 58).

Once you are on HIV treatment, you will continue to have tests to measure liver and kidney function, and the levels of fat (cholesterol) and sugar in your blood, to assess any effects of the drugs on these systems. Some of these are done every time you attend and some once a year.

In some situations, your doctor may start or switch your treatment before results of all the tests are known. If this is the case, your doctor should discuss this with you. You should still be given the results of all your tests when they are available.

Your HIV care will also involve a number of other routine tests. These will monitor your general health, to see if your treatment is causing any side effects.

For more information about regular health monitoring, see NAM's booklet *CD4, viral load & other tests*.

Recommended treatments for HIV

Guidelines from the British HIV Association (BHIVA) list a range of options for people taking HIV treatment. The information below is based on the 2022 draft guidelines.

Most people take a combination of three antiretroviral medications, although some two-drug combinations are now also possible.

In a three-drug combination, two of the medications are sometimes called ‘backbone’ of the combination. They are two drugs from the nucleoside/nucleotide reverse transcriptase inhibitor (NRTI) class.

BHIVA usually recommends a backbone of tenofovir and emtricitabine. (Two versions of tenofovir are available: the older formulation is called tenofovir disoproxil, while the new formulation is tenofovir alafenamide). The backbone must be taken together with a third medication.

The recommended first-line HIV treatments for most people all include an integrase inhibitor: either dolutegravir or bictegravir. It is usually taken together with a nucleotide backbone as part of a three-drug combination.

There are five options:

Dolutegravir / tenofovir disoproxil / emtricitabine

This is usually taken as two pills: *Tivicay* contains dolutegravir, and a pill from a generic manufacturer contains the other two drugs.

Dolutegravir / tenofovir alafenamide / emtricitabine

This is usually taken as two pills: *Tivicay* contains dolutegravir, while *Descovy* contains the other two drugs.

Bictegravir / tenofovir alafenamide / emtricitabine

This is usually taken as one pill, called *Biktarvy*.

Dolutegravir / abacavir / lamivudine

This is usually taken as one pill, called *Triumeq*.

Dolutegravir / lamivudine

This combination includes two drugs, not three. It is usually taken as one pill, called *Dovato*.

Other recommended medications

If the combinations listed above are not suitable for you, or in some other clinical situations, other drugs may be used.

In addition to a ‘backbone’ of **tenofovir** and **emtricitabine**, options for the third medication include **darunavir** (a boosted protease inhibitor), **raltegravir** (an integrase inhibitor) and **doravirine** (a non-nucleoside reverse transcriptase inhibitor, or NNRTI). If you are pregnant or taking tuberculosis treatment, **efavirenz** (a non-nucleoside reverse transcriptase inhibitor) may be taken. In this case, the backbone could be abacavir and lamivudine.

The guidelines also include recommendations for medications if you are changing to a different combination and you have an undetectable viral load. **All of the medications previously mentioned are options.**

In addition, the nucleoside backbone could be **abacavir and lamivudine**, rather than tenofovir and emtricitabine.

Together with the backbone, the following third medications can be used: **elvitegravir** (an integrase inhibitor), **rilpivirine** (a non-nucleoside reverse transcriptase inhibitor), **atazanavir** (a boosted protease inhibitor) and **lopinavir** (a boosted protease inhibitor).

Finally, some two-drug combinations are recommended for people changing treatment. You do not need to take a nucleoside backbone with these.

Cabotegravir and **rilpivirine** are injectable medications, taken every two months. The injections combine an integrase inhibitor with a non-nucleoside reverse transcriptase inhibitor.

As daily tablets, **dolutegravir** (an integrase inhibitor) may be taken with either **lamivudine** (a nucleoside reverse transcriptase inhibitor) or **rilpivirine** (a non-nucleoside reverse transcriptase inhibitor). Finally, a **boosted protease inhibitor** can be taken with **lamivudine**. Protease inhibitors include darunavir, atazanavir and lopinavir.

You can find out more about these medications in NAM’s booklet *Anti-HIV drugs*.

Side effects

Like all medications, anti-HIV drugs can cause side effects, and these can be a reason why people don't take their treatment properly.

The risk of side effects can vary between people and between drugs. It isn't inevitable that your HIV treatment will cause side effects.

However, side effects do happen. If you are concerned about the risk of developing a particular side effect, mention this to your HIV doctor. You'll be able to discuss your concerns, and it may be possible to choose a treatment that doesn't cause the side effect you are worried about.

Quite often, any side effects are mild and happen during the first few weeks of treatment, either becoming more tolerable or going away completely with time.

Your doctor can prescribe a number of medications to help you cope with this initial period if necessary.

Side effects most commonly reported include headache, nausea, diarrhoea, and tiredness. You don't have to 'grin and bear' it – tell your doctor, especially if side effects are interfering with your quality of life. There may be ways of managing them, or other drugs you can try that will suit you better.

"Most side effects are mild and happen during the first few weeks of treatment."

Don't miss doses of your treatment in an attempt to avoid side effects. If you develop a side effect, you shouldn't stop taking your HIV treatment, but do talk to your HIV doctor.

If side effects do persist, changing treatment may be an option. If your viral load is undetectable and you have no resistance to anti-HIV drugs then you should be able to stop the drug that is causing your side effects and switch to a different treatment. But don't do this without first speaking to your doctor.

As all anti-HIV drugs can cause side effects, it is possible that the drug you switch to might have other side effects. There is also a chance that you might not find your treatment easier to take or that it is not as effective as your previous treatment. If this happens, your doctor should be able to find a more suitable combination, or switch you back to the medication you were on before.

Some anti-HIV medications have a very small risk of causing a serious allergic (hypersensitivity) reaction. Certain side effects, such as rash in combination with other symptoms such as a fever can be a sign of this hypersensitivity reaction. Contact your HIV clinic immediately (or A&E if out of hours) if you begin to develop a rash with a fever, or feel seriously unwell after starting a new anti-HIV drug. You can find out more about hypersensitivity reactions in NAM's booklets *Side effects* or *Anti-HIV drugs*.

You will be monitored at your regular HIV clinic visits to see if any side effects might be causing you to develop longer-term health problems.

You can find out more about side effects and how to deal with them in NAM's booklet *Side effects*.

HIV treatment, pregnancy and contraception

When HIV treatment is used during pregnancy, it protects your health as well as playing an important role in preventing HIV being passed on from you to your baby during pregnancy and birth.

In the UK, because of high standards of care, the risk of mother-to-child transmission is very low. For women who have been diagnosed and who receive the right advice, treatment and care, the risk is below 1%. For women who are on effective HIV treatment and who have an undetectable viral load, the risk of transmission to their baby is 0.1%, or one in a thousand.

If you are thinking about becoming pregnant, it's recommended you discuss this with your healthcare team before you try to conceive. You should tell your HIV doctor or another member of your healthcare team immediately if you become pregnant.

You can discuss your treatment options with them, and they will often help to arrange your antenatal care and work with other staff, such as an obstetrician and an HIV specialist midwife, to ensure you get the appropriate care.

Increasingly, evidence suggests that being on HIV treatment during pregnancy is not harmful. Taking HIV treatment during pregnancy greatly reduces the risk of passing on HIV to the baby, so the benefits outweigh any risks. More information continues to be collected on the use of anti-HIV medications during pregnancy; there are some drugs with more safety information available than others. Your doctor will discuss these options with you.

The HIV treatment taken by a father at the time of conception will not affect the baby.

If you are not already on treatment, your doctor will recommend that you start treatment at week 12 of your pregnancy or soon after, unless you have a high viral load.

If your viral load is high, your doctor will encourage you to start treatment immediately to give you the best chance of having an undetectable viral load by the time you give birth.



"HIV treatment taken by a father at the time of conception will not affect the baby."

Adhering to your treatment can be especially difficult during pregnancy or in the period after giving birth. It therefore makes very good sense to tell someone at your HIV clinic if you have any concerns or questions about your treatment or are missing doses. Help will be available. Good adherence to your treatment at this time will help reduce the risk of mother-to-child transmission of HIV to very low levels and also protect your own health.

Some forms of hormonal contraception, including patches and implants, are less effective in women on many anti-HIV medications, because of drug interactions. Most other forms of contraception are unaffected by having HIV or being on HIV treatment and some new drugs do not affect contraception. You can find out more about contraception options from your HIV clinic.

You can find out more about HIV treatment, pregnancy and contraception in the booklet in this series, *HIV & women*.

How anti-HIV drugs are dispensed

Most people living with HIV in the UK attend specialist HIV clinics or sexual health clinics, which can be found in most areas of the country. Most HIV clinics are 'open access'.

This means that you don't need a referral from your GP (family doctor) or anyone else to use one. You can simply phone up and ask to register as a patient. You choose which HIV clinic to use.

GPs are not able to prescribe antiretroviral drugs.

You will get a prescription for your HIV treatment at your HIV clinic. Take this to either the specialist HIV pharmacy (in larger clinics) or to the hospital's outpatient pharmacy. A high-street chemist will not dispense anti-HIV medications, unless your clinic has an agreement with a community pharmacy.

"You can collect prescriptions for your HIV treatment from a specialist HIV pharmacy."

You should be given supplies to last until your next clinic appointment. Once you are stable on HIV treatment, with an undetectable viral load, your clinic will often suggest you receive your anti-HIV drugs by delivery to a place of your choice or by collection from a community pharmacy.

By delivering your HIV treatment in this way, your clinic can save money. However you will still need to attend regular HIV clinic appointments to have your health monitored.

Always make sure you have enough medication to last until your next clinic appointment, as well as a small supply of spares, at home. If you think you might run out before this, contact your clinic as soon as possible to arrange a further supply until your next appointment.

"All HIV care and medications provided by the NHS are free."

The pharmacist will ask you if you are allergic to any medicines and explain how to take the drugs that have been prescribed to you. Pharmacists can help you with managing your medication use, including adherence, side effects, drug interactions, food and drink requirements, storage, pill swallowing, and advice on taking your medicines while travelling. In England, all HIV care and the anti-HIV medications provided through NHS HIV clinics and sexual health clinics are free (including no prescription charge), whatever someone's immigration status is. In Scotland, Wales and Northern Ireland, people are not normally charged for HIV treatment and care, although the law still says they can be if they are of uncertain immigration status.

An HIV support organisation can help you if you are concerned about being charged for treatment. You can look for support organisations in the HIV services finder at www.aidsmap.com/uk-service-finder



Generic medicines

Before a medicine can be widely used in the UK, it must be granted a licence.

This licence indicates that checks have been carried out on the drug's safety and efficacy, and the benefits of the drug are believed to outweigh the risks. In addition to a licence, a pharmaceutical company that is developing a new drug will have a patent that gives it exclusive rights to manufacture it for a period of time. Companies usually market their drug with a brand name, but the drug will also have a name for the 'active' ingredient. This is called the generic name.

After the patent expires, other companies can produce their own version of the same medication. These are called generic drugs. They contain the same active ingredient as the branded products, and they have the same detailed safety and quality requirements as the original product. However, they are usually cheaper because there are fewer research and development costs.

Where possible, the NHS prescribes generic versions of drugs – they work just as well as branded medications, and the money saved can pay for other treatments and services.

"The appearance of your drugs may change occasionally, but the generic name will stay the same."

The original patents for many anti-HIV medications have expired and generic versions of them are available. You may find that you are prescribed a generic drug as part of your HIV treatment. It may have a different appearance – it might be a different colour or shape, for example – the packaging will differ and it will have a different brand name or no brand name at all.

Because more than one company can manufacture generic medications, sometimes your clinic might change which version it buys. As a result, the appearance of the drug may change occasionally, but the generic name (the name of the active ingredient) will stay the same. You should be warned about this but ask your HIV doctor or pharmacist if you have any queries.

Always check the name of the active ingredient, the strength of the tablet or capsule, and the instructions on the dispensing label, which will tell you how many pills to take and how often. If any of these details have changed, it is important to confirm the dosing with your HIV pharmacy team.

What does taking your HIV treatment involve?

Taking your drugs as prescribed is often called ‘adherence’.

Adherence to your HIV treatment means:

- Taking all the medicines that make up your HIV treatment combination in the right quantities.
- Taking your medicines at the right time, as close as possible to the same time each day. Usually, this means taking the drug within a two-hour window (up to one hour either side of the set time).
- Following any instructions about food. Some medicines need to be taken with food so they are absorbed properly, but others need to be taken on an empty stomach (see page 44).
- Checking for interactions with other medicines or drugs. This includes medicines that a doctor prescribes to you, over-the-counter products, herbal and alternative medicines, and recreational drugs (see page 46).

Does it matter if I miss some doses of my HIV treatment?

You should aim to take your pills at the same time each day so that it becomes a habit.

If you are used to taking all or nearly all of your antiretrovirals at the right time and in the right way, you are much better placed if you have a problem such as forgetting a dose, being away for a night without your medication, or running out of pills. If you have already missed a significant number of doses and something like this happens, things are more likely to go wrong.

In studies, missing doses has been associated with an increase in viral load, a fall in CD4 cell count, and an increased risk of resistance. The best results of HIV treatment are seen in people who take all, or nearly all, of the doses of their drugs in the right way.

What should I do if I miss a dose of my HIV treatment?

While you should try to take every dose of your medication as prescribed, most people taking HIV treatment occasionally forget to take a dose or take it late.

What you should do about a missed dose will depend on the circumstances. In most cases, the safest option is to take the missed dose as soon as you realise and then to return to your normal schedule. If you only realise you have missed a dose when you come to the next dose, take the normal dose. Do not take a double dose to compensate for the one you have missed.

If you miss a dose and are not sure what to do, it's a good idea to ring your clinic for advice.

If you vomit (are sick) after taking your HIV treatment, you generally do not need to take another dose, as the drugs will already have been absorbed into your body. Exceptions to this are if it is less than two hours since you took your anti-HIV medications (or less than four hours if you are taking *Eviplera* or rilpivirine), or if you see the pills, or bits of them, in the vomit.

"Take the missed dose as soon as you realise and then return to your normal schedule."

If you are regularly missing doses of your medication, or taking them late, talk about this with your doctor or other staff at your clinic. Your clinic will be able to offer advice and support. In some cases, it may make sense for you to change your treatment to a drug combination with a lower risk of resistance.

"Your clinic will be able to offer advice on any food or drink requirements of your anti-HIV medications."

What food requirements are there with anti-HIV medications?

With many anti-HIV drugs, it doesn't matter if they are taken with or without food. However, some HIV drugs need to be taken with food to be most effective.

Some people find it difficult to take their HIV treatment on an empty stomach because this means not eating for a certain amount of time before or after taking their medicines. Other people prefer to not have to take their anti-HIV medications with food because this reduces flexibility about the times they can eat meals. You may not want people you are eating meals with to see you taking your medications (although you can usually take your tablets within a short period before or after eating if they need to be taken with food).

If you have to take your HIV treatment with food, it's useful to know that it's usually not necessary to eat a full meal. Some solid food, such as a bowl of cereal, is usually sufficient. Rilpivirine (*Edurant*, also in *Eviplera*) is the exception and must be taken with a meal. Ask your doctor, pharmacist or another member of your clinic team about how much food you need to take with your anti-HIV medications.

It is recommended that the anti-HIV drug efavirenz (*Sustiva*, also in *Atripla*) is taken on an empty stomach. This means having a two-hour gap between eating and taking your medication. You should then wait at least one hour before eating again. Taking your pills just before you go to bed can work well and can also reduce the impact of some of efavirenz's side effects. Some people find that taking efavirenz with food also reduces side effects, but avoid taking it with a high-fat meal, which increases absorption of the drug.

If you have a preference or concerns about food restrictions, it makes good sense to let your doctor know this so that you can be prescribed the most appropriate treatment.

Staff at your clinic will be able to offer advice on managing any food or drink requirements of your anti-HIV medications.

There's information on the food requirements of HIV treatment in the NAM booklets *Nutrition* and *Anti-HIV drugs* and in the online tool *My drugs chart*.

"You can find out more about possible interactions with medications in NAM's booklet *Anti-HIV drugs*."

How can I avoid drug interactions?

Many people with HIV need to take medicines to treat other health conditions. Taking two or more different drugs together may result in an alteration in the effectiveness or in the side effects of one or more of the drugs. Some drugs should not be taken in combination with certain antiretrovirals.

It is important that anyone prescribing or dispensing medication knows about all other medicines and drugs that you are taking – this includes those prescribed by another doctor, over-the-counter medicines (including inhalers and nasal sprays), herbal and alternative treatments, and recreational drugs.

Some drug combinations are contraindicated – which means you definitely should not take them together. Reasons for this include serious side effects, or interactions which make one or both drugs ineffective or toxic.

Other interactions are less dangerous, but still need to be taken seriously. Levels of one or both drugs in your blood may be affected and you may need to change the doses you take.

Checking for interactions

Your HIV doctor and pharmacist will check for possible interactions before they prescribe a new medication for you. You can help them do this by keeping a list of all the medicines and drugs you take (note down the name of each drug and what you take it for). Bring it with you whenever you see a doctor or pharmacist.

You can find out more about possible interactions with individual medications in NAM's booklet *Anti-HIV drugs*.

The University of Liverpool provides an online tool to check for interactions between anti-HIV drugs, other medications and recreational drugs. You enter the names of the medication you are taking and the results are provided with a traffic-light system: if the result is red or amber, it's worth checking with your doctor or pharmacist. If it's green, there shouldn't be any problem. Visit **www.hiv-druginteractions.org/checker** or download the Liverpool HIV iChart app for iPhone or Android.

Erectile dysfunction If any other healthcare professional prescribes or recommends a medicine for you, it's important that they know about the drugs you are taking for your HIV. For example, it's known that treatments for erectile dysfunction (such as *Viagra*) can interact with types of anti-HIV drugs that belong to the drug classes protease inhibitors and non-nucleoside reverse transcriptase inhibitors (NNRTIs). Interactions with protease inhibitors can increase blood levels of *Viagra* and similar drugs, increasing the risk of side effects.

Over-the-counter medicines You also need to tell your HIV doctor about any drugs you buy over the counter (at a chemist, for example) or from the internet. Some anti-HIV drugs can interact with antihistamines, asthma inhalers or nasal sprays (which contain steroids), treatments for indigestion and statins (drugs that are used to control cholesterol, or lipid levels). These treatments can either be prescribed or bought over the counter at high-street chemists (community pharmacies).

If you are thinking of using any other drugs, you should tell your HIV doctor or pharmacist, so they can check for possible interactions and recommend the most suitable treatment. Or, when you are buying them, you may wish to tell the pharmacist about the anti-HIV medications you are taking. Community pharmacies often have a private area for consultations, or you could write the name of the drugs down and hand it to the pharmacist. If you do need to mention the name of your anti-HIV drugs, it's very unlikely that anyone around you will recognise what they are used to treat.

Recreational drugs Less is known about interactions with recreational drugs. But there are potential interactions between some recreational drugs (for example, ketamine, ecstasy and methamphetamine [crystal meth]) and some NNRTIs and protease inhibitors. If you use recreational drugs, it is sensible to discuss this with your doctor, HIV pharmacist or other healthcare provider. For more information, read *Interactions between HIV treatment and recreational drugs* on www.aidsmap.com.

Alternative treatments Anti-HIV medications can also interact with herbal and alternative treatments.

For example, St John's wort, a herbal remedy used to treat anxiety and depression, lowers blood levels of NNRTIs and protease inhibitors. It can cause them not to work effectively and there's a risk of developing resistance.

In many cases, the interactions are theoretical, or seen in test-tube studies, and more information is needed about the likelihood of a real-life effect. For example, test-tube studies have indicated that African potato and Sutherlandia may reduce levels of protease inhibitors, NNRTIs and maraviroc (*Celsentri*) in the body.

Inhalers and sprays Interactions can also happen with medicines that are not taken by mouth. For example, ritonavir and cobicistat can interact with inhalers and nasal sprays containing fluticasone, budesonide, mometasone, or salmeterol (e.g. *Flixotide*, *Flixonase*, *Pulmicort*, *Seretide*, *Serevent*, *Nasonex*, *Pirinase*), used to treat asthma and hay fever, potentially causing serious side effects. Cetirizine (*Piriteze*, *Benadryl One-A-Day*, *Zirtek* and *Pollenshield*) is a safe antihistamine to take with anti-HIV medications and can be bought over the counter or prescribed by your GP.

Painkillers You can safely take some painkillers, such as paracetamol, when on anti-HIV medications, unless there are other medical reasons why you shouldn't take this sort of drug. Check with your HIV doctor or pharmacist about the best type of painkiller for you.

Make sure you tell your clinic doctor and HIV pharmacist about **all the medicines you are taking. This includes prescribed medicines, medicines you buy from a chemist, herbal or traditional medicines, and recreational drugs. It's important to check for possible interactions before taking anything new (whether you buy it yourself or have it prescribed by a doctor or dentist).**

Adherence tips

A common reason why people miss doses of their anti-HIV drugs is because they simply forget to take them.

If you forget to take a dose of your medication, try to learn from the experience so you can reduce the risk of it happening again. What was happening that meant you forgot?

Practice before you start Some people have found that taking 'practice' doses of sweets or multivitamins for a few weeks in the same quantities, and at the same time as you will have to take your anti-HIV medications regimen, helps them to adhere to their actual regimen when they start it. While practising, you should also stick to any food restrictions that you will need to follow.

Link your doses with a daily activity It may be easier to form the habit of taking your HIV treatment if you combine it with another established habit, such as brushing your teeth, having dinner or going to bed.

Use a pill box Lots of people find pill boxes useful. These have separate compartments into which you can put each dose of your medicine. Some people find it helpful to fill their pill box at the start of the week so they can keep track of what they need to take, when.

Especially if you are taking a large number of medicines at different times of the day, a pill box with compartments for the days of the week and times of the day may be useful.

Pill boxes might be available for free from your HIV clinic or you can buy them from high-street chemists. Check with your pharmacist that all your medications are suitable for storing out of their original containers. Some pills deteriorate if not kept correctly. The bottle that *Truvada* comes in, for instance, contains a small capsule that keeps the tablets dry.

Set a reminder on your phone Some people find that setting an alarm on their mobile phone or watch helps them to remember to take their medication. There are also some smartphone apps available which will send you a reminder.

- Ask someone to help** If you live with someone who knows about your HIV status, perhaps your partner, a family member or flatmate, you could ask them to help you remember to take your medication.
- Keep a diary** You could try keeping a diary where you record taking each dose of your medicine or use a calendar and tick each day as you take your pills.
- Have spare doses available** Keeping spare doses of pills in a suitable container in your bag, jacket pocket, at work or college, at a friend's or in the glove compartment of your car can mean that you have a dose available if you forget to take your pills or are unexpectedly away from home. It's important to make sure that medicines are stored out of the reach of children. Remember also that medicines can go out of date.
- Plan for nights out** If you are going out for the night and think that there is a chance that you may not go home before your next medication dose, take enough medication with you to cover that period. Be aware that nightclub door staff may not be able to recognise prescription medication and you might be asked about it.

- If you are planning to drink alcohol or take drugs which might affect your memory, try to plan in advance how you might overcome this. This could involve setting an alarm on your phone or telling a friend to remind you when it is time to take your medication. If you are concerned about possible interactions between your HIV medication and recreational drugs, speak to your doctor or another member of your healthcare team. They should be able to offer advice on safely minimising interactions.
- Do not skip doses. For more information, read *Interactions between HIV treatment and recreational drugs* on www.aidsmap.com.
- Be prepared when you travel** Going away for a holiday or a work trip could impact on your adherence. A change to your routine could mean that you are away from prompts that usually help you remember to take your medication. Even if you don't usually need phone reminders or pill boxes to help you keep track, you might find them helpful while you are away.
- You might be with people who do not know about your health. Plan in advance how you might manage this. Simple things such as having a bottle of water by your bed could give you more privacy to take your medication.

Travelling to a new time zone may affect when it's best to take your medication. You should try and ensure that you take your medication at the same intervals as you normally do. Your clinic staff can give you advice on how to do this.

There's more information on the page *Travelling with HIV medications – time zone changes* on **www.aidsmap.com**.

Make sure that you take enough medication with you when you travel, as securing more supplies while overseas might be difficult or even impossible. It's a good idea to take a few extra doses in case you are delayed and to carry your medication in your hand luggage, as this is less likely to get lost. Or you may choose to put some in your hand luggage and some in your suitcase, in case either bag is lost.

If you are travelling to another country it makes good sense to have a copy of your prescription or a letter from your doctor explaining that your medicines are for a chronic medical condition. It's also advisable to keep your medicines in their original container with the pharmacy label attached.

Some countries impose entry restrictions on people with HIV and you may be considering stopping your treatment for the time you're away. This is not recommended; talk to your doctor if you are thinking about doing this.

Talk to your doctor It's a good idea to talk to your doctor if you are forgetting to take a lot of doses of your treatment, or if you are having any other problems with it. Help is available to support you in taking your medication. Or it might be possible to change your treatment so that your medicines are easier to take.

If you have questions or concerns about your treatment, your doctor or someone else in your clinic such as a nurse, health adviser or pharmacist, should be happy to talk to you about it. They may also be able to put you in touch with other people living with HIV for support, either through peer supporters based in the clinic or through peer support organisations.

Resistance to anti-HIV drugs

One of the possible consequences of not taking your HIV treatment properly is that your HIV will develop resistance to anti-HIV drugs. Resistance is an important reason why HIV medication can stop working.

HIV reproduces itself very quickly, making billions of new viruses every day. Because the virus often makes mistakes when copying itself, each new generation differs slightly from the one before. These tiny differences are called mutations.

Some mutations occur in the parts of HIV which are targeted by anti-HIV medications. This can result in strains of HIV developing that are less easily controlled by the drugs. These HIV strains are called drug resistant.

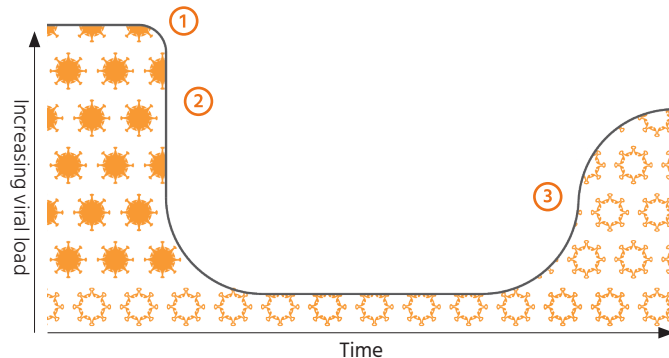
Drug-resistant HIV strains vary – some may be highly resistant to anti-HIV medications, while others may be less so. When an anti-HIV drug is started, HIV that is fully susceptible to that drug disappears rapidly and drug-resistant viruses remain. If the HIV replication is not fully suppressed, these resistant viruses can continue to reproduce themselves despite the drug's presence. The diagram opposite shows how this works.

Resistance is an important reason why HIV treatment can fail. Viral load, which should drop when you start a new drug combination, will increase again if drug-resistant HIV is able to

emerge. However, newer anti-HIV medications provide treatment options for people who have developed resistance to other drugs and resistance does not need to be a reason for someone to become seriously ill because of HIV.

This diagram explains how resistance to anti-HIV drugs can develop. The line represents viral load. Before starting treatment the viral load is high and is made up of both drug-sensitive and drug-resistant HIV.

- 1 Treatment begins
 - 2 Viral load falls as drug-sensitive HIV disappears
 - 3 Drug-resistant HIV continues to grow despite the presence of treatment. Over time, growth of these viruses can cause viral load to rise again.
- ☀ drug-sensitive HIV ☀ drug-resistant HIV



How to reduce the risk of resistance

- Take your HIV treatment exactly as prescribed (see page 12).
- Maintain an undetectable viral load. If you have an undetectable viral load, your HIV cannot become resistant to the anti-HIV drugs that you are taking.
- Take a resistance test before starting HIV treatment for the first time, or before changing treatment. The results will help you and your doctor to choose the combination of medications that is likely to be most effective against your HIV. There's more information on resistance tests later.
- Be honest with yourself and your doctor about the way you live your life. If it's likely that you won't take your HIV treatment properly, then it's important that your doctor knows this. This will allow your doctor to prescribe a combination of anti-HIV medications that has a lower risk of resistance. For example, HIV treatment that includes an integrase inhibitor or a boosted protease inhibitor has a lower risk of resistance than treatment that is based on an NNRTI.

Cross-resistance

Once resistance to one anti-HIV drug has developed, this may mean that your HIV is also resistant to other, similar anti-HIV drugs (that is, drugs from the same 'class') you haven't yet taken. This is called cross-resistance.

However, cross-resistance isn't inevitable if you develop resistance to one drug. The use of resistance tests will help you and your HIV doctor select the anti-HIV drugs that are likely to be most effective against your virus if resistance does develop. The risk of cross-resistance is lower if your treatment combination is changed promptly and also for many newer anti-HIV medications. For these reasons, an undetectable viral load is a realistic aim for most people.

Resistance tests

Blood tests are available which detect whether the HIV in your body is resistant to any anti-HIV drugs.

It's recommended that you have a drug resistance test before you start HIV treatment. This will usually happen when you are first diagnosed with HIV, in case you have a strain of the virus which is already resistant to one or more drugs. Again, you should have a resistance test if you are changing treatment because your viral load is detectable.

Resistance tests are also recommended to help guide the choice of treatment in women who are pregnant, and in children.

Results should be interpreted by someone who is experienced in their use. Test results should be considered alongside your full treatment history, rather than in isolation. This is because drug resistance is not the only reason why HIV treatment can fail – missed doses, poor absorption and drug interactions are other possible causes to consider.

"It's recommended that you have a drug resistance test before you start HIV treatment."

Resistance tests can only be done if your viral load is detectable. They will be more accurate if done while you are still taking a failing combination rather than after you've stopped it. Once you stop taking a drug, the sensitive viruses start to grow rapidly as they are usually more 'fit' than the resistant viruses. The test may give a misleading answer as it may not be possible to detect the smaller number of resistant viruses.



Changing treatment

If your viral load is still detectable six months after starting HIV treatment, or falls to undetectable levels and then becomes detectable again in two consecutive tests, you may need to change your HIV treatment.

Changing HIV treatment promptly can reduce the risk of drug resistance.

But before you change treatment, you should have a resistance test to help select the most effective combination of anti-HIV medications. If you are changing HIV treatment because of resistance, it's very likely that you will need to start a new combination of drugs.



Some anti-HIV medications may still be effective for people who have drug-resistant HIV. The boosted protease inhibitor darunavir (*Prezista* or *Rezolsta*), the integrase inhibitor dolutegravir (*Tivicay*) or the CCR5 inhibitor maraviroc (*Celsentri*) may be options. The NNRTI etravirine (*Intelence*) can work well in most people with resistance to the other NNRTIs.

These drugs mean that an undetectable viral load is a realistic aim for nearly everyone, regardless of their previous treatment history or resistance to anti-HIV drugs.

For more information on these medications, see NAM's booklet *Anti-HIV drugs*.



Transmission of drug-resistant virus

Some people contract HIV that is already resistant to one or more anti-HIV drugs (this has been the case for around 7% of people in the UK). This can happen regardless of how HIV is passed on.

While contracting a drug-resistant strain of HIV can sometimes limit your treatment options, in many cases these strains are resistant to a drug (or drugs) that is no longer widely used. So resistance will not necessarily cause much trouble.

If you have a detectable viral load and drug-resistant virus, then there's a risk that you could pass on a drug-resistant strain of HIV to someone else. Condoms, used carefully and consistently, are a very good way of preventing sexual transmission of HIV.

If you would like to discuss protecting your own or a partner's sexual health, a health adviser at your HIV treatment centre or another member of your healthcare team can help. You can also read more about this in the NAM booklet in this series, *HIV & sex*.

HIV treatment: looking to the future

There have been huge improvements in HIV treatment over the last 20 years.

Compared to many older anti-HIV medications, the ones used most widely today are more powerful, cause fewer side effects, are easier to take and less likely to cause resistance. Currently available HIV treatment is highly effective for most people.

You can keep up with the latest developments in HIV treatment by regularly visiting NAM's website, www.aidsmap.com or by signing up to one of our email bulletins: www.aidsmap.com/about-us-connect-us

Where to go for information, advice and support

To find local organisations offering information and support, talk to staff at your HIV clinic or use the HIV services finder on our website:
www.aidsmap.com/uk-service-finder

British HIV Association (BHIVA)

You can find UK guidelines on HIV treatment and care on the BHIVA website.

www.bhiva.org

You can find summaries of the adult treatment guidelines at
www.bhiva.org/patient-specific

Terrence Higgins Trust (THT)

Information on HIV treatment, as well as on other aspects of living with HIV and support and advocacy services throughout the UK. Details of these and services provided by other HIV organisations can be obtained from THT Direct.

0808 802 1221

Open Monday to Friday, 10am-6pm.

www.tht.org.uk
info@tht.org.uk

HIV i-Base treatment phone line

Individual questions answered on HIV treatment.

0808 800 6013

Open Monday to Wednesday, 12pm - 4pm

www.i-base.info
questions@i-base.org.uk

Positively UK

A national charity championing the rights of people with HIV, Positively UK provides a range of support services, including peer mentoring, for people living with HIV and their families.

020 7713 0444

www.positivelyuk.org
info@positivelyuk.org

Body & Soul

Body & Soul is a charity providing support for children, teenagers and families living with, or affected by HIV.

020 7923 6880

www.bodyandsoulcharity.org
enquiries@bodyandsoulcharity.org

Summary

- Thanks to antiretroviral treatment, many people with HIV now have a normal life expectancy.
- You'll get the most benefit from your treatment if you take all or nearly all your doses at the right time and in the right way. This is often called adherence.
- Missing doses or not taking doses correctly can lead to your HIV becoming drug resistant. This will cause your treatment to fail and possibly limit the drugs you can take in the future.
- Everyone taking HIV treatment should be offered support and advice with adherence.

- You might find adherence easier to manage if you feel ready to start treatment, and if your treatments fit in with your lifestyle.
- Simple techniques, such as keeping a diary, using a pill box, or setting an alarm, might help you to take your treatment.
- Some people contract a strain of HIV which is already drug resistant.
- Resistance tests will be used to help choose the best drug combination for you.

Glossary

- adherence** Taking a treatment 'properly'; that is, taking all the right doses at the right time, exactly as prescribed.
- antiretroviral** A substance that acts against retroviruses, such as HIV.
- CD4** A molecule on the surface of some immune system cells, which HIV can bind with. The CD4 cell count roughly reflects the state of the immune system.
- cross-resistance** When HIV that is resistant to one drug is also resistant to other, similar drugs (drugs from the same 'class').
- genotype** The genetic make-up of an organism.
- mutation** A single change in the gene sequence.
- phenotype** Trait or behaviour that results from a particular genotype.
- resistance** A drug-resistant HIV strain is one which is less susceptible to the effects of one or more anti-HIV drugs.

- resistance test** Blood test which detects resistance to anti-HIV drugs.
- side effect** An unwanted secondary effect of a treatment.
- superinfection** When someone already has HIV, and they are then infected with HIV again, possibly with a different strain, or subtype.
- viral load** Measurement of the amount of virus in a sample of blood. HIV viral load indicates the extent to which HIV is reproducing in the body

HIV helplines

THT Direct 0808 802 1221

Open Monday to Friday, 10am-6pm.
Support, advice and information from the Terrence Higgins Trust.

HIV i-Base 0808 800 6013

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

Positively UK 020 7713 0444

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

More from NAM

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

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

www.aidsmap.com/about-us/connect-us

All of NAM's booklets and resources for members of our Patient Information Scheme are on the clinic portal: **clinic.nam.org.uk**

NAM's booklets

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



Other booklets in the series:

- A long life with HIV
- Anti-HIV drugs
- CD4, viral load & other tests
- HIV & hepatitis
- HIV, mental health & emotional wellbeing
- HIV & sex
- HIV, stigma & discrimination
- HIV & women
- Nutrition
- Side effects
- Your next steps

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About NAM

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

Donate

Please help us

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

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