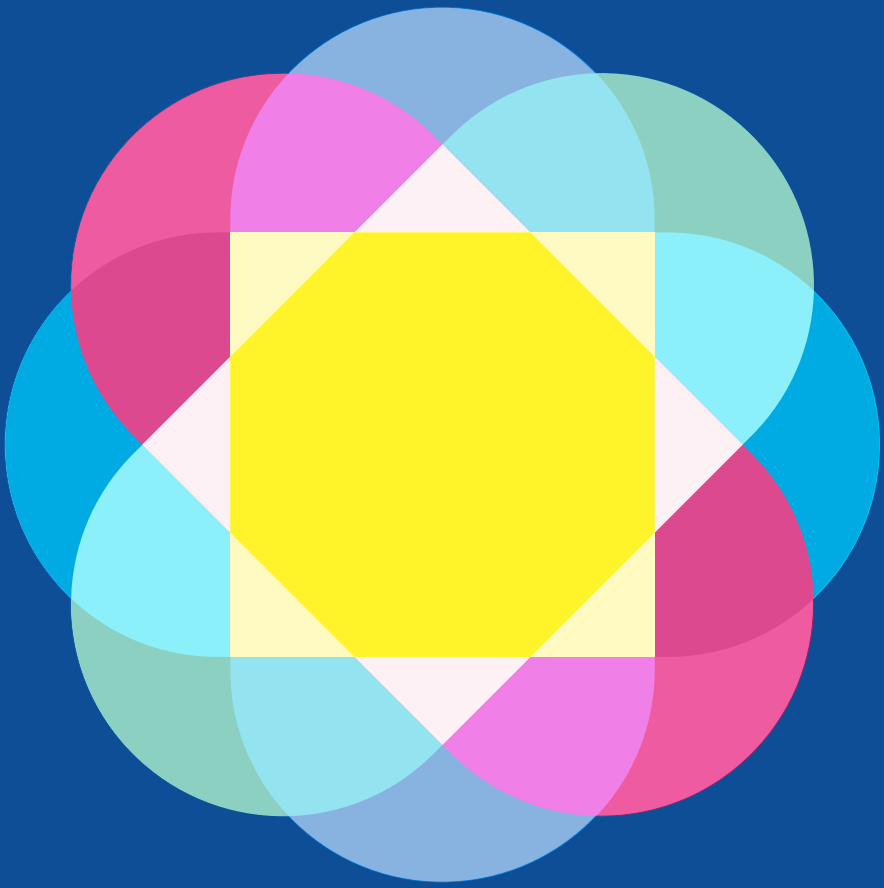
i-base
0808 800 6013

Introduction to ART

January 2016



HIV i-Base
ISSN 1475-2077
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Watch for out-of-date information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 design by No Days Off. Funding thanks to The Monument Trust.

If you have questions, i-Base runs a free treatment information service on all aspects of HIV treatment.

Phoneline 0808 800 6013
Monday– Wednesday, 12–4 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.

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

It is just as relevant for people who want to start as for those already on treatment.

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

Information is based on latest draft UK guidelines (June 2015).

www.bhiva.org

When appropriate we also refer to European and US guidelines from 2015.

www.eacsociety.org

www.aidsinfo.nih.gov

All guidelines stress that HIV treatment should be individualised.

This is a very exciting time for HIV treatment and care. But this is also a time when the NHS is facing funding difficulties.

This means that some changes - mainly the broader use of earlier and better treatment - might take time to change in all clinics.

This is a good time to take an active part in your own health care and to connect with other positive people.

This booklet is updated every year. If you are reading this after December 2016, please call i-Base for a new edition.

The main changes in this edition are:

- UK guidelines now routinely recommended HIV treatment for everyone who is HIV positive.
- Your CD4 count is no longer used to decide (or delay) when to start treatment.
- HIV treatment is so effective that a long period of monitoring and counselling before ART is no longer a barrier to starting. This important support can all come later as needed.
- The time that someone is not on treatment is more of a concern now than any risk from taking drugs.
- Using ART in very early infection (within 1, 3, or 6 months) might have additional benefits (page 16).
- Having an undetectable viral load is probably the single most effective way to stop HIV transmission (page 18).
- UK guidelines no longer recommend the HIV drug efavirenz as a preferred first treatment. Efavirenz can cause mood changes and vivid dreams. This will make starting treatment easier (pages 31 and 38 to 40)
- Information is included on drugs and formulations that might become available over the next year (page 39).
- The 4-page drug chart in the centre pages now only includes the most commonly used HIV meds.
- Information about other drugs are still in the online version.

  www.i-base.info/guides/starting

First questions: what, when, why?

What is ART?

ART stands for antiretroviral treatment. It is also called therapy or 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 single pills contain a complete combination.

Does ART really work?

ART has reduced HIV-related deaths and illnesses in every country.

More than 15 million people are now on treatment worldwide.

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

Taking drugs exactly as prescribed reduces the virus in your body to tiny amounts.

Even though you will still be HIV positive, ART reduces the chance that you can transmit HIV.

Some cells in your body will always contain HIV. But research to find a cure might even overcome this in the future.

Does everyone need ART?

Mostly, yes.

This is a big change in 2015.

We now know that HIV can cause serious problems even with a strong immune system.

Treatment 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 2015 guidelines say you can begin ART whenever you are ready.

For some people this will be straight away and others might take more time.

Timing depends on your individual situation and whether you need other test results (see pages 16 to 17).

Even in your first appointment, your HIV doctor should talk about ART.

What about side effects?

ART in 2015 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.

Your quality of life should be as good or better on ART than before you started.

See pages 20 to 21.

"As an HIV positive advocate at i-Base, this has been an exciting year for our care.

The START study showed that it is better for your health to be on ART, even at high CD4 counts.

This was irrespective of age, gender, other health risks and where in the world you live.

Guidelines agreed. The UK guidelines made their biggest changes for over 10 years.

Two other studies (PARTNER and HPTN 052) showed how dramatically ART also prevents HIV transmission.

And HIV negative people using PrEP (in the UK PROUD study) were protected against HIV and reduced their anxiety and fear about HIV.

These three things together should help reduce the stigma that still exists around HIV.

ART will increasingly become the routine next step after finding out you are HIV positive. This is easier when using better drugs.

Starting ART can be one of the most empowering ways to deal with the shock of being diagnosed.

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

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 count has unexpected changes.

Viral load (VL)

- The VL test shows how much virus is in a small sample of blood. Results are given as copies of the virus per millilitre (copies/mL).
- VL tests show how well ART is working. The aim is to reduce this to less than 50 copies/mL. This is called undetectable.
- If VL doesn't become undetectable within 3-6 months, or it increases later, you might need to change treatment.
- This is because the drugs might not be working or you may not be taking them correctly.

How do HIV drugs work?

HIV drugs stop the virus from making copies of itself.

This reduces viral load to very low levels. Your CD4 count then has a chance to grow stronger again.

When not on treatment, your immune system works in overdrive. HIV infects CD4 cells and makes more virus.

Your body produces new CD4 cells to fight the virus. Then HIV uses these new cells to produce more virus. It is like a dog chasing it's own tail. See Figure 1.

Over time, and without ART, your immune system gets worn out.

How long will the drugs work?

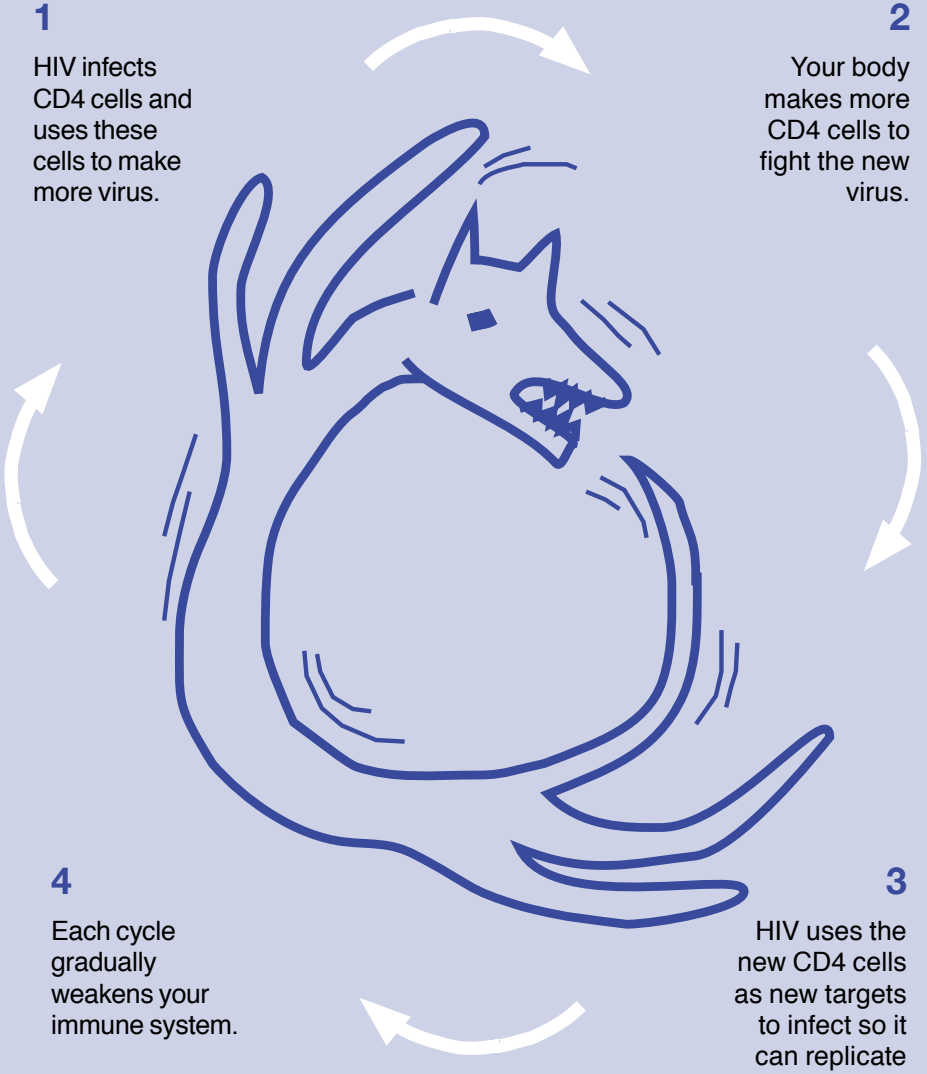
As long as you do not develop drug resistance, the same drugs can work for years or even decades.

This involves getting viral load to undetectable (less than 50 copies/mL).

This is also why it is important to take your drugs on time, to follow advice on taking with or without food, and 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 continue to be undetectable for each following year.

Figure 1: When not on ART, your immune system is like a dog chasing its tail ...



After viral load becomes undetectable on ART, your body stops this over production of CD4 cells. This immune activation cycle is stopped.

Your immune system then gets the chance to repair itself and to grow stronger.

Can I change drugs?

Yes, this is easy.

Although most people do well on their first choice, if it is difficult you can change one or all or the drugs.

This will not harm your long-term health. It will not reduce your treatment options. You can still use the same drugs in the future.

You have many choices, especially if your viral load is already undetectable.

You do not have to put up with difficult side effects.

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

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

Everything in HIV care is individual.

See pages 20-21.

Can I stop treatment?

If you have problems with ART, do not stop taking your drugs without first speaking with your doctor.

Contact your HIV clinic to book an early appointment.

Unless there is a medical need to stop, taking a break in ART is not usually recommended.

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

- Stopping ART is not generally a good idea.
- Your viral load is likely to increase within days. Each time you stop there is a risk of drug resistance.
- Your CD4 count is likely to drop. It will be more difficult to recover when you restart ART.
- If you really want to take a break, then first talk to your doctor.

  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.

What about if I have been doing well without ART?

The 2015 guidelines recommended that everyone can benefit from ART.

This means that some people will be now be thinking about ART earlier than they expected, because the advice from their doctor has changed.

Previous UK guidelines included the option to wait until the CD4 count was 350.

If your CD4 count is still above 500, it is still okay to take time to think about this. The risk of complications at high CD4 counts is still relatively low.

Also, the NHS might be slow in making changes depending on where you are treated.

In general though, your doctor is right to be talking about starting ART and this is good information.

What about slow progressors?

The range of responses to HIV has always been very wide. Some people become ill within 1 to 2 years of infection. Others can have a strong immune response that lasts for many years.

If your CD4 count stayed above 500 for more than ten years without ART you a long-term slow progressor (LTSP). If viral load is also undetectable, this is called an elite controller (EC).

The benefits of ART are now thought likely to be important for people with LTSP and EC responses.

This is because HIV may have been affecting other parts of your body than just your CD4 count.

Does ART always work?

Nearly everyone can get an undetectable viral load on ART.

If you do not get a full response it can be for one (or more) of the reasons below.

- Drug interactions (page 12).
- Side effects (pages 20 to 21).
- Adherence (pages 24 to 27).
- Drug resistance (pages 28 to 29).
- Choice of drugs (pages 30 to 38).

Knowing a little about each issue is good before starting ART.

With all these factors covered, if you have a good doctor and you take your drugs carefully, everyone starting ART should be able to get an undetectable viral load.

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, if you would like this.

Pages 22 to 23 are tips to help get the best care from the NHS.

See also:

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

Review ART every year

New research can change the way that ART is used. The drugs that your doctor prescribes today may be different from last year. And they may be different again next year.

This isn't just because of new drugs or formulations.

It is because of better understanding about many things.

- How the drugs work.
- Why drugs sometimes do not work.
- The impact of HIV when not on treatment.
- Long-term safety of drugs.

UK guidelines include that your doctor should review your treatment every year.

Should I enter a study?

Many HIV clinics are research centres and you may 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. You should not feel pressured into taking part.

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.

Your future care will not be affected if you decide not to join a study.

However, well-planned research studies can often include closer monitoring and care than your regular clinic. This may mean a few more clinic visits.

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

"I was diagnosed in Feb 2014 after one low-risk experience. I knew immediately that I wanted to start treatment and I wanted to be less infectious to any future partners, even if we are using 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 treatment, I asked for a second opinion and I changed my doctor. This led to me starting treatment when I was still within six months of infection, which may be important.

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 knew 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 and recreational drugs?

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?

The current drugs are a treatment, but they are 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.

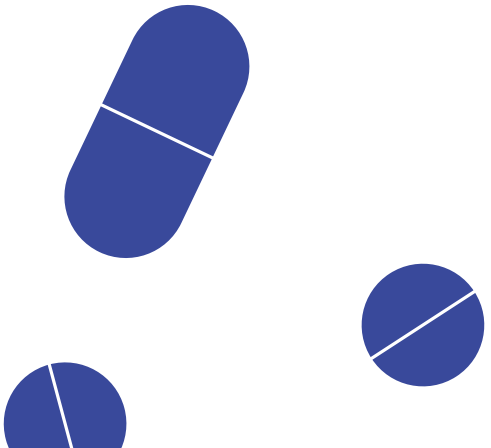
Most of your immune cells are meant to be resting. These cells are not in your blood but in lymph nodes.

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 curing HIV 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.

Research into the search for a cure for HIV 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.



"I got a shock diagnosis in January 2002 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 started on 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 medication 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.
- Some adult drugs are not yet available for young children –so there are fewer choices for treatment.

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 may 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.

Complications from HIV are likely to be reduced by using earlier ART – because there is so little virus.

Although the decision to start ART is no longer related to age, because ART is now recommended for everyone, the benefits from ART are especially important for older people. This is because we are more vulnerable as we get older.

Ageing itself is related to many health problems, and these need to be taken seriously as you grow older.

This is why lifestyle factors 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

HIV itself may also be a risk for heart disease, especially if you are not taking ART.

However, the biggest risks for heart disease are smoking, poor diet and low exercise.

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 with a link to heart disease are abacavir, maraviroc, fosamprenavir/r, lopinavir/r and saquinavir/r, and most of these are now rarely used.

It is important that your HIV doctor checks your risk of heart disease when you are first diagnosed, before ART and then every year.

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.

As with HIV negative people, lifestyle changes to reduce your risk of heart disease is good advice if you are HIV positive.

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.

Treatment during pregnancy involves specialised care. For more information see the i-Base guide: *HIV, Pregnancy and Women's Health*.

Is gender important in response to 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 after trans is used to show the diversity of transgender people.

Starting treatment

Is starting ART easy?

Generally yes. But you need to know about a few important differences between ART and other medicines.

- It is important not to miss doses of HIV drugs (see page 24 on adherence and page 30 on resistance).
- Although everyone worries about side effects, these are rarely serious (see page 20).
- You have a choice of drugs and you can be involved in this choice (see page 30).
- Once started, it is better to carry on rather than stop and start.

In practice, most people find that being on ART is much easier than they expected.

How soon do I need to start?

As with all treatment decisions this is individual. You are the person who has to take the drugs. You have a choice over when to start and the 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.

For anyone who is likely to have been infected more than six months ago and who still has a high CD4 count, starting a few weeks or months earlier or later is unlikely to make much difference.

- Take time to 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.

Early diagnosis and primary infection

Primary HIV infection is defined as being infected within the last 4 to 6 months.

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.

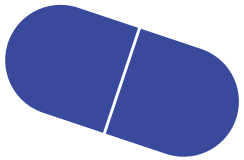
Also, the results only give a rough guide, so are interpreted with your recent risks.

This is important to know because there may be additional benefits from starting ART very soon after infection.

- To minimise the damage to your CD4 count and other aspects of your immune system.
- To reduce the risk of transmission when viral load is very high.
- To reduce the number of resting CD4 cells with HIV and to perhaps benefit from cure-related research in the future (see page 12).
- There is also a very small chance that you might be able to stop ART in the future – based on results from a French study called the Visconti cohort. This is now being studied in the UK.

If you are starting ART during primary infection, 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.



Late diagnosis and low CD4s

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

About 1 in 4 (25%) 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, across all age ranges, only find out they are HIV positive when they become ill and are admitted to hospital.

This often means starting treatment on the same day that you first see an HIV doctor.

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.

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.

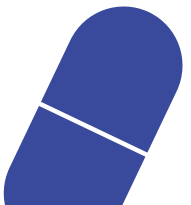
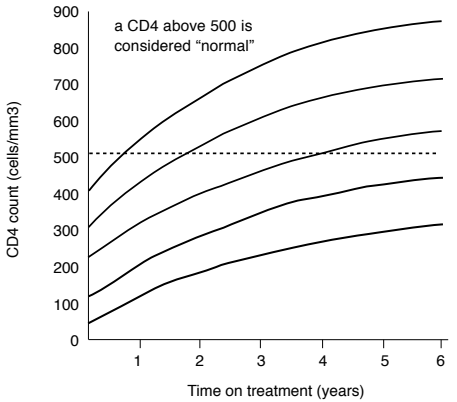


Figure 2: CD4 increases on ART



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

This may be important over 20, 30 or 40 years because your CD4 count gradually declines in older age.

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 – 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)

Another significant change in 2015 was the acceptance of how ART reduces the chance of transmitting HIV.

With an undetectable viral load, in many cases this risk is close to zero.

Although this has been known for many years, there is now much better evidence, including for gay men as well as heterosexual couples.

- The PARTNER study reported no transmissions from the positive partner with an undetectable viral load. This was after 44,500 times that people had vaginal or anal sex without condoms.
- This study is still ongoing for gay men because there were more heterosexual couples in the first part of the study.
- Condoms are still important if you want to protect against pregnancy and some STIs.

The HPTN 052 –also in couples where one person was positive and the other was negative – showed that this protection for ART continues for years when viral load is undetectable.

These facts should improve the quality of life both for anyone who is worried 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.

ART as prevention

UK guidelines recommend that all HIV doctors should talk about how ART reduces the risk of transmission.

Taking ART will benefit your own health and reduce the risk of sexually transmitting HIV.

Public health and personal choice

TasP is changing the approach to HIV treatment.

But it is important to understand the difference between public and personal benefits of ART. 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.

- Many HIV positive people do not put others at risk. This relates to their choice of sexual activity including condom use or they have partners who are also positive.
- Most new infections are likely to currently 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.
- An undetectable viral load can reduce the anxiety and worry even when you are using condoms.
- Many HIV positive people on ART like the feeling they are not infectious. Many people stop having sex after they are diagnosed because of this fear. ART makes it easier to continue to date and have full relationships.

"We are both HIV positive and not using condoms is a special part of our relationship.

We are both on treatment and have no 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.

This is 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 decides to have 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 are usually mild.
- It is easy to switch to another HIV drug or to use medication to manage the side effect.
- There is only a small risk of serious side effects. It they occur, they should be picked up by routine monitoring.
- 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.
- If you need to modify your combination, there are other drugs that may be better for you.

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 (feeling sick), diarrhoea and tiredness, are less common now than with older 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.

If the first anti-nausea or diarrhoea medications do not help, ask for more effective drugs.

Efavirenz can affect your mood and cause vivid dreams that affects how well you sleep (see page 38). 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 may 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 may reverse if you switch to different HIV drugs. Exercise and dietary changes can also help.

Fat loss (from arms, legs, face and buttocks) was due to drugs that are no longer used in the UK.

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 your combination.

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

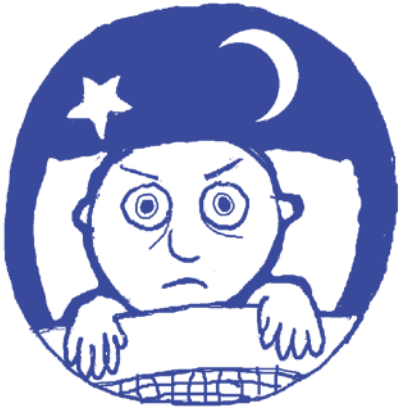
www.i-base.info/guides

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

For a free copy please call 020 7407 8488.

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.

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

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 an HIV clinic on the NHS to anyone living in the UK.

This is even for people who do not have permanent resident status.

Both you and the people involved in your care 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 seen within 30 minutes of your appointment. If the clinic is running late, this should be explained.
- 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.
- 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. This should not affect your current and future care.
- 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.
- 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, one advantage of sometimes seeing a different doctor or specialist nurse 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 regular clinic visits 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. Tell them about any other drugs that you are taking. This includes alcohol, legal and illegal drugs and complementary treatment.
- It is important to talk about your real level of adherence (see page 24). If the people managing your care don't know you are having problems, they can't help.
- Remember that your HIV doctor may not be able to treat every health issue. Your GP and other specialists might be needed to get the best care.

Why is 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 treatment.

It will make sure that all the drugs in your combination are at high enough levels to control HIV for 24 hours a day. If these levels drop too low it increases the risk of resistance.

Adherence can be difficult. You may 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 treatment when you have a few unstressed days to adjust to the changes.
- During the first few weeks, getting your treatment 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 to aim for. Even missing one or two doses a week can cause some drugs to fail, especially when starting treatment.

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 may have a bit more flexibility, but it is still important to take adherence seriously.

Tips to help

- Choose a treatment you think you can manage.
- Find out what is involved before you choose your treatment: 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. i-Base can sometimes provide these free – call the phoneline for details.

- 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! Perhaps set the alarm just after the right time, so it is a reminder and not something you rely on.
- Link 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 taken once-daily. This usually means taking them every 24 hours. Twice-daily drugs need to be taken every 12 hours.

What if I forget to take my drugs?

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 assess how adherent you are.
- If your adherence is not good, you need more support. It is available but you will need to ask.

If you regularly take your HIV drugs late or miss doses completely, talk to your doctor, nurse or pharmacist about other options.

- There may 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 pill.

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 into the night, but the dizziness after taking my pill would prevent me from doing so.

I continued for a few weeks, but was unhappy with the effect the pill was having on my life. So I switched the efavirenz to raltegravir.

My life quickly came back to normal. I am sleeping 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, even though this means I take a twice daily treatment."

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 occurs when the virus changes its structure in a way that stops a drug from working. These changes are called drug mutations.

- The risk of resistance increases when drug levels drop below a minimum active level. This usually only occurs if you miss doses or stop treatment. (See Figures 3 and 4).
- Resistance only develops if you are on treatment or in the short period after stopping treatment.
- You can be infected (or reinfected) with drug resistant HIV.

About 1 in 10 new infections in the UK 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 may 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 6 months, you can develop resistance.

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 within 2-4 weeks of the first blood sample.

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 the combination is failing it is good to confirm this early.

You will get a better response to a second treatment if you change when viral load levels are still low.

See the i-Base *Guide to changing treatment and drug resistance* for more information:

www.i-base.info/guides

How do I avoid resistance?

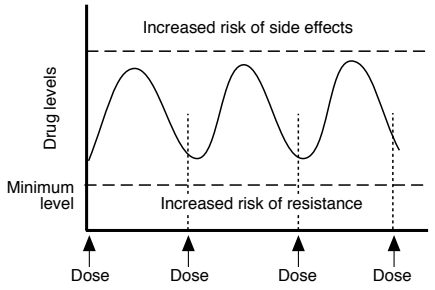
The best way to avoid resistance is to take your drugs every day and on time.

Avoiding resistance is more important than increasing your CD4 count because it will let your treatment work for many years.

Having an undetectable viral load (less than 50 copies/mL) dramatically reduces the risk of resistance.

Some drugs have a higher risk of resistance. If you are having trouble with adherence, your clinic can suggest ART that allows for this.

Figure 3: Drug levels with good adherence



Drug doses are based on average levels being high enough to be active against HIV for 24 hours. They are also low enough to minimise the risk of side effects.

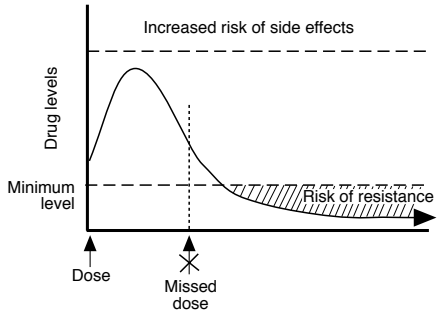
What is cross-resistance?

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.

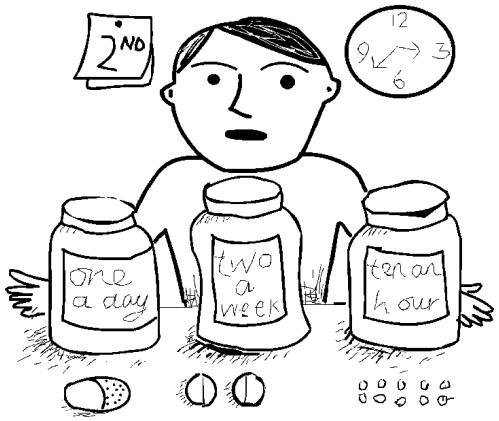
So if you develop resistance to one NNRTI such as rilpivirine then efavirenz (another NNRTI) is unlikely to work.

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.

Choosing your drugs



Main types of HIV drugs

There are six main types (or classes) of drugs that work at different parts of the HIV life cycle. (See Table 1 and Figure 5).

Table 1: Main types of HIV drugs

Abbreviation	Full names
NRTIs/NtRTIs ("nukes")	Nucleoside/tide reverse transcriptase inhibitors or nucleoside/tide analogues
NNRTIs ("non-nukes")	Non-nucleoside reverse transcriptase inhibitors
PIs	Protease inhibitors
INIs (or INSTIs)	Integrase (strand transfer) inhibitors
CCR5 inhibitors	CCR5 inhibitors are a type of entry inhibitor
Fusion inhibitors	Fusion inhibitors are a type of entry inhibitor

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

What is the best combination?

Guidelines recommend preferred combinations but also include alternatives. The most commonly used ones are discussed on the next few pages.

There isn't one best combination though because people are very different. This is why you should be involved in the choice.

Any combination should be:

- Strong enough to reduce your viral load to undetectable levels.
- Easy to tolerate and adhere to, including any dietary restrictions.

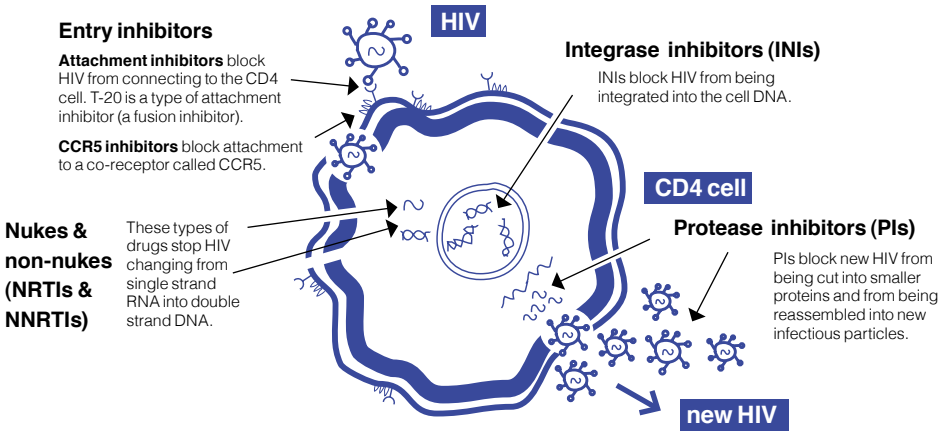
Talk to your doctor about your choice of treatment.

If you have taken HIV drugs before, or have drug resistance, this will affect your choice.

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

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

If a CD4 cell is infected by HIV, this cell is used to produce hundreds of new copies of HIV. Different drugs block different parts of this HIV life cycle.



First combination drugs

UK guidelines recommend ART that has two nukes plus a third drug from a different class.

The two columns in Table 2 show preferred drugs and alternatives.

Table 2: UK recommended drugs for first-line ART

	Preferred	Alternative *
Two nukes	tenofovir DF + emtricitabine (Truvada)	abacavir + lamivudine (Kivexa) **
Plus a third drug	atazanavir - boosted PI ***or*** darunavir - boosted PI ***or*** dolutegravir - integrase inhibitor ***or*** elvitegravir - boosted integrase inhibitor ***or*** raltegravir - integrase inhibitor ***or*** rilpivirine - NNRTI *	efavirenz (NNRTI) ***

Adapted from BHIVA guidelines (June 2015, draft). * Drugs that can only be used in some situations.
** abacavir + lamivudine (Kivexa) can be used at any viral load when used with dolutegravir.
*** Although efavirenz is no longer a prefered drug, it might still be offered in some clinics.

The two nukes

Nukes were the first type of HIV drugs to be developed. They are still the basis of most HIV combinations.

Two widely-used formulations include two nukes in the same pill. One is called Truvada (tenofovir DF + emtricitabine) and the other Kivexa (abacavir + lamivudine).

UK guidelines recommend Truvada as a better choice for most people. They suggest Kivexa is an alternative.

These are once-daily drugs

They both generally have a low risk of serious side effects. None of these nukes have been linked to fat loss (lipoatrophy), nerve pain (neuropathy) or damage red blood cells (anaemia).

Tenofovir (TDF) is processed by your kidneys but your kidney function will be monitored if you use this drug.

You also need to be careful of other drugs that can affect the kidneys.

TDF also causes a greater reduction in bone density than other drugs.

If you already have kidney or bone problems it might be better to use alternatives to TDF.

Emtricitabine (FTC) is generally very easy to tolerate.

A mild rash on the palms of the hands was reported in about 10% in black people. This is now thought to be less common.

FTC is very similar to lamivudine (3TC), but it may have slight advantages for adherence as drug levels stay higher for longer.

Abacavir is widely used with low risk of side effects. It should not be used if your viral load is over 100,000 copies/mL unless this is with dolutegravir.

Abacavir might increase the risk of heart problems **in people who already have a high risk of heart problems**. This is not a concern in people who have lower risks for heart disease.

Abacavir can cause an allergy reaction. A genetic test (called HLA B*5701) will be used to decide if you can use this drug. If negative, this risk is very, very, low.

Allergy symptoms include fever, rash, headache, sore throat, diarrhoea, abdominal pain, tiredness, nausea, vomiting and flu-like aches that get worse each day.

Anyone who gets these symptoms must seek urgent medical advice with a view to stopping the abacavir.

If you stop abacavir because of this side effect, you must never take it again.

Lamivudine (3TC) is very similar to FTC. If nukes are prescribed separately rather than a combined pill, then either FTC and 3TC can be used.

3TC was approved in the 1990s and generic versions are less expensive than FTC.

"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 therapy 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 8 months of resisting treatment I eventually started ARVs. 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

Nukes that don't mix

Although one nuke can often be switched for another, some nukes should not be used in the same combination.

- 3TC + FTC.
- Abacavir + tenofovir (unless there are special reasons, and usually more than one other drug).
- Any triple-nuke combination

Choice of the third drug

The choice for the third drug can be an integrase inhibitor (boosted or unboosted), a boosted PI or an NNRTI, see Table 2.

- dolutegravir (INI) ***or***
- elvitegravir/cobicistat (boosted INI) ***or***
- raltegravir (INI) or
- atazanavir/b (boosted PI) ***or***
- darunavir/b (boosted PI) ***or***
- rilpivirine (NNRTI).

All combinations are very effective against HIV. Small differences are mainly related to side effects, but these are also generally mild.

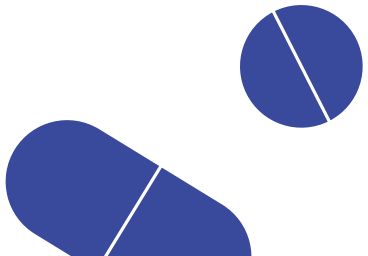
Some need to be taken with food and some have more cautions for drug interactions.

Integrase inhibitors are the newest family of drugs and are also linked to fewer side effects. Raltegravir has to be taken twice-daily.

These differences show why you need to be involved in your choice of drugs.

However, if you have problems with one drug it will be easy to switch to another.

Drugs listed as alternative rather than preferred in UK guidelines can still be good for some people.



Integrase inhibitors

Dolutegravir is an integrase inhibitor that is mainly used once-daily and that doesn't need boosting. Dolutegravir was approved in Europe in January 2014.

Dolutegravir is notable for study results that found it was at least as good as earlier preferred drugs and was often significantly better. This included studies in first-line treatment, second-line treatment and in people with more extensive drug resistance. The differences were largely due to fewer side effects than the comparison drugs.

In people with drug resistance to other integrase inhibitors, dolutegravir is taken twice-daily.

Dolutegravir results were also good in people who started treatment with viral load above 100,000 copies/mL, including if they used abacavir/lamivudine as background nukes.

A single pill of dolutegravir/abacavir/lamivudine called Triumeq is also available.

Elvitegravir is a once-daily integrase inhibitor that needs to be boosted by cobicistat

Both drugs are included in a 4-in-1 single combination pill (with tenofovir and emtricitabine) called **Stribild**.

Stribild involves taking fewer daily pills than a boosted PI, but has a similar side effect profile. This includes nausea, diarrhoea and lipid changes related to the small boosting dose of cobicistat.

Raltegravir is an integrase inhibitor that is taken twice-daily.

Compared to other first line drugs that need boosting, It probably has fewer side effects like nausea, diarrhoea and lipid changes.

It has does not have side effects that affect sleep or your mood.

Raltegravir is a twice-daily drug.

It can be taken with or without food, but needs to be taken roughly every 12 hours.

If you are taking other drugs twice a day, then raltegravir might be a good choice.

Otherwise, most people find that adherence to once-daily ART is much easier than twice-daily.

Boosted protease inhibitors (PI/b)

Only two PIs are widely used: atazanavir and darunavir. Both need to be boosted by either ritonavir or cobicistat. Sometimes atazanavir can be used unboosted (see below).

The booster ensures better and more constant drug levels of the PI and this reduces the risk of resistance.

Even with the booster, these PIs need to also be boosted with food.

Currently, ritonavir or cobicistat are given as a separate pill. However, single pill versions of atazanavir/cobicistat and darunavir/cobicistat are being developed.

Ritonavir and cobicistat have similar side effects. These include stomach upset, diarrhoea, nausea and increases in lipids.

Atazanavir is a once-daily PI.

The recommended daily dose is 300 mg (taken as one 300 mg or two 150 mg capsules), boosted by 100 mg of ritonavir.

Atazanavir is generally very well tolerated but the main side effect is increased levels of a chemical in your body called bilirubin.

Although harmless, it can make your skin and whites of your eyes to look more yellow. About 1 in 10 people switch to an alternative because of this.

Bilirubin is only a worry if levels go higher than 60 to 70 mmol/L.

Sometimes the booster may not be needed and a higher atazanavir dose (400 mg) is used. But drug levels need to be checked if you do this.

Unboosted atazanavir should not be used in a combination with tenofovir.

Atazanavir interacts with some indigestion drugs like antacids (proton pump inhibitors, aka PPIs).

Darunavir is a PI that is mainly used once-daily (800 mg) plus 100 mg ritonavir or 150 mg cobicistat.

With some patterns of drug resistance, darunavir is dosed twice-daily (600 mg plus 100 mg ritonavir). This is rare though for first ART.

Darunavir is generally easy to tolerate and fewer people switch than with atazanavir.

As with other PIs, potential side effects include rash, nausea, diarrhoea and lipid changes.

NNRTIs

Rilpivirine is a once-daily NNRTI that is approved as a first-line drug, but only when viral load is less than 100,000 copies/mL.

Rilpivirine needs to be taken with food – about 500 calories (kcal). It has similar side effects to efavirenz but they are less common. It has cross-resistance with efavirenz and nevirapine.

A single pill combination of rilpivirine plus tenofovir/emtricitabine is called **Eviplera**. This formulation needs slightly less food (about 400 kcal).

"I was diagnosed with HIV in 1997 and had to start on treatment when I was still in shock. I discussed the pros and cons of each drug with the nurse but most of it went in one ear and out of the other.

I needed time to find out about the different drugs and side effects, but with a low CD4 count I needed to start treatment soon. The information I got from the clinic was detailed and complex.

I was lucky. I had a good network of positive friends and got sound advice in terms I could understand.

Over the past 18 years, I have seen treatments become easier to take with far less side effects.

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, just with a manageable illness.

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

Alternative first-line options

There are two alternative drugs that your doctor may talk about. Abacavir/lamivudine (Kivexa) is discussed above and efavirenz is discussed below.

Efavirenz – an NNRTI

Efavirenz is once-daily NNRTI. It is also in a single pill (with tenofovir and emtricitabine) called Atripla.

In 2015, UK guidelines decided other drugs are better when starting ART.

But some regions of the UK may still want to use efavirenz because it has been effective for many years and generic efavirenz is much cheaper than other drugs.

As this booklet went to press the differences between the clinical (BHIVA) guidelines and the regional prescribing guidelines were still unclear. This might change over the next year.

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 this 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.

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.

Non-standard combinations

Alternative combinations to two nukes plus a third drug are only used in specific circumstances 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.

Future HIV drugs

Over the next year, several new drugs and formulations are likely to be approved in Europe.

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

If you urgently need these drugs before approval, early access is often available.

Otherwise, this will depend on the time taken for NHS approval, and this in turn is related to the price of the drugs.

The drugs closest to approval are listed below. Watch out for further updates from conferences and on community web sites.

A new version of tenofovir DF called TAF is only being produced in pills with other HIV drugs.

- With emtricitabine (called F/TAF).
- In a TAF version of Stribild (called E/C/F/TAF).
- With boosted darunavir plus emtricitabine (called D/C/F/TAF).
- With rilpivirine (called R/F/TAF).

Depending on the price, access to TAF might be restricted to people at highest risk of kidney and/or bone complications.

New formulations of darunavir and atazanavir that have a booster dose of cobicistat in the same pill.

- darunavir/cobicistat (Prezcobix).
- atazanavir/cobicistat (Evotaz).

Although further away, some HIV drugs are being studied as a monthly injection.

Generic HIV drugs and HIV care on the NHS

In the UK, the NHS provides a very high quality of HIV care.

Access to free testing, monitoring and treatment, makes this some of the best in the world.

This will continue in the future and is helped by community and health organisations.

Drug costs and treatment choice

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

- HIV drugs are not based on the price but on being most effective.
- 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 drugs are first approved, the company that developed them gets a license to be the only manufacturer. This usually provides 10-15 years to profit from the investment costs.

After the patent ends, other companies can make the same drugs. These are called generic drugs.

- In the UK, 60-85% of all NHS prescriptions are for generic medicines.
- These savings enable the NHS to continue to provide free health care.

- Some of the HIV drugs that are still widely used are now off-patent and more will follow.

Just like in other health areas, the NHS is likely to move to 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, Kivexa, Triumeq and Truvada might be used less often.

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

The structure of HIV services: the case of efavirenz

The NHS structure will continue to change. So long as HIV continues to be commissioned as a specialised service HIV care will be managed by seven regions. There are four regions for England (North, South, Midlands and London) plus Scotland, Wales and Northern Ireland.

Standards of care should remain high wherever you are treated. There might be differences between regions for how drugs are prescribed. This is because each region negotiates its own drug prices.

All drugs will still be available in every region, but you could choose a clinic in a different region as a last resort.

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.

The low cost of efavirenz might lead to some regions in the UK to want to use it. This is even though BHIVA guidelines no longer recommend it as a preferred choice because of the higher complications with side effects.

How the different guidelines (treatment vs prescribing) resolve this issue was not clear when this booklet went to print.

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 7407 8488 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 if your doctor changes at your clinic.
- Help if you speak to other health care 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 are used to monitor your health and your response to treatment.

Even rough figures from your previous history are useful and your doctor can provide 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.

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 2010	335	21%	120,000

Date (month/year)	CD4 (cells/mm3)	CD4%	Viral load

Antiretroviral treatment history

Your choice of new and future drugs 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	Mar 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 confused about how my clinic worked, even when I was on treatment. One day I asked the nurse to explain the tests and what a 'good' or 'bad' result might mean.

It was tremendously helpful. I used to be happy with doctors saying 'everything's okay' but now I want to know details about a few key things - my cholesterol, my bone health, my liver and kidneys."

Matt, Brighton

"I was very scared of treatment. I did not think it worked cause I had just arrived from Zimbabwe.

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. It is amazing what the disparity of wealth does to countries.

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

Now I tell everyone that the drugs are fantastic because they have given me a new lease of life."

Hosanna, UK

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.

Woman 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. Unfortunately, the antibody response to HIV is too late to be effective.

antigen
A protein found on the surface of a virus or bacteria. It is recognised by the immune system which then generates 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.

regimen
Another word for combination.

seroconversion
The time after HIV infection (usually a few weeks) when your body generates an immune response to HIV.

side effect
An effect from a drug other than the reason it is used. 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.

HIV i-Base

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

www.i-Base.info

UK-CAB

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

www.ukcab.net

Community treatment information

The following community sites, most of which are based in the US, have information on individual HIV drugs, factsheets, more detailed referenced research, conference reports and treatment news.

www.aidsinfonet.org
www.aidsmeds.com
www.tpan.com
www.aidsmap.com
www.natap.org

Pipeline drugs

i-Base and the US activist organisation TAG produce a pipeline report each year.

This review covers new drugs and cure research for HIV, hepatitis and TB.

www.pipelinereport.org

HIV and ageing

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

www.justri.org

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

UK guidelines, including standards of care are posted to the BHIVA website.

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

"Get involved in choosing your treatment. It needs to fit to your life, schedules and routines as much as possible.

Being able to share with my relatives and close friends has helped me a lot. My boyfriend always asks me if I took the pills on time.

I've been taking HIV treatment for the last 20 years. When I started, no one would have imagined the choice we have now. I now feel truly optimistic about the future.

As new drugs become available, choices will become even more individualised. A good relationship with our doctors and nurses is important: we'll probably need to see them for years!"

Xavi, Barcelona

"Part of the reason I started combination therapy 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 about their treatments and want to learn."

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

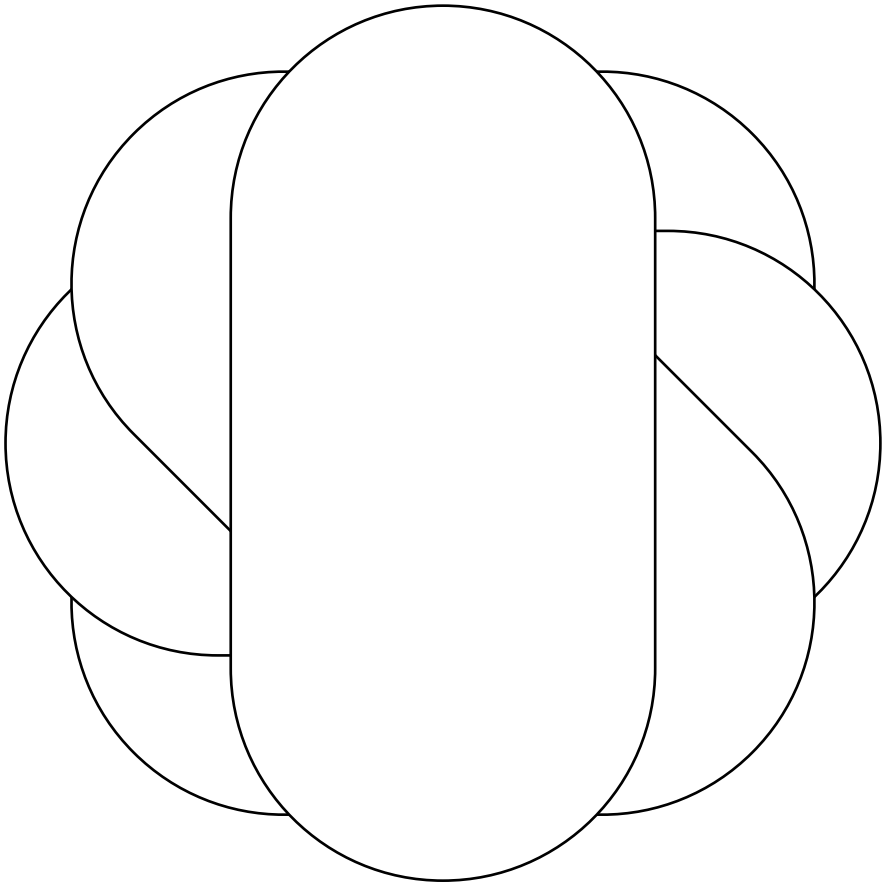
Comments can also be posted free to:

FREEPOST RSJY-BALK-HGYT, i-Base, 57 Great Suffolk Street, London SE1 0BB.

Notes

ARV chart 2016

January 2016



A supplement to the i-Base Introduction to ART

i-base 0808 800 6013

Drug names		Recommended adult dose *	Total daily pills
Fixed dose combinations §			
Atripla (efavirenz 600 mg + emtricitabine 200 mg + tenofovir DF 300 mg)		One tablet, once-daily. Take at night and not with a high fat meal. See info on separate drugs.	1
Eviplera (rilpivirine 25 mg + emtricitabine 200 mg + tenofovir DF 300 mg)		One tablet, once-daily, with food (390 kcal). See separate drug info.	1
Stribild (elvitegravir 150 mg + cobicistat 150 mg + emtricitabine 200 mg + tenofovir DF 300 mg)		One tablet, once-daily, take with food. See info on separate drugs.	1
Triumeq (dolutegravir 50 mg + abacavir 600 mg + lamivudine 300 mg)		One tablet, once-daily. Take with or without food. See info on separate drugs.	1
Genvoya (elvitegravir 150 mg + cobicistat 150 mg + emtricitabine 200 mg + TAF 10 mg)		One tablet, once-daily. Take with food. See info on separate drugs.	1
Nukes: nucleoside or nucleotide reverse transcriptase inhibitors (NRTIs)			
Dual nukes			
Truvada (tenofovir DF 300 mg + emtricitabine 200 mg)		One tablet, once-daily.	1
Kivexa (abacavir 600 mg + lamivudine 300 mg)		One tablet, once-daily.	1
Single nukes			
lamivudine (3TC) ++ (Epivir [pictured] - or generic)		1 x 300 mg or 2 x 150 mg (150 mg shown), (taken as a once-daily or twice-daily dose).	1 if 300 mg 2 if 150 mg
abacavir (Ziagen)		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)		1 x 300 mg tablet, once-daily.	1

§ New fixed dose combinations and coformulations might become available during 2016.

* Different doses and formulations might be used - always check the dose with your doctor and pharmacist.

++ Generic versions of lamivudine, nevirapine and efavirenz may be a different colour and shape.

°° Elvitegravir is only available as a separate drug on expanded access from the manufacturer.

∞ PK boosters: ritonavir is the most widely used pharmacokinetic (PK) booster. Cobicistat can only be used to boost atazanavir, darunavir and elvitegravir.

Some drugs are not recommended for first-line therapy. Smaller pills are for children or if larger pills are difficult to swallow. Some syrups are available. Pictures approximate to actual size.

Drug names		Recommended adult dose *	Total daily pills
NNRTIs: non-nucleoside reverse transcriptase inhibitors (non-nukes)			
efavirenz ++ (Sustiva) 600 mg or 200 mg		1 x 600 tablet (or 3 x 200 caps) once-daily; at night, not with high fat meal.	1 tablet (or 3 capsules)
nevirapine ++ 200 mg and nevirapine 400 mg (Viramune PR)		200 mg once-daily for first 14 days. Then 1 x 200 mg tablet, twice-daily or 2 x 200 mg once-daily; OR 1 x 400 mg prolonged release tablet once-daily (pic on right).	1 or 2 (based on 200 mg or 400 mg)
etravirine (Intelence)		1 x 200 mg tablet, twice daily, take with food. Dispersible in water.	2
rilpivirine § (Edurant)		1 x 25 mg tablet, once-daily, take with main meal (500 kcal).	1
INIs: integrase inhibitors			
raltegravir (Isentress)		1 x 400 mg tablet, twice-daily. Take with or without food.	2
elvitegravir (Vitekta) °° (see also Stribild). Named patient access only.		1 x 85 mg or 1 x 150 mg tablet, once-daily in boosted PI. Take with food.	1 (+ 1 booster)
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
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 * § (Prezista)		1 x 800 mg + booster once-daily (or 1 x 600 mg + 100 mg booster twice-daily if resistance). Take with food.	1 or 2 (+ 1 or 2 boosters based on dose)
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

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 AZT, ddI, d4T, Combivir, Trizivir, lopinavir/r, fosmprevanvir, tipranavir and T-20.

Future drugs and combinations

Several new drugs and combinations are likely to be approved during 2015/16.

Details of these will be posted online.

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

The include single pills that include the PIs atazanavir and darunavir with the booster cobicistat.

Several new fixed dose combinations in development use a new version of tenofovir DF called TAF.

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

i-base
www.i-Base.info

HIV PHARMACY ASSOCIATION
www.hivpa.org

i-base
0808 800 6013

i-Base publications

All i-Base publications are available free

Treatment guides are written in everyday language

HTB is written in more technical medical language

Please photocopy or cut out this form and post to

HIV i-Base

4th Floor, 57 Great Suffolk Street, London, SE1 0BB

or fax to 020 7407 8489

or order online www.i-Base.info

Please send me

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Intro to ART (new A7 pocket-size version of this guide) ..... ☐

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i-Base would like to thank The Monument Trust for their support in funding this publication

Call us on
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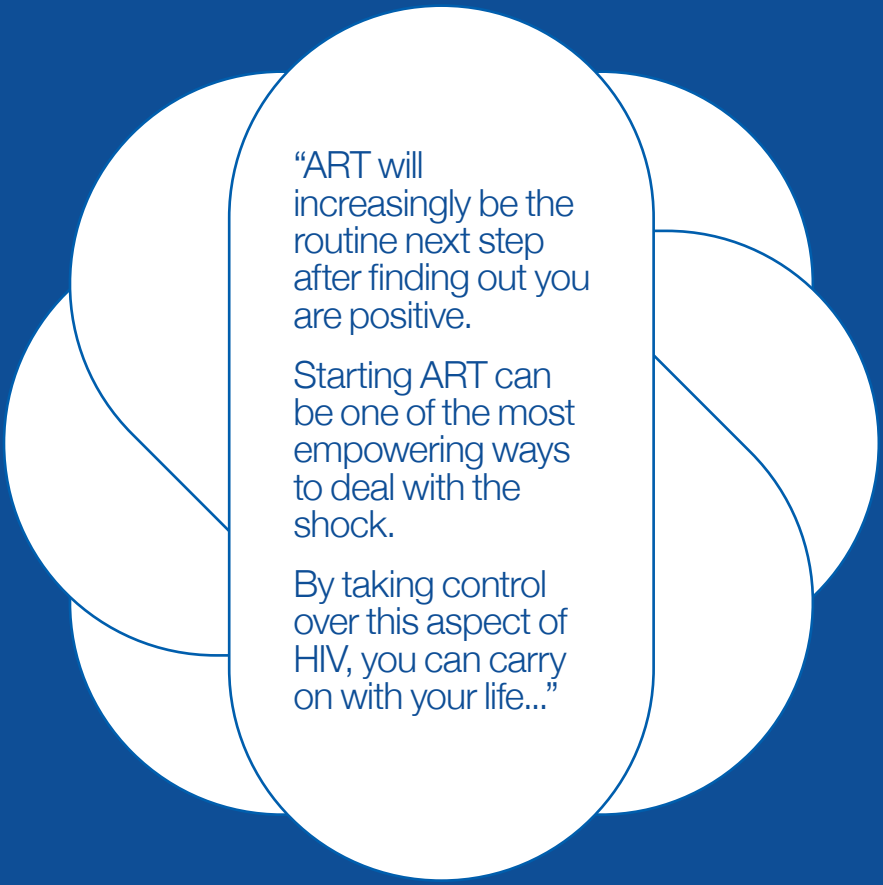
Monday to Wednesday
12 noon to 4pm



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

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