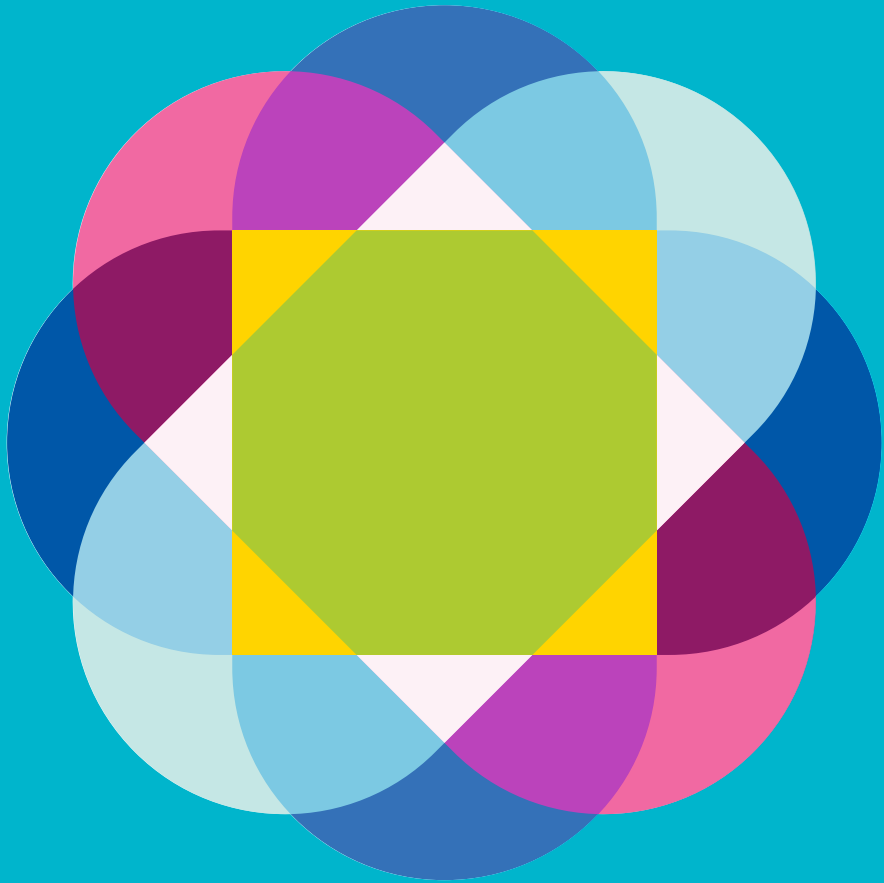


i-base
0808 800 6013

Introduction to ART

October 2019



HIV i-Base
ISSN 1475-2077
www.i-Base.info
Watch for out-of-date information

First questions
You and your doctor
Adherence and resistance
Treatment choices

Contents

Introduction	3
First questions: what, when, why?	4
Age, heart disease, gender and pregnancy	14
Starting treatment	16
U=U and Treatment as Prevention (TasP)	18
What about side effects?	20
You and your doctor	22
Why adherence is so important	24
Adherence diary	27
Drug resistance	28
Choosing your drugs	30
Future HIV drugs	39
Generic HIV drugs and HIV care in the UK	39
Your treatment history	41
Glossary	47
Further information	48
Feedback and notes	50
ARV chart 2018/19	centre pages



Thank you to the advisory group of HIV positive people and community advocates for support and comments.

Written and compiled by Simon Collins at HIV i-Base. Original cover design by No Days Off.

Disclaimer: information in this booklet is not intended to replace information from your doctor. Decisions relating to your treatment should always be taken in consultation with your doctor.

Thanks to MAC AIDS Fund for funding this publication.

23rd edition, October 2019.

Not-for-profit copying is encouraged or please call for free print copies

i-Base runs a free treatment information service on all aspects of HIV treatment.

Phoneline 0808 800 6013
Monday– Wednesday, 12 noon – 4 pm

The website also has a question and answer service where you can ask questions online and by email.

www.i-Base.info/qa

Introduction

This is a booklet for anyone interested in HIV treatment (called ART).

It is especially for HIV positive people to feel more in control of this part of life.

The guide was written and reviewed by HIV positive people, activists and health professionals.

Information is based on latest UK guidelines.

www.bhiva.org

When appropriate, we also refer to latest European and US guidelines.

www.eacsociety.org

www.aidsinfo.nih.gov

All guidelines stress that ART should be individualised for you.

Changes in this update include:

- The section on choice of first-line ART has been updated to focus on the most commonly used combinations.
- Additional information is included about choice of ART and current guidelines. This includes that both EU and US guidelines now recommend integrase inhibitor-based treatment for first-line ART.

It also includes recent options for two-drug ART.

- The section on future drugs has been updated.
- The guide and 4-page drug chart in the centre pages have been updated to include new drugs and formulations. Pill sizes approximate to actual size.

Detailed information about every drug is at this link:

<http://i-base.info/guides/category/arvs>

- The online version has additional information.

www.i-base.info/guides/starting

ART:

Antiretroviral treatment

HIV:

Human Immunodeficiency Virus

First questions: what, when, why?

What is ART?

ART stands for antiretroviral treatment. It is also called combination therapy or HIV treatment.

What are ARVs?

HIV drugs are called antiretrovirals (ARVs) because HIV is a type of virus called a retrovirus.

ART generally includes three active drugs but a few new options only use two drugs.

Some pills contain more than one drug and some pills contain a complete combination (of 2, 3 or 4 drugs).

Does ART really work?

Yes. Amazingly well. ART has reduced HIV-related deaths and illnesses in every country. It also stops HIV transmission.

More than 22 million people are now on ART.

ART works for adults and children, for women and men. It works for transgender and cisgender people. It works no matter how you were infected, whether this was sexually, through injecting drugs, at birth, or by blood or blood products.

Taking ART at the right time and in the right way will reduce HIV to tiny levels in your body.

When your viral load becomes undetectable on ART, you are no longer infectious. So your partners are also protected.

Cisgender: people who live in the gender they were assigned at birth.



Does everyone need ART?

Yes. Even with a high CD4 count, HIV can still cause serious problems.

ART is very effective and easy to take. It often involves only one or two pills a day.

How soon do I need to start?

UK guidelines say you can begin ART whenever you are ready.

For most people this will be soon after they first test positive.

How long you wait before starting ART also depends on your individual situation.

Even if you don't start straight away, your HIV doctor should talk about ART in your first appointment.

What about side effects?

ART has a very low risk of serious side effects.

Mild side effects are more common when you first start. These are usually easy to manage and improve within the first few weeks.

If side effects are difficult or do not improve, you can change to other drugs.

“It is an exciting time if you are HIV positive.

ART is now recommended for everyone, even at a high CD4 count. This is for all ages, genders, other health risks and where in the world you live.

By taking control over this aspect of HIV, you can carry on with your life.

The PARTNER study proved that ART also prevents HIV transmission.

PrEP is also more widely used by people who are HIV negative. This makes HIV prevention a more shared experience and reduces fear of HIV.

Starting ART is now a routine next step after finding out you are HIV positive. This can be one of the best ways to move forward after the shock of being diagnosed.”

Simon, London

Two essential blood tests

Your CD4 and viral load are the main blood tests used to monitor HIV.

CD4 count

- The CD4 count tells you about your immune system. Results are given as cells per cubic millimetre (cells/mm³).
- The range for HIV negative adults is from about 400 to 1600. Getting above 500 is considered normal.
- Even with a very low CD4 count, ART can boost your immune system much higher.
- The CD4 percentage (CD4%) is also good to know in case your CD4 result is ever lower than expected. The normal range is from about 25 to 60% with the average about 40%.

Viral load (VL)

- VL shows how much virus is in a small sample of blood. Results are given as copies of the virus per millilitre (copies/mL).
- VL also shows how well ART is working. The aim is to reduce this to less than 50 copies/mL. This is called undetectable.
- If VL does not become undetectable within 1 to 3 months – or if it increases later – the drugs might not be working or you might not be taking them correctly. This means you might need to change treatment.

Finding out you are positive

Getting an HIV diagnosis is still a shock for most people.

It is likely to take time to come to terms with this change in your life.

Referrals to other services can help. This can include peer support from other positive people who have been through similar experiences.

See pages 22 to 23 about getting the best NHS care.

See also:

<http://i-base.info/just-found-out>

How does ART work?

ART stops HIV from replicating - ie from making copies of itself.

This reduces viral load to very low levels. Your CD4 count then gets stronger again by itself (ie ART doesn't directly increase your CD4 count).

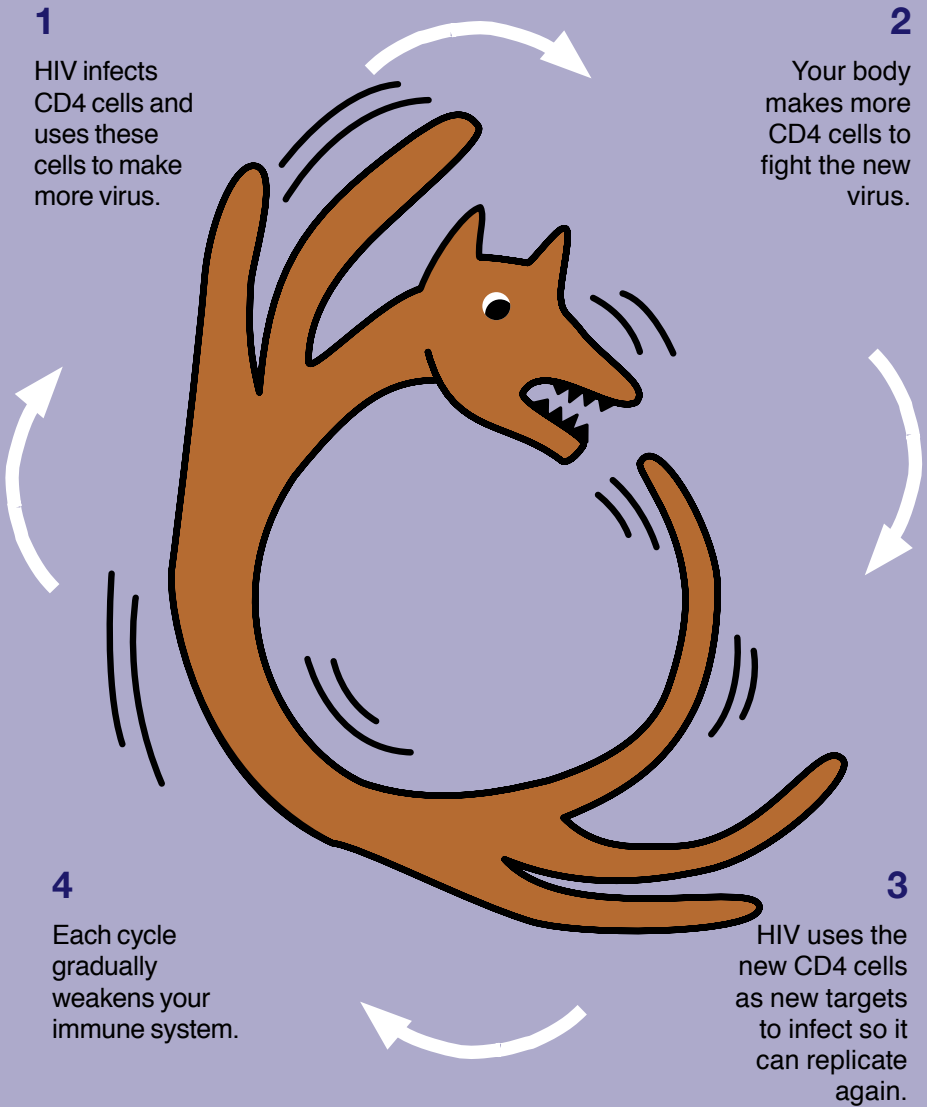
When not on ART, your immune system works in overdrive.

- HIV infects CD4 cells and uses them to make more virus.
- Your body produces new CD4 cells to fight the new HIV.
- HIV then uses these new cells to produce even more virus.

Over time, without ART, your immune system gets worn out. It is like a dog chasing it's own tail. See Figure 1.

After starting ART, your body stops over-producing CD4 cells. Your immune system then gets the chance to repair itself and to grow stronger.

Figure 1: Without ART, your immune system is like a dog chasing its tail ...



How long will ART last?

As long as you do not develop drug resistance, the same drugs can work for years or even decades.

This involves getting viral load to undetectable and not missing doses.

This is why these three points are important.

- To take your drugs on time.
- To follow advice on taking with or without food.
- To not miss doses.

Around 19 out of every 20 people (95%) in the UK whose viral load stays undetectable for the first year, will always stay this low.

Can I change meds?

Yes, it is easy to use a different combination.

Although most people do well on their first ART, it is easy to change one or all of the drugs if you need to.

Changing to a different combination will not affect your long-term health. It will not reduce your future choices. You can still use the same drugs if you need to in the future.

If you are having trouble with side effects, changing treatment is easy. You do not have to put up with difficult side effects.

For most people it is often better to see whether side effects get easier after the first weeks or month.

A few people change ART more quickly, even after only a few days.



Can I stop treatment?

Stopping ART is not generally a good idea, unless there is a medical need to do this.

- Your viral load is likely to increase within a few days.
- Within a few weeks it might be back to pre-ART levels.
- Your CD4 count is likely to drop. It will be more difficult to recover when you restart ART.
- Each time you stop there is a risk of drug resistance.

Staying on ART is generally better for your long term health. It will keep your CD4 count high and keep HIV under control.

Even if you have problems with ART, speak to your doctor rather than just stopping ART.

If you really want to take a break, your doctor can help.

- If this is because side effects are difficult or you don't like the food advice, there are other drugs that might be better.
- If you still want to stop, your HIV doctor can tell you how to do this as safely as possible.
- If you are not on ART, then monitoring your CD4 and viral load is more important.

What about if I am feeling well without ART?

Even if you are feeling well without ART, HIV will be damaging your immune system.

Even with a high CD4 count, ART reduces the risk of serious problems including heart disease and some cancers.

What if I am a slow progressor?

A small percentage of people have a very strong immune response to HIV.

People whose CD4 count stayed above 500 for five years without ART are called long-term slow progressors (LTSPs). If viral load also stayed undetectable, they are called elite controllers (ECs).

ART is still recommended for the roughly 5% of people who are LTSPs or less than 0.1% who are ECs.

This is because HIV might be progressing in ways that are not shown by your CD4 count and viral load.

Does ART always work?

Nearly everyone can get an undetectable viral load after starting ART.

If this does not happen, this could be because of one or more of the following reasons.

- Side effects.
- Missing doses.
- Drug resistance.
- An interaction with other drugs.
- Choice of drugs.

Each issue is discussed in this booklet.

Review ART every year

UK guidelines say that your doctor should review your ART every year.

New research might have changed the way that ART is used. Newer drugs might have become available.

The drugs that your doctor prescribes today might be different from last year.

And they might be different again next year.

Should I enter a study?

Many HIV clinics are also research centres and you might be asked to join a study.

If you are interested, take time to find out about the details.

It is your choice whether to join a study. Your future care will not be affected if you decide not to join a study.

Ask about the alternatives to the study treatment. Ask what advantages or risks the study offers over existing care. You can ask for advice from i-Base or other HIV organisations.

Some studies include closer monitoring and care than your regular clinic. This might mean a few more clinic visits.

Research is essential to improve how we use both new and existing drugs.

“I was diagnosed after one low-risk experience. I knew that I wanted to start ART and I wanted to be less infectious to any future partners, even if we used condoms.

I also learned from my support group that because I was diagnosed soon after I was infected, there may be additional benefits from early treatment.

When my first doctor didn't offer me ART, I asked for a second opinion and I changed my doctor. This led to me starting ART within a week - when I was still within six months of infection.

Since then, my experience of HIV – both at the clinic and from support organisations – has been really positive. And it was great when my viral load became undetectable.

I know I was really unlucky in catching HIV, but learning and understanding how the treatment works and then deciding to use it has been an important part of how I chose to move forward.”

Lenny, London

What about drug interactions, including: alcohol, drugs, supplements and vitamins?

Some HIV drugs interact with chems, recreational and street drugs, methadone, vitamins and supplements and over-the-counter medicines.

Interactions can be complex. They can increase or decrease levels of the HIV drugs or the other drugs.

It is therefore important that your HIV doctor and pharmacist know about other drugs or supplements that you take, even if you use them rarely and even if they are not legal.

Your doctor will treat this information in confidence.

Although alcohol does not interact with HIV drugs, the side effects of alcohol might lead to missing doses. This is because alcohol can change your mood, priorities and sense of time. It is easy to forget your HIV meds including if you oversleep the next day.

For these reasons, people who drink more alcohol have a higher risk of ART failure. This is another thing that it is good to talk about with your doctor.

What about a cure?

ART is really effective treatment, but it is not a cure.

Even people who have an undetectable viral load for years, still have small amounts of HIV in their body. This HIV is mainly in CD4 cells that are resting.

Most of your immune cells are meant to be resting. These cells are not in your blood but in lymph nodes.

The resting cells are like books on the shelves in a reference library. When they become active in response to an infection, it is like someone taking the book they need off the shelves.

The HIV in resting cells is why finding a cure is so difficult. These cells might sleep for 50 years – or wake up at any time. This is why you need to continue taking ART.

Cure research is making exciting progress, though this is likely to still take many years.

Even if a cure takes a long time, if you take your drugs and look after your health, you are likely to live into old age.



“When I was diagnosed I was in shock and immediately worried about dying. I pictured myself as a person in the media adverts for African people with AIDS who were just bones and skin.

My viral load was 650,000 and my CD4 was less than 10. Therefore I had to start ART immediately.

I read the leaflets and could not believe I was on treatment for HIV.

Because my CD4 count was so low, the increase in CD4 cells caused TB to become active.

So I needed a short course of TB treatment. I asked the pharmacist to have the TB meds as an oral solution as I couldn't swallow the large tablets.

Now, 17 years on, I take my HIV meds every day and at the right time.”

Memory, London

Age, heart disease, gender and pregnancy

How do children use ART?

HIV treatment for children is similar to adults, but there are two main differences.

- Young children are usually monitored by their CD4 percentage (CD4%) rather than the CD4 count. A CD4% of 25 to 30% is similar to an adult CD4 count of about 500.
- Some adult drugs are not yet available for young children –so there are fewer choices for ART.

The immune system and drug absorption can be different in babies, children and adults. Children of all ages need to be treated by a paediatric doctor with experience in looking after HIV positive children.

There are separate treatment guidelines for children. However, they tend to be updated less frequently than adult guidelines. It is therefore important to be aware of changes in adult care that might be just as relevant for children.

For more information about children and HIV, visit the Children with HIV Association (CHIVA) and PENTA web sites:

www.chiva.org.uk

www.penta-id.org

Is age an important factor in adults?

Many researchers are looking at HIV in older people.

This is becoming a specialised subject and HIV services are changing to reflect this.

By 2020, about half the HIV positive people in the UK will be older than 50. This includes people who have been positive for many years and people who only recently became positive.

Although researchers were worried that HIV might cause faster ageing, more recent studies have not shown this to be true.

While ART is now recommended for everyone, the benefits from ART are especially important if you are older.

Ageing is related to many health problems, and these can overlap with complications from HIV.

This is why lifestyle factors that affect our health are just as important if you are HIV positive.

These include a healthy balanced diet, keeping mentally and physically active and not smoking etc.

Age, HIV drugs and heart disease

Most HIV drugs are very safe for your heart - and they reduce the risk from HIV-related heart disease.

The biggest risks for heart disease are smoking, poor diet and low exercise. As with HIV negative people, lifestyle changes to reduce your risk of heart disease is good advice if you are HIV positive.

Of these, stopping smoking has the biggest impact on long term health. The NHS has lots of support for quitting, including online and from your GP.

<http://www.nhs.uk/livewell/smoking>

High cholesterol can be an independent risk and this is included in HIV monitoring.

Other risk factors include: age (over 45 for men and over 55 for women), sex (male), family history of heart disease, alcohol use, high blood pressure and diabetes.

HIV drugs linked to heart disease are abacavir, maraviroc and darunavir. Also, some older drugs that are now rarely used (ddl, fosamprenavir/r, lopinavir/r and saquinavir/r).

Your HIV doctor should check your risk of heart disease when you are first diagnosed, before ART and then every year. Using alternative drugs is important if your heart disease risk is high.

BHIVA recommend several online risk calculators:

www.hivpv.org

www.qrisk.org

www.qintervention.org

The q-intervention calculator also looks at risk for type-2 diabetes.

What about ART in pregnancy?

HIV drugs are very effective during pregnancy. Having an undetectable viral load also reduces the risk of transmitting HIV to your baby to almost zero.

ART used in pregnancy is sometimes different to standard adult treatment, This is to make sure the safest HIV drugs are used for you and your baby.

Pregnancy involves specialised care. See the i-Base guide: *HIV, Pregnancy and Women's Health*.

Does gender affect ART?

HIV treatment works in a similar way for people of all genders.

Some aspects of women's care is different to men, but ART works the same way, with similar side effects.

However, social factors affect women, men and trans* people differently and this can include access to care and support.

Trans* people and HIV drugs

HIV drugs are safe and effective for trans* people.

The main caution is to not use HIV drugs that interact with hormone treatment. Your doctor needs to understand these important potential interactions.

CliniQ is a leading centre to support all aspects of sexual health and wellbeing for trans* people (not just HIV). It is based at Kings College Hospital in South London.

www.cliniq.org.uk

* The asterisk is used to show the diversity of transgender people.

Starting treatment

Is starting ART easy?

Generally yes. Most people find that being on ART is much easier than they expected.

- It is important not to miss doses of HIV drugs.
- Although everyone worries about side effects, these are usually mild and only temporary.
- You have a choice of drugs and you can be involved in this choice.
- Once started, it is better to carry on rather than stop and start.

How soon do I need to start?

As with all treatment decisions, this is individual. You are the person who has to take ART. You can choose when to start and which drugs you use.

Many people start in the same week they are diagnosed, sometimes on the same day. But as long as there is not a medical urgency (such as pregnancy or a very low CD4 count), you can take time.

- Ask about the different drugs. What are the good and bad things about each of them?
- Take time to think about what you want. Do not feel rushed into doing something you don't understand.

However, it is more urgent to start quickly if:

- If your CD4 count is very low.
- If you are pregnant.
- If you were very recently infected.

In all these situations the earlier you start the better. Every week earlier might be important.

This includes the option to start on the first day that you see your HIV doctor.

Early diagnosis and primary infection

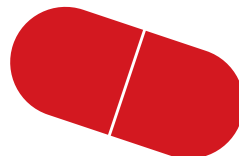
Early HIV infection is defined as being diagnosed within six months of infection.

A special HIV test called STARHS or RITA can help confirm this. This test has been recommended for all new diagnoses since 2011, but you still might need to ask your clinic to do this.

Also, the results only give a rough guide, so are interpreted with your recent risks.

There are several reasons to consider very early treatment.

- To minimise damage to your immune system.
- To reduce the risk of transmission when viral load is very high.
- To perhaps benefit from cure-related research in the future.
- To have a smaller reservoir of infected resting cells.



Late diagnosis and low CD4s

In the UK, about 40% of all new diagnoses are made when the CD4 count is already less than 350.

About 1 in 5 (20%) are even later, with a CD4 count below 200.

Late diagnosis can be related to:

- Fear of testing.
- Denial: “it will never happen to me”.
- Fear of stigma and prejudice.
- Lack of up-to-date information about HIV and treatment.

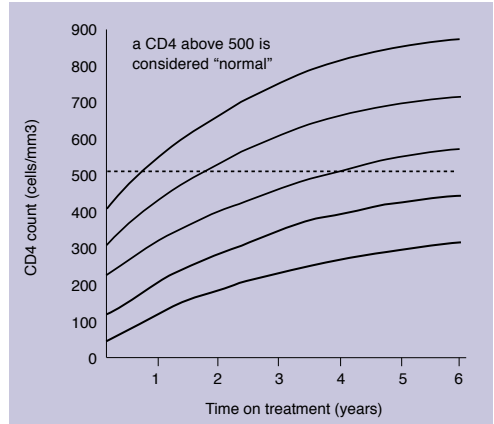
Some people only find out they are HIV positive when they already have a low CD4 count. This often means starting treatment on the same day that you first see an HIV doctor.

If you have serious symptoms and are admitted to hospital, you might need other infections treated first. ART will be started shortly afterwards.

Even with a very low CD4 count – even below 100 – if you take your drugs carefully, you have a good chance that ART will work. Your viral load will drop and your CD4 count will rise to safer levels.

However, starting with a very low CD4 count can cause some infections to activate, such as TB. This is called Immune Reconstitution Inflammatory Syndrome (IRIS) and is serious, but usually easy to treat.

Figure 2: CD4 increases on ART



The higher your CD4 count when you start treatment, the more likely that it will reach – or stay above – 500).

But for people who started with very low CD4 counts, getting above 350 or even 200 will still reduce the chance of most HIV complications.

This graph shows average levels of CD4 increases – some people respond better or worse than average.

Nearly everyone starting above 350 will get above 500. Starting with a CD4 count above 500, means you might never have an HIV-related illness.



U=U and Treatment as Prevention (TasP)

As well as being good for your health, ART also prevents transmission.

Having an undetectable viral load on ART protects your partners, even if you don't use condoms.

Since 2016, the global U=U community campaign has focussed on Undetectable = Untransmittable.

Your HIV doctor should talk about this. It is sometimes called Treatment as Prevention (TasP).

The PARTNER and Opposites Attract studies both reported zero transmissions when the positive partner has an undetectable viral load.

In PARTNER 1 there were no linked infections after 58,000 times that couples had vaginal or anal sex without condoms. PARTNER 2 had no transmissions after gay couple had sex more than 77,000 times.

This means condoms are only important if you want to protect against pregnancy and some STIs.

This evidence should reduce the worry and anxiety for couples where one partner is positive and the other is negative, even if they still chose to use condoms.

It should also help reduce fear and stigma about HIV.

Links

The evidence for U=U:
<http://i-base.info/htb/32308>

U=U campaign
<https://www.preventionaccess.org>



Public health and personal choice

U=U has changed the approach to HIV and ART.

But your decision to use ART should always be your personal choice.

If you do not want to take ART for your own health, you should not be under pressure to take ART for TasP.

- Most HIV positive people never put their partners at risk.
- Most new infections are likely to come from people who are not yet diagnosed. This is related to people being most infectious in early infection, or having a high viral load in later infection.
- Many HIV positive people find that the greater awareness of U=U has improved their life. It is good to no longer have to worry about whether your partners are at risk.
- ART makes it easier to have relationships without the fear of HIV.

“We are both HIV positive and not having to use condoms is a special part of our relationship.

We are both on ART with no drug resistance. We don’t usually have other partners, but agree to use condoms if this happens, so that we would reduce the risk of STIs...”

Steve, Manchester

“I am positive and so is my partner.

I am happier to continue using condoms because I feel better to be in control of this part of my life.

At least I don’t have to worry about my health if he has other partners...”

Paula, London

What about side effects?

All medicines have a risk of side effects (or adverse events). This is a real and common worry.

However:

- Many people do not get side effects/
- If they do get them, they are usually mild.
- Within a few weeks of starting, most people find that ART is much easier to take than they expected. It usually becomes an ordinary part of everyday life.
- There is only a small risk of serious side effects. If they occur, they should be picked up by routine monitoring.
- It is easy to switch to another HIV drug. Sometimes changing how you take your meds can also stop side effects. For example, changing timing in relation to food or sleep.

Before you start ART, ask your doctor, nurse or HIV pharmacist about the most common side effects of the drugs that you might use.

- Ask how likely they are to occur.
- Even rough estimates will give you a good idea of what to expect.
- Ask how many people stop treatment because of side effects – usually it is very few.

Common side effects

Side effects like nausea, diarrhoea and tiredness, are now much less common with modern HIV drugs.

If they occur, they usually become easier within the first few weeks.

Very rarely, nausea and tiredness can be a symptom of another illness. This is why you should talk with your doctor about any problems.

However, efavirenz and some integrase inhibitors can affect your mood and cause vivid dreams. These drugs can also affect how well you sleep (see page 36).

Even though these side effects usually improve, this is why efavirenz is no longer a preferred first choice in UK guidelines.

Metabolic changes: how your body processes fat and sugar

Changes in fat cells and the distribution of body fat were side effects of early HIV drugs. This is much less common with newer drugs.

Changes in blood lipids (fats) like cholesterol and triglyceride levels are a common side effect.

Changes in blood glucose (sugar) levels are important to check for early signs of diabetes.

These changes might be because of HIV drugs, HIV itself or for other reasons.

You will be monitored by routine blood and/or urine tests.

Diet, exercise, changing treatment or using lipid-lowering drugs can all help.

If you are worried, your doctor should take your concerns seriously and act on them.

Fat accumulation to the stomach or breasts and/or across the shoulders or neck has been linked to many combinations. It is not understood why some people are affected.

Mild symptoms might reverse if you switch to different HIV drugs. Exercise and dietary changes can also help.

Fat loss (from arms, legs, face and buttocks) is *not* a side effect of modern HIV drugs.

Other side effects

There is a very low risk of serious side effects with modern ART. **Any rash should always be reported to your doctor, as this is an example of when rare side effects can be serious.**

Ask about the potential side effects for all the drugs in your combination, before you decide on your combination.

The i-Base booklet: *HIV and your quality of life: a guide to side effects and long term health* includes information for each drug:

www.i-base.info/guides

This guide also has information about long-term health issues that might be related to both HIV and some of the drugs used in treatment.

For a free copy please call 020 8616 2210.

The i-Base website includes information on each drug.

<http://i-base.info/guides/category/arvs>



You and your doctor

A good relationship with your doctor and other health workers can help your health in the long term.

Nurses and pharmacists can give you support and advice on all aspects of your treatment. This includes adherence and side effects.

They can make referrals to other professionals, including dieticians, psychologists and social workers.

It is important to involve your general doctor (GP), especially as you get older. Find a GP or a surgery that you are happy with.

Your HIV team might not cover all your medical conditions. Your GP has expertise in other areas and for other referrals.



Your rights as a patient

HIV testing, monitoring and treatment is free at any NHS HIV clinic to anyone living in the UK.

This is even if you do not have permanent resident status.

As a patient you have certain rights and responsibilities. Some of these are listed below.

- To be fully involved in all decisions about your treatment and care.
- To be treated with respect and confidentiality.
- To have choices of drugs explained. This should include the risks and benefits of each drug.
- To have your doctor or nurse explain any test results.
- To be seen within 30 minutes of your appointment. If the clinic is running late, this should be explained.
- For your records to be kept securely. They should be made available for you to see if you ask.
- To choose whether to take part in research trials.
- To be able to make a complaint about your treatment. Any complaint must be fully investigated. Again, this must not affect your future care.
- To have a second opinion from a suitably qualified doctor.

*HIV treatment is free to everyone living in the UK.
This is even if you are not a permanent resident.*

- If you write to your hospital or clinic, you should have a written response within 14-28 days.
- To change your doctor or treatment centre without it affecting your future care. You do not have to give a reason for changing doctor or clinic. But giving a reason might help resolve the problem and prevent it again in the future.
- To have test results and a summary of your treatment history forwarded to your new doctor or clinic.

Things you can do to help

- Find a clinic that is convenient to you and that you feel comfortable with.
 - Find a doctor who you like. If you are a woman and want to see a female doctor then ask for this.
 - If you are a gay man and want to see a gay doctor, this might be available or might affect your choice of clinic.
 - Turn up for your appointments on time. Tell the clinic if you can't make it. Then they can give your slot to another patient.
 - Make a list of things you want to discuss with your doctor. Remember to take it to your appointment!
 - Ask to see the same doctor at each visit at least until you are settled with your care. This is important. It's difficult to develop a good relationship if you always see a different doctor.
- Once you are more settled, an advantage of sometimes seeing a different doctor is to get a second opinion and different perspective.
- Treat all people involved in your care with the same respect you would wish to receive yourself.
 - Have your routine blood tests taken 2-3 weeks before your clinic visit so the results are ready for your appointment.
 - Listen carefully to the health advice that you are given, and act upon it.
 - If you don't understand something, ask your doctor to explain it again or in a different way.
 - Be open with those caring for you. Your discussions are in confidence.
 - If you have any problems taking ART, the people involved in your care need to know before they can help.
 - Tell your doctor about other things in your life, including any other drugs that you are taking. This includes alcohol, legal and illegal drugs and complementary treatment. Perhaps bring a list with you.
 - Remember that your HIV doctor might not be able to treat every health issue. Your GP and other specialists might be needed to get the best care.

Why adherence is so important?

What is adherence?

Adherence is a word used to describe taking your drugs exactly as prescribed.

This includes:

- Taking them at the right time.
- Following advice to take with or without food.
- Avoiding any drug interactions.

Adherence is the most important thing you have to think about when you start ART.

Good adherence makes sure that all your meds are at high enough levels: 24 hours a day, 7 days a week.

Sometimes, adherence can be difficult. You might need some support to get used to the changes treatment makes in your life. A routine or daily schedule can really help.

- Pick a time to start ART when you have a few unstressed days.
- During the first few weeks, getting ART right should be your only priority.
- Some clinics and/or support organisations have someone who can help. This can include HIV positive people working as a peer mentor.

How much is enough?

Aiming to take every dose – or almost 100% – is still the best goal. Even missing one or two doses a week can cause some drugs to fail, especially when starting.

However, a window period of about an hour either side of your usual time is okay for most drugs and most people.

Once your viral load becomes undetectable, you have a bit more flexibility. A few hours either side will be fine. But it is still important to take adherence seriously.

Tips to help

- Choose a combination that fits with your life.
- Find out what is involved before you choose your ART. How many tablets? How big are they? How often do you need to take them? How exact do you have to be with timing? Are there food restrictions? Are there easier options?
- Use a weekly pill box. Then you can see if you miss a dose. If your clinic does not provide one, most chemists sell them for about £2.



- Plan your timetable (see page 27). For the first few weeks, mark the time that you take each dose.
- Use the alarm on your mobile phone or watch for all doses. Then take your meds when it beeps!
- Link ART to another daily routine - for example, brushing your teeth.
- If you travel, take additional drugs with you in case flights or other arrangements change.
- Keep an emergency supply where you might need them – at work or a friend’s house.
- Ask a friend to remind you at difficult dose times, for example, when you are out at night.
- Ask how other people manage and if they have tips. Your clinic or support group can usually arrange for you to talk to someone who is taking the same ART.
- Contact your clinic if you have side effects. They can prescribe additional drugs to help or change the treatment if needed.
- Many combinations are once-daily. This usually means taking them every 24 hours. Twice-daily drugs need to be taken every 12 hours.

What if I forget?

Almost everyone will forget or be late at some time – and this will be fine.

But there is a difference between an occasional missed dose and regularly forgetting on a daily or weekly basis.

- Be strict with yourself to work out how adherent you are.
- If you often miss doses, you need more support. It is available but you will need to ask.

If you often miss doses, talk to your doctor, nurse or pharmacist about other options.

- There might be an easier combination.
- You need a regimen that you can follow everyday. This includes both during the weekend and in the different situations involved in life.
- There are always things that can help improve adherence, whatever your lifestyle.

Taking days off treatment is a risky way to use HIV drugs.

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, do not take a double dose.

“I started treatment on a once-daily pill containing tenofovir, emtricitabine and efavirenz. I had nightmares the first night, but these went away. What I couldn’t get used to though was feeling dizzy a few hours after taking my meds.

Even though I took the pill at night, I could not sleep properly. Perhaps because of poor sleep I felt agitated during the day. Sometimes I need to work late at night, but the dizziness after taking my pill would prevent me.

I continued for a few weeks, but was unhappy with the change in my life. So I switched the efavirenz to raltegravir.

My life quickly came back to normal. I now sleep properly. No sweats, no tossing and turning, no insomnia, no weird dreams, no dizziness, no falling over when I go to the bathroom!

I am much happier.”

Nathan, Cape Town

Adherence diary

Use the table below to mark when you take each drug in the first few weeks of your combination. This will help you know if you have just taken a dose – or if you are late or miss a dose. Getting everything right from the start is important.

Date at start of week _____

	Drugs & times (morning)	Drugs & times (evening)
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		
Saturday		
Sunday		

Date at start of week _____

	Drugs & times (morning)	Drugs & times (evening)
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		
Saturday		
Sunday		

Drug resistance

What is drug resistance?

Drug resistance can develop when HIV changes in a small way that stops a drug from working.

These changes are called mutations.

- The risk of resistance occurs when drug levels drop below a minimum level. This usually only occurs if you miss doses or stop treatment. (See Figures 3 and 4).
- Drug resistant HIV can also be transmitted. So some people are infected (or reinfected) with drug resistant HIV, even though they have not taken HIV drugs yet.

In the UK, about 1 in 12 new infections have resistance to at least one drug or class of drug.

This is why in the UK everyone should have a resistance test when they are diagnosed and before starting ART.

But you might need to ask for this test, so it is important to check.

When does resistance occur?

Mutations that cause drug resistance generally only develop on ART when your viral load is detectable.

If your viral load is still above 500 copies/mL after 2-3 months, or above 50 copies/mL after six months, resistance can develop.

If your viral load increases on ART this can also cause drug resistance.

Your doctor should look for why this happened. This will involve talking about adherence and side effects.

You might need a drug resistance test or to check your drug levels.

What happens if my viral load becomes detectable again?

If your viral load becomes detectable, the viral load test needs to be repeated when you get these results.

Often this is a laboratory or test error.

Small increases that go back down again are called 'blips'.

The second test will help find out what is happening. If ART has really stopped working, it is good to confirm this as soon as possible.

The *i-Base Guide to changing treatment and drug resistance* discusses these situations in more detail.

www.i-base.info/guides

Figure 3: Drug levels with good adherence

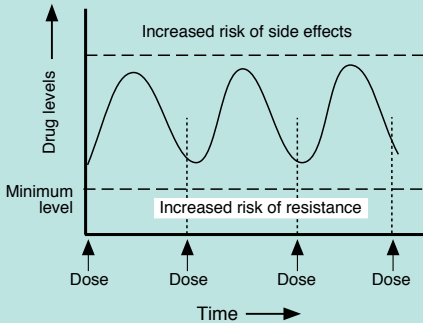
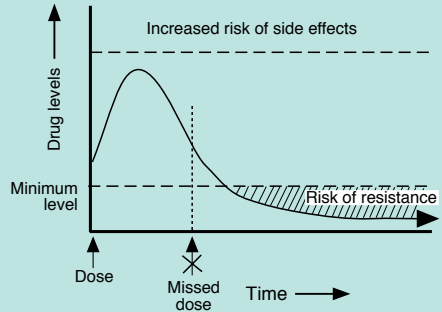


Figure 4: A missed or late dose increases the risk of resistance



Drug doses are based on average levels being high enough to be active against HIV for the whole dose period. They are also low enough to minimise the risk of side effects.

How do I avoid drug resistance?

The best way to avoid resistance is to take your drugs every day and on time.

Avoiding resistance will let your treatment work for many years.

Having an undetectable viral load (less than 50 copies/mL) makes drug resistance much less likely.

Missing or being late with a drug lets the drug levels fall to a level where resistance can develop. The more often you are late, the greater the chance of resistance.

What is cross-resistance?

Cross-resistance is when a drug mutation against one drug causes other similar drugs to fail, even if you have never taken them before.

This is particularly true of drugs in the same class.

So if you develop resistance to one NNRTI such as rilpivirine then efavirenz (another NNRTI) is unlikely to work.

In a similar way, resistance to the integrase inhibitor raltegravir might stop dolutegravir from working, unless you switch quickly.

Choosing your drugs

Main types of HIV drugs

There are six main types (or classes) of drugs.

Each class works at a different stage of the HIV life cycle. (See Table 1 and Figure 5).

Table 1: Main types of HIV drugs

Abbreviation	Full name
NRTI/NtRTI (‘nuke’)	Nucleoside/tide reverse transcriptase inhibitor or nucleoside/tide analogue
NNRTIs (‘non-nukes’)	Non-nucleoside reverse transcriptase inhibitor
PI	Protease inhibitor
INIs (or INSTIs)	Integrase strand transfer inhibitor
CCR5 inhibitor	CCR5 inhibitor
Fusion inhibitor	Fusion inhibitors are a type of entry inhibitor
mAb	Monoclonal antibody

There are more than 30 HIV drugs and formulations. Luckily, only a few combinations are now commonly used.

What is the best combination?

Although there are more than 30 approved drugs and formulations, only a few combinations are widely used.

All the main recommended combinations are very good. They are similarly effective and easy to take.

There isn’t one best combination. The combination that is best for you depends on your medical history and your choice.

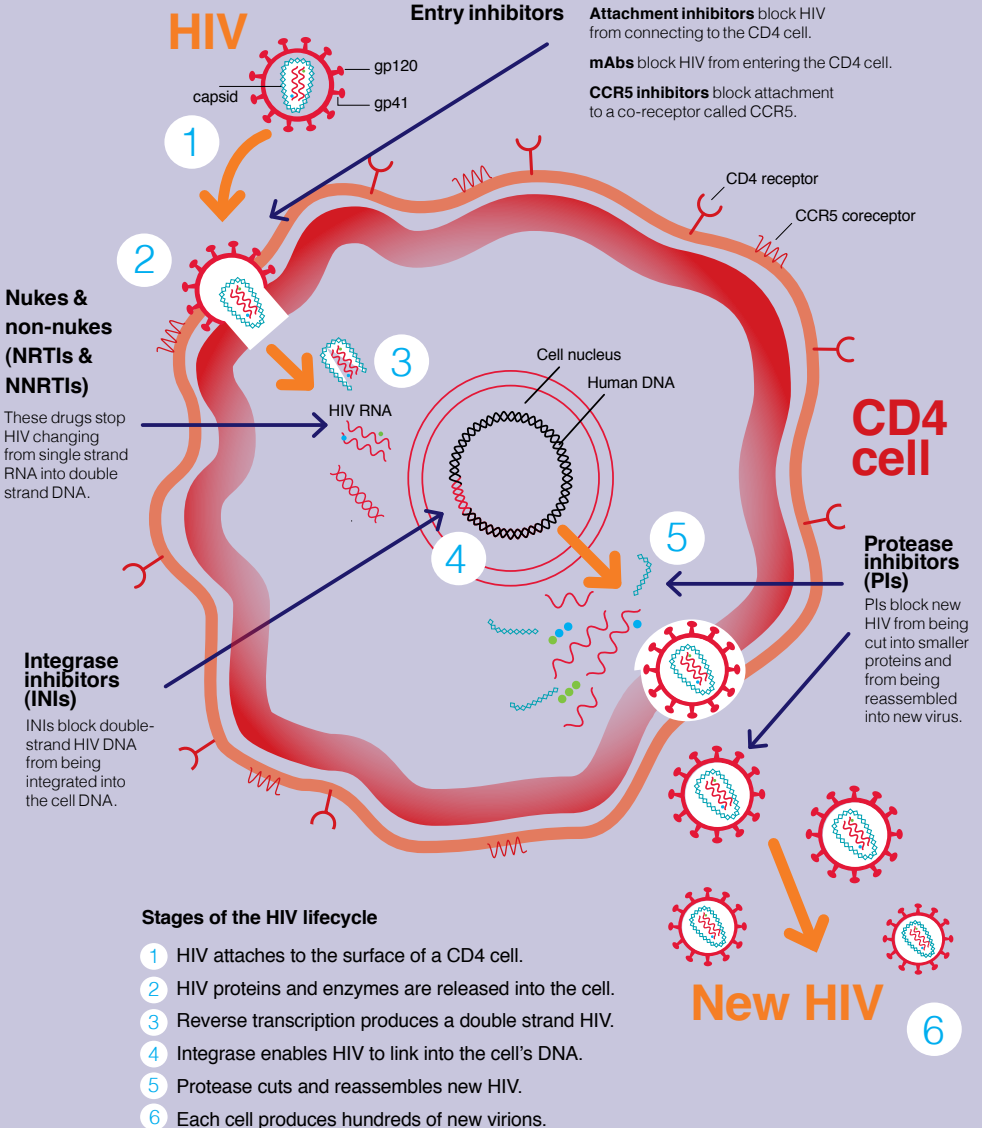
All modern combinations are effective enough to reduce your viral load to undetectable levels.

This means the main focus is to choose drugs that are easy to tolerate and adhere to.

Talk to your doctor about your choice of treatment. If you have taken HIV drugs before, or have drug resistance, this will affect your choice.

Information about dosing, pill size and side effects will help you pick a combination that is right for you.

Figure 5: HIV lifecycle – how drugs work in different ways



First combination: integrase-based ART

As UK guidelines (from 2016) were still due to be updated when we printed this booklet, this section is based on the more recent EU and US guidelines (2019).

The online version of this guide will be updated as soon as new UK guidelines are available (expected in 2020).

<http://i-base.info/guides/starting>

Most guidelines now recommend first ART that uses three drugs: an integrase inhibitor (INI) plus two nukes.

More recently, the choice of a two-drug combination has also been approved: using the integrase inhibitor dolutegravir plus one nuke (lamivudine).

An integrase inhibitor is recommended (rather than an NNRTI or PI) because they reduce viral load more quickly and often have fewer side effects.

With three-drug ART, the options for the two nukes are described on page 34.

Info on each drug

<http://i-base.info/guides/category/arvs>

Generic HIV drugs

<http://i-base.info/guides/12423>

Some combinations include a booster drug (making four drugs overall). Boosting involves slowing down how your liver processes a drug. This makes drug levels of the boosted drug stay higher for longer.

The two drugs used as boosters are ritonavir and cobicistat; they can be given as separate pills or, for some treatments, combined with one or more other drugs in a single pill.

Alternatives: using a PI or NNRTI NNRTI- or PI-based ART is an alternative in certain situations.

In these cases, guidelines recommend darunavir as the boosted PI and rilpivirine or doravirine as the NNRTI.

These drugs have limitations though. Both rilpivirine and darunavir need to be taken with food, darunavir needs to be boosted and rilpivirine can not be used if you start with a high viral load.

Doravirine is a more recently approved NNRTI that can be taken with or without food.



“Seeing people get better on ART is without a doubt the most extraordinary thing I have ever seen. It made me become an activist.”

Polly, London

“My first reaction was to put off starting ART for as long as possible. I tried to improve my immune system by stopping smoking and using supplements, until I realised that my best bet was to use ARVs. They are the only way to ensure my long-term survival.

After eight months of resisting I eventually started ART. I do not say that I gave in, but that I became more clever!”

Vladimir, St Petersburg

“No-one wants to take drugs every day and I certainly didn’t, so I put it off.

Looking back, I wish I had started sooner.

I still wonder whether the three years I spent waiting for my CD4 count to fall would have been happier and more active ones if I had started treatment at a higher CD4 count, when my doctor recommended this.”

Matt, Brighton

The two nukes

Two nukes are the basis of most combinations, with both drugs usually in a single pill. These are once-daily drugs with a low risk of side effects.

- abacavir (ABC) + lamivudine (3TC) *
- tenofovir DF (TDF) + emtricitabine (FTC) *
- tenofovir AF (TAF) + FTC

UK guidelines recommend TDF or TAF over abacavir, except when the third drug is dolutegravir.

Abacavir involves having a blood test first (called HLA B*5701) to rule out the small chance of a sensitivity reaction.

Abacavir should not be used if you have a high risk of heart problems.

TDF is widely used except in people who already have kidney or bone problems.

TAF is similar to TDF but with less impact on kidney and bone health. However, it is more expensive than either abacavir or TDF, both of which are either available as generics or will be shortly (see pages 39 to 49).

Lamivudine (3TC) and emtricitabine (FTC) are very similar drugs with few side effects. Either can be used, but they should not be taken together.

* abacavir/lamivudine (Kivexa) and tenofovir/emtricitabine (Truvada) are already off-patent. Generic versions of these drugs are now widely used in the UK.

Choice of integrase inhibitor

Integrase inhibitors (INIs) are the newest family of drugs.

There are four oral integrase inhibitors.

- dolutegravir (DTG)
- elvitegravir/cobicistat (EGV/c)
- raltegravir (RAL)
- bictegravir (BIC).

They are also in these fixed dose combinations (FDCs).

- Triumeq (DTG/3TC/abacavir)
- Dovato (DTG/3TC)
- Stribild (ELV/c/FTC/TDF)
- Genvoya (ELV/c/FTC/TAF)
- Biktarvy (BIC/FTC/TAF)

All these once-daily drugs are very effective. However, about 5% of people report mood changes or interrupted sleep. This can sometimes be reduced by taking ART in the morning.

Weight gain has been recently reported as a side effect that might be higher with dolutegravir or bictegravir, and might be higher in women compared to men.

Elvitegravir/c need to be taken with food.

The raltegravir dose involves two pills. Sometimes raltegravir is also dosed twice-daily.

Dolutegravir has a lower risk of drug resistance and it can sometimes overcome other integrase resistance (when it is used twice-daily).

The main drug interactions with INIs are with supplements that contain calcium, magnesium or aluminium. These can sometimes still be taken by separating the dosing times. See the prescribing leaflet for each drug.

Two-drug ART

Dovato is a two-drug combination of dolutegravir plus lamivudine in a single tablet.

This combination is approved and recommended as first line ART based on results showing it works just as well as three-drug ART.

This new combination is increasingly being offered as first-line ART.

Boosted protease inhibitors (PI/b)

Darunavir is the most widely used PI in the UK. However, atazanavir is still sometimes used. Both are usually boosted by either ritonavir or cobicistat. Sometimes atazanavir can be used unboosted.

Side effects from ritonavir and cobicistat include stomach upset, diarrhoea, nausea and increases in lipids. This is why PIs are not a preferred first choice.

The booster ensures better and more constant drug levels of the PI and this reduces the risk of drug resistance, *but PIs still need to be taken with food*. Also, boosters interact with other meds including inhaled, injectable, nasal sprays and steroid creams.

Ritonavir or cobicistat can be given as separate pills. There are also single pill versions of atazanavir/cobicistat (Evotaz) and darunavir/cobicistat (Rezolsta).

Darunavir is mainly used once-daily (unless there is extensive PI resistance)

Darunavir is generally easy to tolerate and fewer people switch than with atazanavir. Side effects include rash, nausea, diarrhoea, lipid changes and a higher risk of heart disease, especially with long-term use.

Atazanavir is a once-daily PI that is used less.

NNRTIs

Doravirine is a once-daily NNRTI that can be taken with or without food. It was approved in 2019 and is also available as part of a single pill **Delstrigo** with TDF and lamivudine.

Rilpivirine is a once-daily NNRTI that can only be used when viral load is less than 100,000 copies/mL.

Rilpivirine needs to be taken with a solid meal (not a protein drink). It has similar side effects to efavirenz, but they are less common. Rilpivirine is not an option if you have drug resistance to efavirenz or nevirapine.

Rilpivirine is available in two single pill combinations: **Eviplera** (with tenofovir DF/emtricitabine) and **Odefsey** (with TAF/emtricitabine). These formulations need slightly less food.

Efavirenz is a once-daily NNRTI that was widely prescribed for more than 15 years.

However, since 2015, UK guidelines have recommended using other drugs when starting ART because they have fewer side effects than efavirenz.

The main side effects of efavirenz include mood changes such as anxiety, euphoria and depression, and sleep disturbance that includes vivid dreams and nightmares.

Nearly everyone will get some side effects, but these usually get easier after a few days or weeks. About 10-20% of people stop efavirenz because of this.

Less than 3% of people get severe psychiatric symptoms, but using a different drug is important if this occurs.

If you are worried about these side effects you can use another drug.

Efavirenz can be safely used during pregnancy and when trying for a baby, even though the information that comes with efavirenz does not say this.

Efavirenz is in the single pill **Atripla** (with TDF and emtricitabine) .

Non-standard combinations

Alternatives to two nukes plus a third drug are sometimes used in individual cases or in research.

If you are already using an unusual combination that is working well, you do not need to change treatment unless there are reasons to do so.

Please ask your doctor or contact i-Base if you are unsure about your current drugs.

The following drugs are sometimes used - though rarely - when starting ART.

Juluca

Juluca is another two-drug combination. It includes dolutegravir plus rilpivirine in a single tablet.

Juluca is approved as a switch option for people who have undetectable viral load for more than six months on their current ART.

Ibalizumab - a monoclonal antibody

Ibalizumab is a new type of HIV treatment. This drug is an immune-based treatment that is given as an intravenous (IV) infusion every two weeks.

It is only used for people with extensive drug resistance.

Maraviroc (a CCR5 inhibitor) is usually only used in second-line treatment or in studies. Before using maraviroc you need a special test to check it is likely to work.

Etravirine is used if you have resistance to other NNRTIs, often in combination with boosted darunavir.

Nevirapine is an NNRTI that is no longer used because of a risk of serious side effects when you first start. If you are already doing well on nevirapine, it is a very safe drug.

Lopinavir/r (Kaletra) and **fosamprenavir/r** are older PIs that are no longer recommended in the UK.

“I’d been using efavirenz for years and I always considered myself lucky. I slept well with no vivid dreams, or obvious depression. But after several years my mental state was going down.

But later, stress at work became unbearable, I had a difficult time sleeping, and I couldn’t shake my depression and anxiety.

Instead of antidepressants, my doctor suggested first stopping efavirenz. Two weeks after switching, everything felt much more manageable.

The difference was unbelievable.”

Tim, NYC

“HIV treatment is not rocket science. You can easily learn about it. I am sure I get better treatment for my HIV because I understand what is going on. This gives me the confidence that I should live a long and happy life.

I talk with my doctor and I take an active role in my choice of treatment. I always say if I have problems with side effects or adherence.”

Paul, London

Future HIV drugs

The following new drugs and formulations might become available in 2019/20.

Learning about new research shows how your care might change in the future.

How quickly these drugs become available in the UK will depend on several factors.

Cabotegravir/rilpivirine injections

Many people are interested in ART that uses injections rather than pills.

These two long-acting drugs might mean ART can come from having subcutaneous injections (under the skin, not into a vein) every 1-2 months.

If approved, this option might become available in the UK in 2020/21.

It is already being used by people who are unable to use pill-based ART.

Islatravir (EFdA)

Islatravir is a new type of nuke that is being studied for HIV treatment and for prevention (PrEP).

It is being used in combination with the NNRTI doravirine and might be included in UK studies over the next year.

Generic HIV drugs and HIV care in the UK

In the UK, the NHS provides world-class HIV care. Access to testing, monitoring and treatment is free and this will continue in the future.

However, NHS funding restrictions mean that many services are running under tight budgets. Some services are changing and some have already been cut.

This is helped by community and healthcare organisations producing guidelines such as the British HIV Association Standards of Care for People Living with HIV (2018).

Drug costs and treatment choice

UK treatment guidelines are clear that the choice of HIV drugs should be based on best medical need.

- HIV drugs are based on being most effective - not just on the price.
- But if two similar drugs are just as good, the least expensive should be used first.
- If there are clinical reasons to use more expensive drugs, these will continue to be available.

Generic ARVs

When a drug is first approved, the manufacturer is given a license – called a patent. This usually allows 10 or more years for a company to profit from its investment.

After the patent ends, other companies can make the same drug. These generic drugs are the same quality but they are usually much cheaper.

- In the UK, 60-85% of all NHS prescriptions are for generic medicines.

- The cost savings enable the NHS to continue to provide free health care.
- Some of the HIV drugs that are widely used are now off-patent and more will follow.

Just like in other health areas, the NHS will use generic HIV drugs unless the original manufacturers lower their prices.

- Generic drugs are just as carefully made as the originals. They are the same high quality with the same active ingredients.
- Generic drugs are just as effective as the original versions.
- Generic drugs might be a different shape and/or colour to the original drug. The packaging, manufacturer and brand name are different but the active ingredients are the same.

Your doctor and pharmacist should always explain when you are changing to a generic drug.

Generic drugs and single pill combinations

Generic drugs might mean that individual drugs are used rather than a combined pill.

Depending on their cost, combination pills like Atripla, Dovato, Eviplera, Genvoya, Kivexa, Odefsey, Triumeq and Truvada might be used less often. Instead, generic components might be prescribed.

This would only increase the daily pill count by one or two pills, depending on the combination. Although an extra pill is less convenient, the savings will enable other important HIV services to continue.

“No one in the UK should still put up with side effects from efavirenz”.

The structure of HIV services

Over the last few years the structure of providing HIV care has been changing. One controversial change has been to separate HIV care from sexual health services in some parts of the country.

However, so long as HIV continues to be commissioned as a specialised service HIV care will be managed by seven different commissioning groups.

These are Scotland, Wales, Northern Ireland plus four regions for England (North, South, Midlands and London).

As each region commissions services independently, there might be differences between regions for how drugs are prescribed because each region negotiates its own drug prices.

Standards of care should remain high wherever you are treated. All drugs will still be available in every region, but different prices might affect prescribing policies. This means you might choose a clinic in a different region to access a specific drug.

The NHS is running under financial pressure from government budget restrictions. Each year, your HIV clinic has to look after more people but on the same basic budget.

Continued use of efavirenz

As mentioned earlier, efavirenz is no longer a preferred drug in any treatment guidelines.

This is because although efavirenz has a long history of being widely used and is now very cheap, many people have difficult side effects.

Some regions in the UK might continue to use this drug for the cost savings. As side effects often become manageable within a few weeks, some people might still be asked to try efavirenz first.

The only way this proposal will work will be for people who have side effects to be able to easily change if they have problems.

No one in the UK should have to put up with side effects from efavirenz.

This means if you find that efavirenz affects your sleep, your moods or your confidence, or if it makes you feel more anxious and nervous, your treatment should be switched to an alternative HIV drug.

Efavirenz should not be prescribed for anyone who is anxious or depressed or who has a history of these symptoms. It is not usually prescribed for people who work shifts.

Your treatment history

The next pages are to record your treatment and medical history.

These have been taken from the i-Base Treatment Passport which is available free from i-Base.

If you'd like a copy of the more detailed booklet please call 020 8616 2210 or go online:

www.i-Base.info

Why keep a treatment history?

Keeping a record of your treatment history can:

- Help you understand your health and treatment.
- Help empower you to manage your own treatment.
- Help if your doctor changes at your clinic.
- Help if you speak to other healthcare workers or to a treatment advocate for advice.
- Help if you ever change hospitals or clinics, if you want a second opinion, when on holiday or abroad or if you move to another country.

Any treatment choice for your future care is closely linked to your previous treatment history.

This includes results from blood tests like the CD4 count, viral load and resistance tests, as well as the history of drugs you have used and your reasons for changing them.

As treatment improves you could need this record for 20 years or more. This history will inform whether you can use new drugs in the future.

This record is important. If you change clinic you should ask for your medical records to be forwarded. Because this does not always happen or is delayed, make sure that you have a record of your hospital or clinic number.

Your own notes will help provide a useful record in all these situations.

Your doctor can help you to fill in these pages but it does not replace your medical notes.

All patients have the right to see their medical records. You can also make photocopies but you need to let the clinic know beforehand.

If you are changing clinic, it is sometimes easier to take a summary copy of your notes with you.

CD4 and viral load results

These blood tests monitor your health and your response to ART.

Even rough figures from your history are useful and your doctor can give you these.

The lowest CD4 count and highest viral load results when you were first diagnosed and before you started treatment are the most important.

Many clinics now no longer monitor the CD4 count once your CD4

count is above 500 (or perhaps 350) once you are on stable ART.

The **CD4 count** checks your immune system.

The **CD4 percentage (CD4%)** is similar to the CD4 count but is more stable, so helps interpret changes in the CD4 count.

Viral load measures the amount of HIV in a sample of blood. It shows how well ART is working.

Date (month/year)	CD4 (cells/mm ³)	CD4%	Viral load
----------------------	---------------------------------	------	------------

e.g. July 2014 335 21% 120,000

Date (month/year)	CD4 (cells/mm ³)	CD4%	Viral load
----------------------	---------------------------------	------	------------

ART history

Your choice of ART now and in the future will depend on the drugs you have used in the past and the reason you stopped using them.

It is important to know whether you stopped earlier drugs because of drug resistance or side effects.

If you can't remember exact details, even rough dates are useful (i.e. taking efavirenz for a month in 2014 etc.).

Pictures of the most common drugs with their different names are in the ARV chart in the centre page pull out section of this guide.

Drugs and/or combination details (name & dose)	Date started	Date stopped	Reason for change
e.g. efavirenz	Feb 14	May 14	Disturbed sleep.

“I was scared of ART when I arrived from Zimbabwe. I did not think it would work.

I came to the UK after my husband died and I needed treatment immediately. I told my doctor that I did not want to be on d4T and ddl and he laughed because these drugs were no longer used in the UK.

I never used to read about the meds but after my experience with efavirenz (which I changed) I now read about every drug.

I tell everyone that the drugs are fantastic because they gave me a new lease of life.”

Hosanna, UK

“I was confused about how my clinic worked. One day I asked the nurse to explain what a ‘good’ or ‘bad’ result meant.

It was really helpful. I used to be happy if my doctor just said ‘everything is okay’ – but now I want to know details. I want to know about my cholesterol, my bone health, my liver and kidneys.”

Matt, Brighton

Vaccinations and screening tests

Keep your vaccination history: hepatitis A and B, pneumovax, flu, tetanus and holiday vaccinations, etc. HIV positive people no longer need 'non-live' vaccines with a CD4 count above 500. HIV positive people on immune suppressants need special advice on vaccines. Please ask your travel clinic or GP about this.

Women over 25 need a cervical smear every year, so include this as well.

Date	Vaccination or screening test

Date	Vaccination or screening test

Trials and studies

Study name and treatment received	Dates

Resistance tests

Date	Results (continue summary on notes pages if necessary)

Glossary

adherence

The term to describe taking medication exactly as prescribed – at the right time and following any food advice.

antibody

Part of the immune system that fights an infection.

antigen

A protein found on the surface of a virus or bacteria. When the immune system recognises an antigen recognised it makes antibodies.

antiretroviral (ARV)

An HIV drug – because HIV is a retrovirus.

ART

Antiretroviral treatment.

CD4 cells

A type of white blood cell that helps your body fight infections.

first-line therapy

The first combination of HIV drugs that you use. Second-line ART is your second combination.

mutation

A change in the structure of the virus. Some mutations stop HIV drugs from working.

opportunistic infection (OI)

An infection that occurs after your immune system has been damaged by HIV.

post exposure prophylaxis (PEP)

A one month course of HIV drugs used by HIV negative person after a risk of HIV exposure.

pre exposure prophylaxis (PrEP)

When HIV negative people take HIV drugs before sex to protect against HIV.

resistance

When HIV changes it's structure so that a drug no longer works as well.

seroconversion

Very early HIV infection (usually a few weeks after infection) when your body responds to HIV.

side effect

A symptom caused by a drug. Side effects are usually negative effects.

therapeutic drug monitoring (TDM)

A test to measure the levels of a drug in your blood.

toxicity

A side effect – or the term for harm caused by a drug.

treatment-experienced

Someone who has previously used HIV treatment.

treatment-naive

Someone who has never taken any HIV drugs before. People who are treatment naive can have drug resistance if they were infected with a drug resistant strain of HIV.

triglyceride

A type of body fat related to cholesterol.

viral load test

A test to measure the amount of HIV in blood, genital fluid, semen or spinal fluid. Tests can only measure down to certain cut-off level (i.e. 50 copies/mL).

viral rebound

When viral load increases on ART from undetectable to detectable levels.

wild-type

HIV that has no drug resistant mutations. About 90% of people are first infected with wild-type virus.

Further information

If you have questions after reading this guide or would like to talk about treatment, contact the i-Base information service.

www.i-Base.info/qa

i-Base

The i-Base website has other treatment guides including translations, technical reports, an online Q&A service and many other resources.

This includes guides to changing treatment, side effects, pregnancy and hepatitis C coinfection.

www.i-Base.info

For info on each individual HIV drug:

<http://i-base.info/guides/category/arvs>

UK-CAB

A community network that focuses on treatment, including peer-support and training.

www.ukcab.net

Community support

A network of HIV support groups provide direct services for HIV positive people.

Positively UK (positivelyuk.org)

Positive East (positivееast.org.uk)

HIV Scotland (hivscotland.com)

THT online forum (tht.org.uk/myhiv)

Aidsmap run an online directory of organisations (aidsmap.com)

HIV and ageing

A UK guide to HIV and ageing (called *Coming of Age*) is available from:

www.justri.org/coming-of-age

Drug approval agencies

Detailed information on every HIV drug is available from the European Medicines Agency (EMA). This is the European organisation responsible for drug approval and drug safety.

Information is in most European languages and other scientific documents are included.

www.ema.europa.eu

UK guidelines

About 18 UK guidelines are posted to the BHIVA website.

These include treatment guidelines and UK standards of care.

www.bhiva.org


Patient rights in the UK

For information about your rights as a patient, see *Your Guide to the NHS*, available by phoning 0800 555777 or online:

nnuh.nhs.uk/docs%5Cleaflets%5C36.pdf

Information about healthcare services including how to make a complaint are on the 'About the NHS' link on the NHS homepage:

www.nhs.uk



“When I started ART 25 years ago, no one imagined the choice we have now. This makes me truly optimistic about the future.

As new drugs become available, ART will become even more individual.

A good relationship with your doctors and nurses is important – you will be seeing each other for years!”

Xavi, Barcelona

“Part of the reason I started ART was hearing the experiences of other people living with HIV and seeing how well they looked.

I am very happy on Atripla and don’t get side effects. I now run treatment workshops with African people in the UK. People want to know more and learn about their treatments.”

Winnie, London

Feedback

Your feedback on this guide helps us develop new resources and improve this resource. All comments are appreciated.

These can be made using an online survey at:

<http://www.surveymonkey.com/s/978R8F9>

Comments can also be posted to:

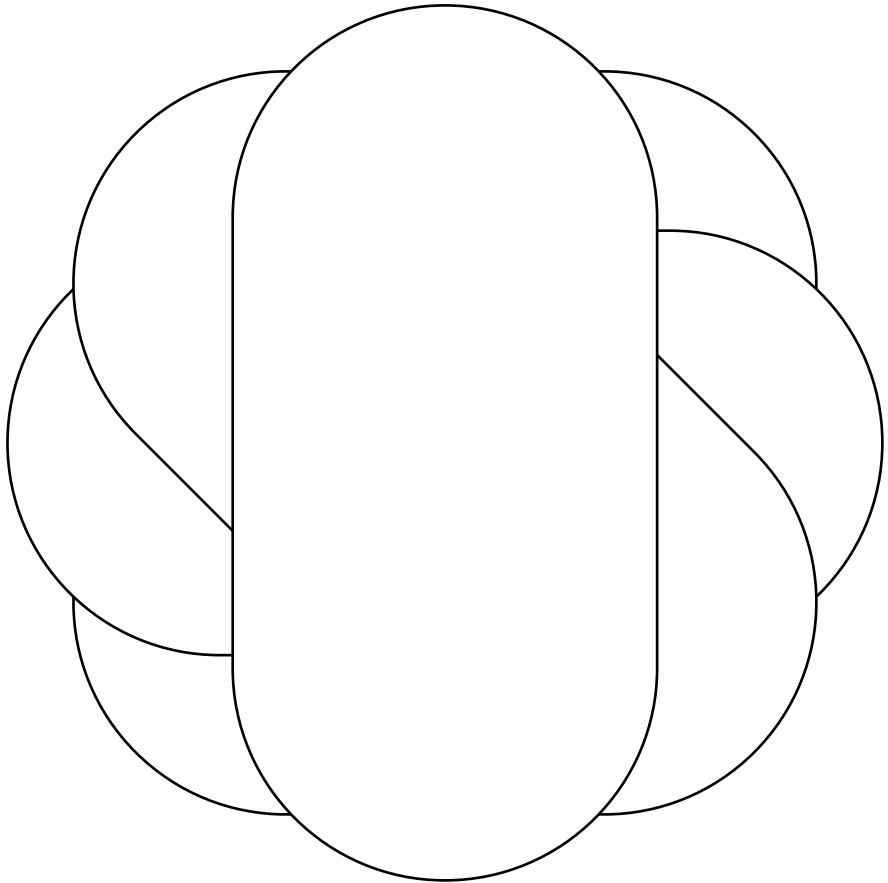
i-Base, 107 The Maltings, 169 Tower Bridge Road, London SE1 3LJ.

Other notes

ARV chart

2019/20

October 2019



A supplement to the i-Base
Introduction to ART

Drug names		Recommended adult dose *	Total daily pills
Fixed dose combinations			
	0 5 10 15 20mm	<i>Approximate to actual size.</i>	
Atripla (efavirenz + emtricitabine + tenofovir DF)		One tablet, once-daily. Take at night and not with a high fat meal. See info on separate drugs.	1
Biktarvy (bictegravir + TAF + emtricitabine)		One tablet, once-daily. Take with or without food. See info on separate drugs.	1
Eviplera (rilpivirine + emtricitabine + tenofovir DF)		One tablet, once-daily, with food (400 kcal). See separate drug info.	1
Odefsey (rilpivirine + emtricitabine + TAF)		One tablet, once-daily, take with food. See info on separate drugs.	1
Triumeq (dolutegravir + abacavir + lamivudine)		One tablet, once-daily. Take with or without food. See info on separate drugs.	1
Genvoya (elvitegravir + cobicistat + emtricitabine + TAF)		One tablet, once-daily. Take with food. See info on separate drugs.	1
Stribild (elvitegravir + cobicistat + emtricitabine + tenofovir DF)		One tablet, once-daily, take with food. See info on separate drugs.	1
Symtuza (darunavir + cobicistat + emtricitabine + TAF)		One tablet, once-daily, take with food. See info on separate drugs.	1
Delstrigo (doravirine + lamivudine + tenofovir DF)		One tablet, once-daily, with or without food. See info on each drug.	1
Dovato (dolutegravir + lamivudine)		One tablet, once-daily, with or without food. See info on each drug.	1
Juluca (dolutegravir + rilpivirine)		One tablet, once-daily, take with food. See info on separate drugs.	1






Dual nukes: nucleoside or nucleotide reverse transcriptase inhibitors (NRTIs)			
tenofovir DF 300 mg + emtricitabine 200 mg (Truvada [pictured] or generic) **		One tablet, once-daily.	1
TAF (10 mg white or 25 mg blue) + emtricitabine (200 mg), Descovy		One tablet, once-daily.	1
abacavir 600 mg + lamivudine 300 mg (Kivexa or generic) **		One tablet, once-daily.	1



Single nukes (NRTIs)


Single nukes are only used in a few situations. See back page of this leaflet for single versions of tenofovir DF, emtricitabine, abacavir and lamivudine.



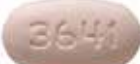

* Different doses or formulations might be used - always check doses with your pharmacist.

** Generic versions might be a different colour and shape. § EU approval pending.





NNRTIs: non-nucleoside reverse transcriptase inhibitors (non-nukes)			
efavirenz 600 mg or 200 mg (Sustiva, [pictured] or generic) **		1 x 600 tablet (or 3 x 200 caps) once-daily; at night, not with high fat meal.	1 tablet (or 3 capsules)
nevirapine PR 400 mg (Viramune [pictured] or generic) **		1 x 400 mg once a day. Take with or without food.	1 x 400 mg
etravirine (100 mg or 200 mg) (Intencele)		2 x 100 mg OR 1 x 200 mg, twice daily, take with food. Dispersible in water.	2 or 4
rilpivirine (Edurant)		1 x 25 mg tablet, once-daily, take with main meal (500 kcal).	1
doravirine (Pifeltro)		1 x 100 mg tablet, once-daily, take with or without food.	1


INIs or INSTIs: integrase inhibitors			
raltegravir 400 mg (pink) & 600 mg (yellow) (Isentress)		1 x 400 mg, twice-daily OR 2 x 600 mg tablet, once-daily. Take with or without food.	2
dolutegravir (Tivicay) *		1 x 50 mg tablet, once-daily (or 1 x 50 mg twice -daily). With food if twice-daily but with or without otherwise.	1 or 2
elvitegravir and bictegravir are only in combination pills – see Stribild, Genvoya and Biktarvy.			1

CCR5 inhibitors (entry inhibitor)			
maraviroc * (Celsentri)		150 mg or 300 mg or 600 mg, as directed, depending on other ARVs in the combination.	1 or 2 or 4

b/PI: boosted protease inhibitors			
atazanavir * (Reyataz)		1 x 300 mg cap + booster, once-daily. Take with food. 150 mg and 200 mg capsules also available.	1 (+ 1 booster)
darunavir 600 mg (orange) & 800 mg (red), (Prezista) *		1 x 800 mg + booster once-daily (OR 1 x 600 mg + 100 mg booster twice-daily with resistance). Take with food.	1 or 2 (+ 1 or 2 boosters)
atazanavir/cobicistat (Evotaz)		1 tablet, once-daily. Take with food.	1
darunavir/cobicistat (Rezolsta)		1 tablet, once-daily. Take with food.	1

PK (pharmacokinetic) boosters			
cobicistat (/c) (Tybost)		150 mg tablet, once daily. Used to boost atazanavir, darunavir and elvitegravir.	depends on boosted drug
ritonavir (/r) * (Norvir)		100 mg tablets used at different doses to boost other PIs.	depends on PI

Drug names		Recommended adult dose *	Total daily pills
Single nukes (NRTIs)			
lamivudine (3TC) ** (EpiVir [pictured] or generic)		1 x 300 mg (shown) or 2 x 150 mg, (taken as a once-daily or twice-daily dose).	1 if 300 mg 2 if 150 mg
abacavir ** (Ziagen [pictured] or generic)		2 x 300 mg tablets (taken as a once-daily or twice-daily dose).	2
emtricitabine (FTC) (Emtriva)		1 x 200 mg capsule, once-daily.	1
tenofovir DF * ** (Viread [pictured] or generic)		1 x 300 mg tablet, once-daily.	1

bNAbs (broadly neutralising monoclonal antibody) - an immune-based treatment			
ibalizumab § (Trogarzo)	 not to scale	150 mg/mL given as single IV infusion every two weeks.	none

Notes to drug chart

Some drugs are not recommended for first-line therapy.

Paediatric formulations can sometimes be used in adults if larger pills are difficult to swallow. Sometimes granules or liquids are available.

Pictures approximate to actual size.

Drugs that are used less frequently

Many older HIV drugs are now rarely used.

Information about these older drugs is available online.

<http://i-base.info/guides/category/arvs>

Please call i-Base if you would like information about other drugs printed and posted to you.

These include zidovudine (AZT), stavudine (d4T), zidovudine with lamivudine, Trizivir, lopinavir/r, fosamprenavir, tipranavir and efavirtide (T-20).

Future drugs and combinations

If new drugs are approved during 2020, details will be posted online.

<http://i-base.info/guides/category/arvs>

After drugs are approved in Europe it usually takes the NHS from 6 to 12 months to decide on UK access.



www.i-Base.info



www.nivpa.org



i-Base publications

All i-Base publications are available free.

Treatment guides are written in everyday language.

Please photocopy or post this form to

HIV i-Base, 107 The Maltings,

169 Tower Bridge Road, London SE1 3LJ.

or fax to 020 8616 1250 or order online www.i-Base.info

Please send me

Pocket size leaflets

- | | | | |
|--------------------------------------|--------------------------|-------------------------------|--------------------------|
| Intro to ART | <input type="checkbox"/> | Hepatitis C coinfection | <input type="checkbox"/> |
| Side effects & long-term health | <input type="checkbox"/> | PrEP in the UK | <input type="checkbox"/> |
| HIV and pregnancy | <input type="checkbox"/> | PrEP for women | <input type="checkbox"/> |

Treatment guides (A5 booklets)

- Introduction to ART (this guide)
- Changing treatment: what to do if viral load rebounds
- HIV, pregnancy & women's health
- HIV & your quality of life: side effects and your long term health
- Guide to hepatitis C for people living with HIV
- UK guide to PrEP
- HIV testing and risks of sexual transmission

ART in pictures: HIV treatment explained (A4 booklet)

HIV treatment bulletin (only by email)

Name

Address

Postcode **Tel**

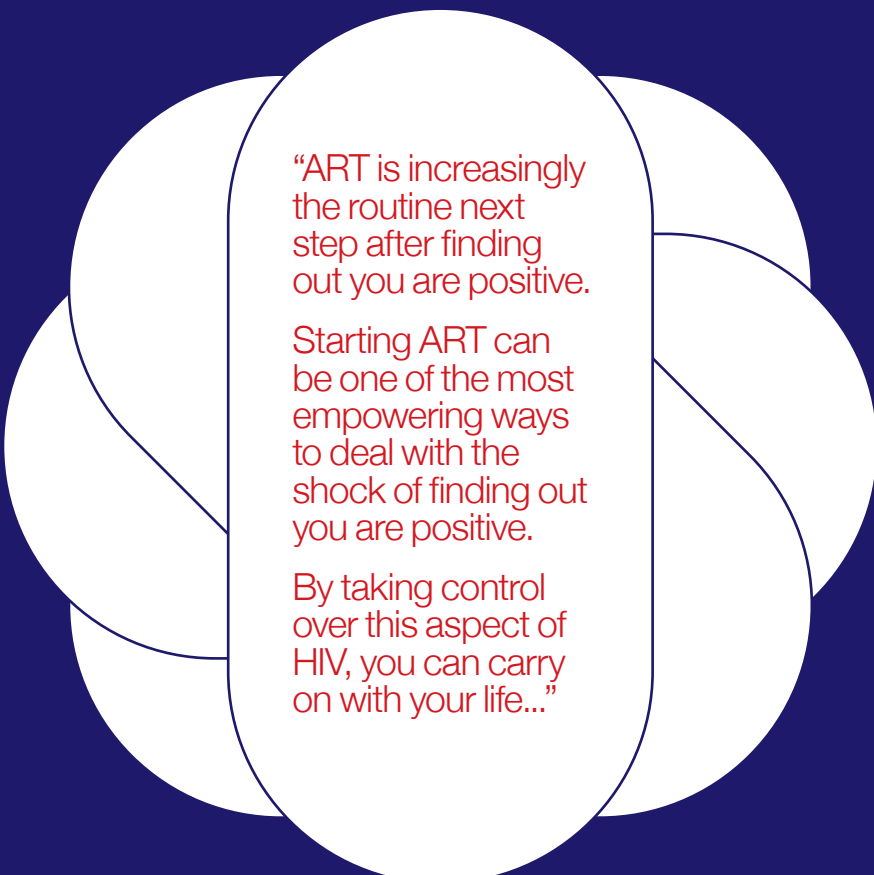
Email

Call us on

0808 800 6013

**i-Base Treatment
Information Phonenumber**

**Monday to Wednesday
12 noon to 4pm**



“ART is increasingly
the routine next
step after finding
out you are positive.

Starting ART can
be one of the most
empowering ways
to deal with the
shock of finding out
you are positive.

By taking control
over this aspect of
HIV, you can carry
on with your life...”

i-Base can also answer your
questions by email or online

questions@i-Base.org.uk
www.i-Base.info/questions