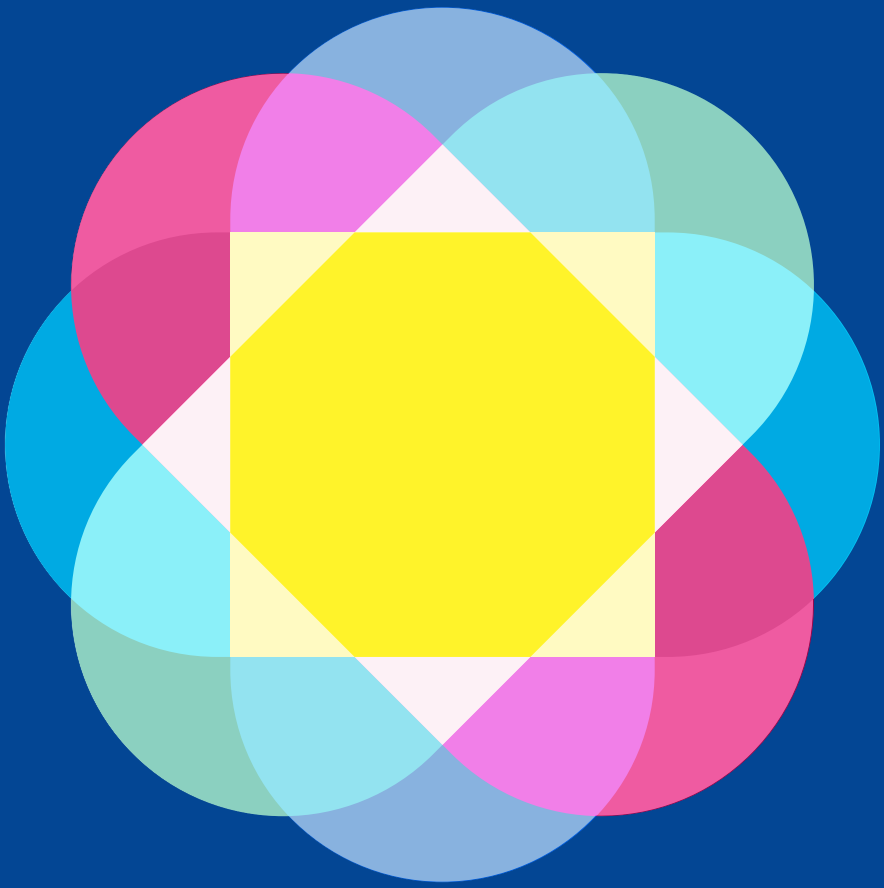
i-base
0808 800 6013

Introduction to ART

May 2018



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www.i-Base.info
Watch for out-of-date information

Contents

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.

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22nd edition, April 2018.

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.

ART:

Antiretroviral treatment

HIV:

Human Immunodeficiency Virus

Changes in this update include:

- The section on choice of meds 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 US guidelines recommend integrase inhibitor-based treatment for first-line ART.
- Information about Treatment as Prevention now includes the U=U campaign. An undetectable viral load stops HIV transmission.
- The sections on changes in NHS care have been revised.
- Information on efavirenz is updated. Although UK guidelines no longer recommend efavirenz as first treatment, it is likely to still be prescribed. This is because the generic version is now very cheap. This guide stresses that no-one should continue with efavirenz side effects: there are lots or easier choices.
- 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

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 nearly always includes at least three active drugs.

Some pills contain more than one drug and some pills contain a complete combination (of 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.

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 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.

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

"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/mm^3).
- 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.

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 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 the meds don't directly increase your CD4 count).

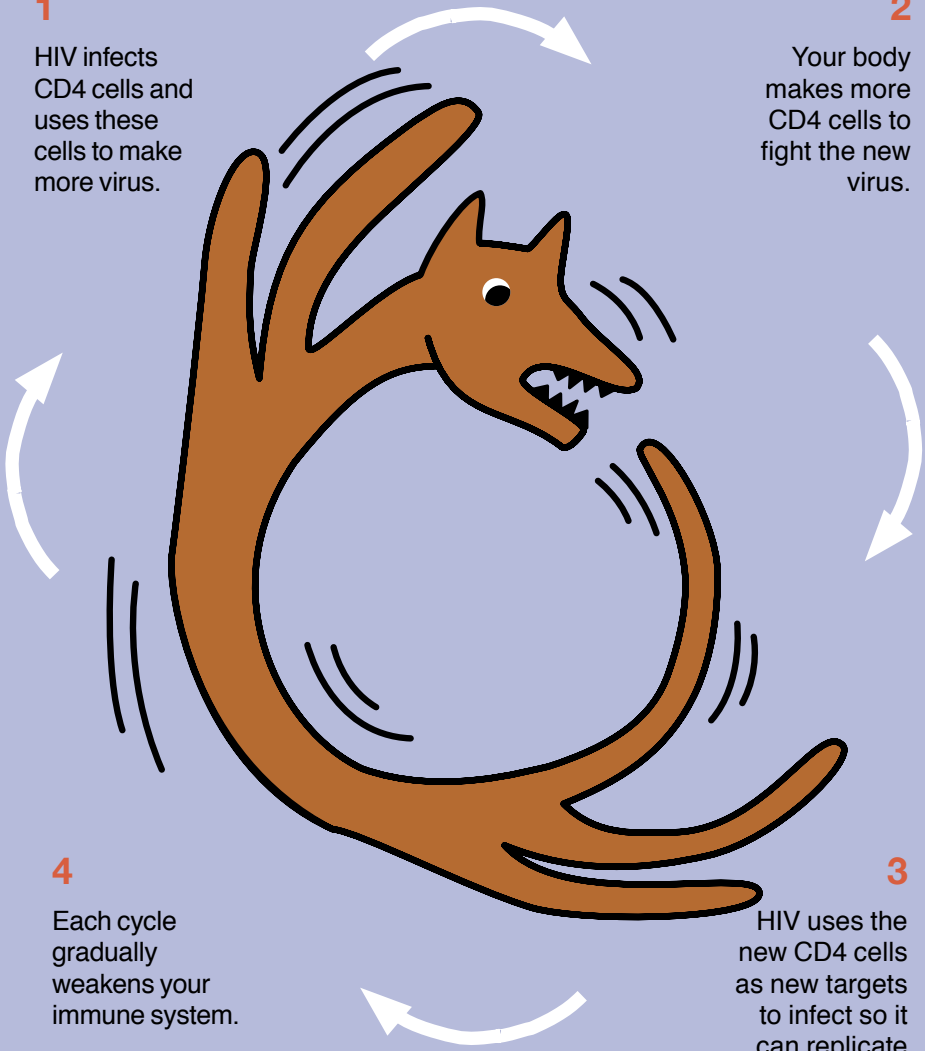
When not on ART, your immune system works in overdrive.

- 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 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 does 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 would 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.

Even after 5 to 10 years without ART, their CD4 count can stay above 500 cells/mm^3 and viral load stays very low or undetectable.

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

The benefits of ART are likely to be important for people who have LTSP or EC responses.

This is because HIV might be damaging other parts of your body than your CD4 count.

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.

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

Each issue is discussed in this booklet.

Review ART every year

Your doctor should review your ART every year. This is in UK guidelines.

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, 15 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 that the CD4 count. A CD4% of 25 to 30% is similar to an adult CD4 count of about 500.
- Many 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 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.

Although 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 (ddI, 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.

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 56 Dean Street in central 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 chose when to start and which drugs you use.

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

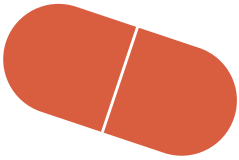
Early HIV infection is defined as being diagnosed within six months of infection.

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.

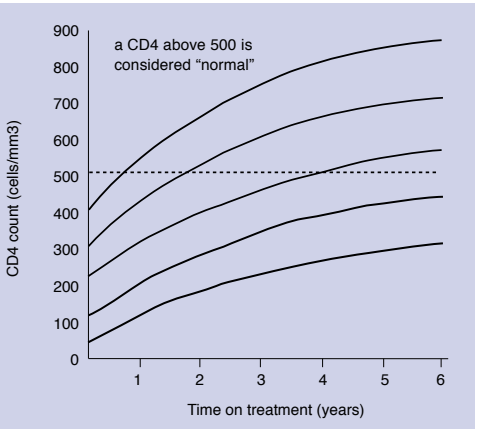
Some people only find out they are HIV positive when they already have a low CD4 count. This often means starting treatment on the same day that you first see an HIV doctor.

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.

Treatment as Prevention (TasP)

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

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

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

- The PARTNER and Opposites Attract studies have both reported zero transmissions from the positive partner with an undetectable viral load. In PARTNER, this was after 58,000 times that couples had vaginal or anal sex without condoms.
- Since 2016, the global U=U community campaign has focussed on Undetectable = Untransmittable.

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

This evidence should reduce the worry and anxiety about HIV.

It should reduce any 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

TasP 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:

- Most side effects from HIV meds 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. It 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 is 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 all 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:

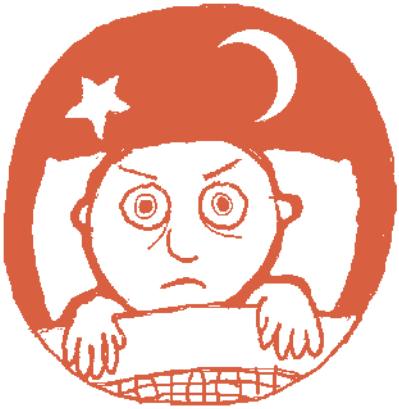
www.i-base.info/guides

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 your meds, 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.
- 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 is adherence 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 etc.
- 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.

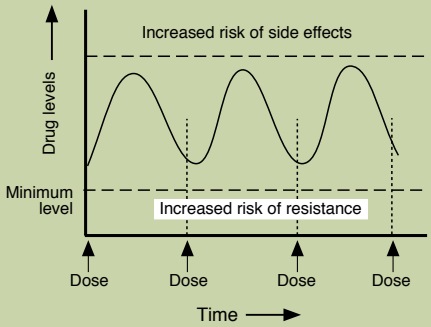
Small increases that go back down again are called 'blips'.

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.

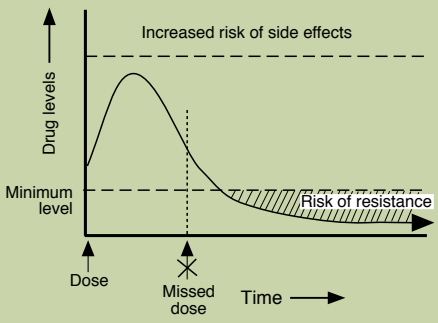
www.i-base.info/guides

Figure 3: Drug levels with good adherence



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.

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



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.

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.

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 individual aspects of your medical history and your choice.

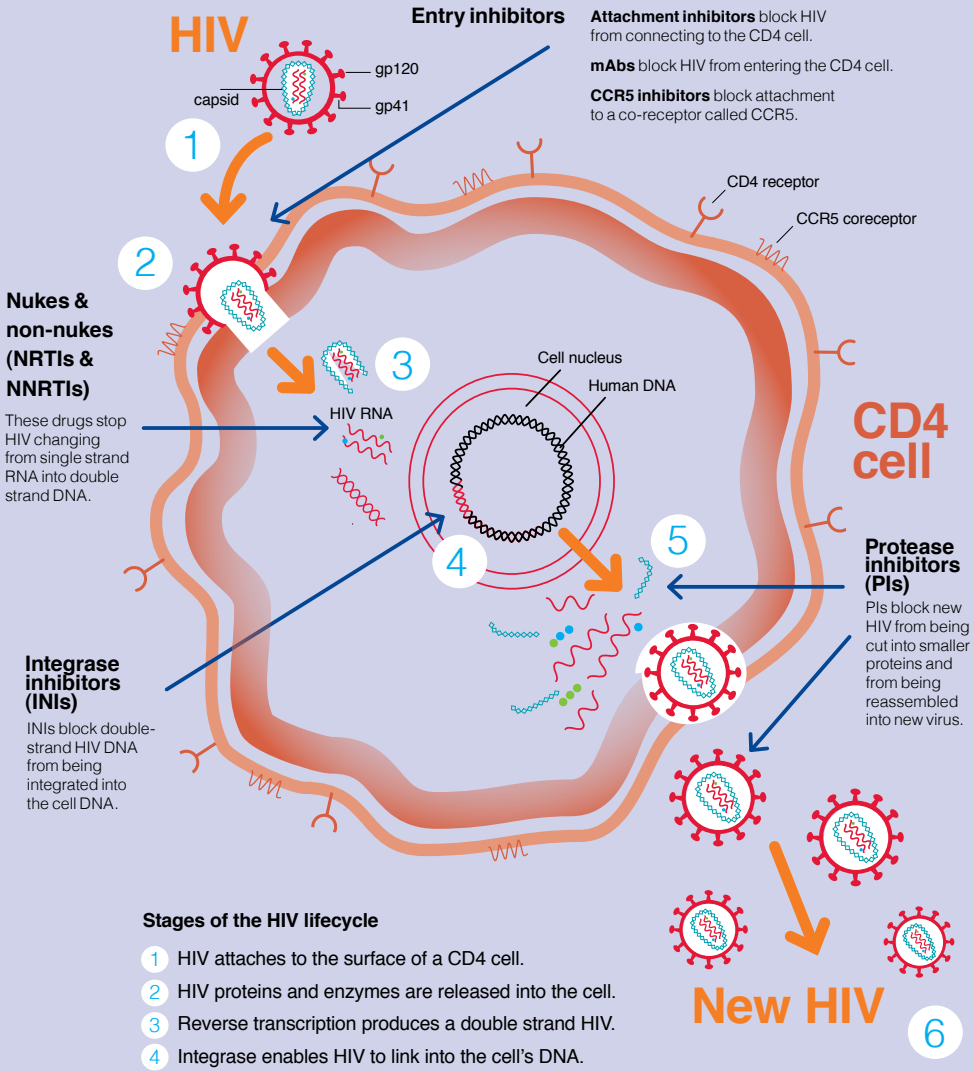
All modern combinations are effective enough to reduce your viral load to undetectable levels.

This means the main focus is to chose 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



Stages of the HIV lifecycle

1. HIV attaches to the surface of a CD4 cell.
2. HIV proteins and enzymes are released into the cell.
3. Reverse transcription produces a double strand HIV.
4. Integrase enables HIV to link into the cell's DNA.
5. Protease cuts and reassembles new HIV.
6. Each cell produces hundreds of new virions.

First combination

As UK guidelines (from 2016) were due to be updated when we printed this booklet, this section of the booklet also talks about the more recent US guidelines (2018).

The online version of this guide will be updated as soon as new UK guidelines are available (expected in late 2018/early 2019).

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

All guidelines recommend ART that includes two nukes plus a third drug from a different class.

The three options for the two nukes, have small differences that might affect your choice (see page 34).

Sometimes the third drug is boosted (making four drugs overall). Boosting involves slowing down how your liver processes a drug, so the levels 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.

US guidelines recommend that the third drug, should be an integrase inhibitor (INI) rather than an NNRTI or PI. This is because INIs are very good at reducing viral load and often have fewer side effects than PIs or NNRTIs.

For these reasons the US guidelines prefer an INI and only recommend an NNRTI or PI as an alternative in certain situations.

The most recent UK (2016) and EU (EACS) guidelines (2017) also recommend integrase inhibitors as preferred first choice. But both these guidelines also include at least one PI (boosted darunavir) and one NNRTI (rilpivirine) as a first-line option.

As both these darunavir and rilpivirine involve limitations, the US guidelines are probably a more up-to-date approach.

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.

Info on each drug

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

Generic HIV drugs

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

"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 tenofovir 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 either already off-patent or will be soon. Generic versions of these drugs are likely to be widely used in the UK.

Choice of integrase inhibitor

Integrase inhibitors are the newest family of drugs.

There are three approved oral integrase inhibitors, with the fourth (bictegravir) likely to be approved in Europe soon.

- dolutegravir (DTG)
- elvitegravir/cobicistat (EGV/c)
- raltegravir (RAL)
- bictegravir (BIC) - EU approval expected later in 2018.

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

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).

There are some drug interactions including with some supplements containing calcium, magnesium or aluminium. These supplements can sometimes still be taken by separating the dosing times. See the prescribing leaflet for each integrase inhibitor.

Some integrase inhibitors are included in fixed dose combinations (FDCs).

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

Alternative third drugs

Current UK and EU guidelines recommend other drugs as the third drug.

The most widely used alternatives are:

- A boosted PI (usually darunavir, but sometimes atazanavir).
- An NNRTI (either rilpivirine or efavirenz).

Boosted protease inhibitors (PI/b)

Darunavir is now the most widely used PI in the UK. 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 always 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 topical steroids.

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 often because of a side effect that can make skin and eyes look yellow. This is reversible if the drug is changed.

Atazanavir has an important drug interaction with over-the-counter antacid drugs including PPIs (proton pump inhibitors) and others.

NNRTIs

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.

Some regions in the UK still want to use efavirenz because it is now a generic drug that is very cheap.

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. If you get side effects from efavirenz you can change to another drug.

Efavirenz can be 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.

Several studies are looking at two-drug combinations.

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

Juluca

Juluca is the brand name for a two-drug combination of dolutegravir plus rilpivirine in a single tablet.

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

Although Juluca was approved in the EU in May 2018, it might take time for the NHS to decide on whther it will be used in the UK.

Other drugs that are sometimes used when starting ART

The following drugs are rarely used when starting ART.

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. This is to see whether your HIV uses CCR5.

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

Nevirapine is an NNRTI that is rarely 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 2018/19.

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.

Dolutegravir/rilpivirine (Juluca)

Approved in the US in November 2017 and in the EU in May 2018, Juluca is a dual combination without nukes.

It was approved as a switch option once viral load is undectectable on first ART.

Bictegravir/FTC/TAF (Biktarvy)

This integrase inhibitor was approved in the US in February 2018.

It is only available as part of a fixed dose combination with FTC/TAF (called Biktarvy).

EU approval is expected later in 2018.

Doravirine - an NNRTI

This NRTI is being developed as a both single drug and as part of a fixed dose combination (with generic TDF and 3TC).

Doravirine is also being studies as part of and FDC with 3TC and a new NRTI called MK-8591 (EFdA).

Dolutegravir/3TC

Two large ongoing studies are using this dual combination.

If effective, this might become another dual therapy option in the future.

Cabotegravir/rilpivirine injections

Many people are interested in ART that uses injections rather than pills. If effective - and early results are encouraging - this option is inlikely to be available in the UK until 2020.

Ibalizumab - a monoclonal antibody

Ibalizumab is a new type of HIV treatment that was approved in the US in March 2018. This drug is only for people with extensive drug resistance. It is not yet available in Europe.

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 manutacturer 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, an other company can then 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, 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.

In 2018, no one in the UK should have to 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 part 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 the UK treatment guidelines (or in US or European 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.

In 2018, 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 should not be precribed 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 with 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/mm3)	CD4%	Viral load
e.g. July 2014	335	21%	120,000

Date (month/year)	CD4 (cells/mm3)	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.

Other infections, STIs and illnesses

e.g. blood pressure (if high), diabetes, hepatitis, PCP, shingles, syphilis, TB etc.

Illness or infection	Treatment & dose	Dates

Side effects and allergies

Main side effects or drug allergies.

Side effect or symptom	Suspected drug	Date started/stopped

"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 ddI 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 a history of vaccination and immunisation – hepatitis A and B, pneumovax, flu, tetanus and holiday vaccinations, etc. HIV positive people usually need to use 'non-live' vaccines so you need to ask your travel clinic or GP about this. HIV positive people on immunosuppressants need special advice on this.

Women over 25 need a cervical smear every year, so keep a record of 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
The term for the degree to which a drug can cause harm.

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 focusses 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 (positiveeast.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

i-base
0808 800 6013

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 ☐
- Side effects & long-term health ☐
- HIV and pregnancy ☐
- Hepatitis C coinfection ☐
- PrEP in the UK ☐
- PrEP for women ☐

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 .....

.....

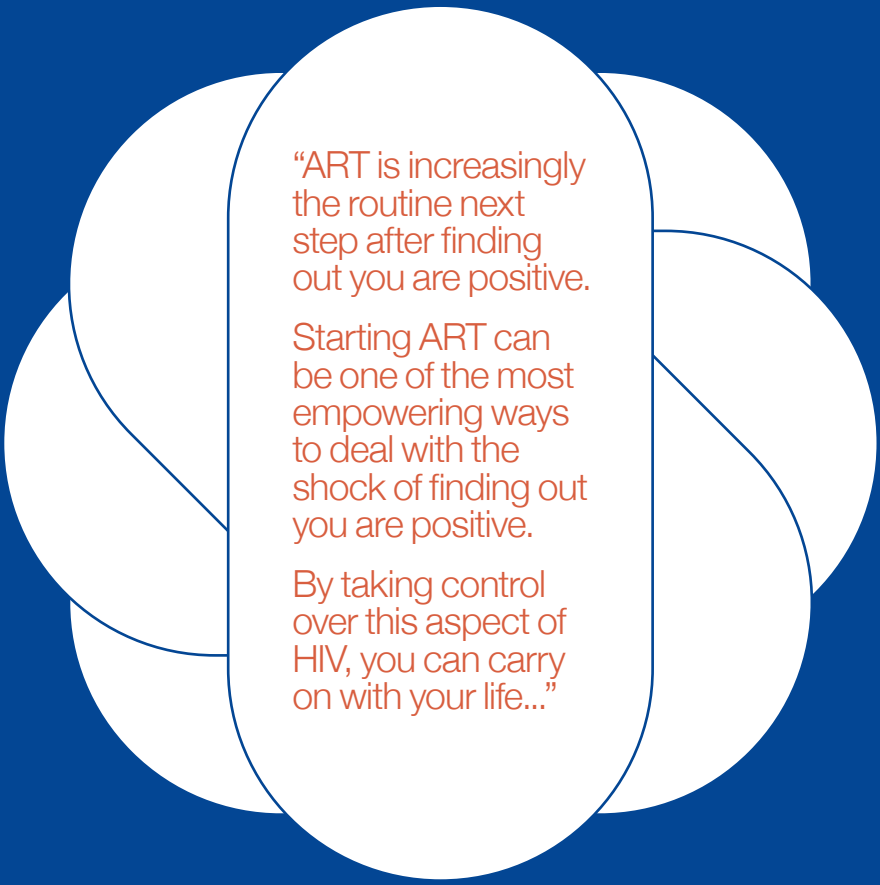
Postcode ..... **Tel** .....

Email .....

Call us on
0808 800 6013

i-Base Treatment Information Phoneline

Monday to Wednesday
12 noon to 4pm



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

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