

My medication

Key

- R** A **right** you have as a user of a service
- E** An **expectation** you should have as a user of a service, based on best practice and professional standards
- A** This is **advice** on how to get the most out of your services

Will I start HIV treatment (medication) straight away?

When you start your HIV treatment (medication) depends on your CD4 count after diagnosis. Some people have to start treatment immediately if their health is at risk but for many people there will be a delay which may be months or years.

The treatment for HIV is a combination of medications called 'antiretroviral therapy', (sometimes called ART or HAART). Once you start taking treatment, you will normally have to take it every day for the rest of your life.

Your HIV doctor will recommend you start treatment when your CD4 count has fallen to around 350.¹ **E** However, your doctor should have started talking to you about treatment before this point, so you feel informed and ready to start treatment at this time. You can ask your doctor for information about treatment at any point, even if you do not need to start taking it yet.

You or your doctor may also suggest starting treatment earlier for specific reasons. These are:

- If you are pregnant, to prevent transmission of HIV to your baby² **E**
- If you also have Hepatitis C¹ **E**
- If you are in a relationship with someone who is HIV negative. Being on HIV treatment makes you much less likely to pass on HIV to your partner.¹ **E**
- If you are in a relationship with someone who is HIV negative and you want to conceive a baby naturally while reducing the risk of passing on HIV.¹ **E**

[1] BHIVA Guidelines for the Treatment of Adults with Antiretroviral Therapy 2012 http://www.bhiva.org/TreatmentofHIV1_2012.aspx

[2] BHIVA Guidelines for Management of HIV in Pregnant Women 2012 <http://www.bhiva.org/PregnantWomen2012.aspx>

This resource was proposed by an advisory board, attended by an expert panel of voluntary sector/patient organisations. The writing of the resource was undertaken by NAT (National AIDS Trust). Merck Sharp & Dohme Limited (MSD) funded and attended the advisory board, and had the opportunity to check the resource for accuracy and balance. Final editorial control was held by NAT, taking account of input from the advisory board members and other experts.

What does starting HIV treatment (medication) involve?

HIV is treated with a combination of medications called antiretroviral therapy (also known as ART or HAART). These must be prescribed by a suitably qualified doctor or nurse who will use the BHIVA treatment guidelines <http://www.bhiva.org/Guidelines.aspx> to help decide what medication is right for you.

You should receive information on:

- how well treatment works and its safety
- the different benefits and risks of different treatment options, including potential side-effects
- the importance of 'adherence' to your medication (taking it as recommended)

Your doctor or nurse should also talk to you about how HIV treatment can best fit with your personal circumstances. This includes:

- any other physical or mental health issues you may have
- how easy you will find it to take your medication during the day
- any food restrictions that apply to the medication (these are rare)

After getting information about your treatment options, you can ask to have some time to think about it before starting treatment.

As well as getting information from your doctor, nurse and other staff at your HIV clinic, you can find out more from independent and community-based organisations who are expert in treatment, including the following:

- **NAM** provides independent, clear and accurate information about HIV including treatments in a variety of formats. They also have a tool <http://www.aidsmap.com/resources/Get-set-for-HIV-treatment/page/2580444/#intro> which you can use to find out if you are ready to start treatment. www.aidsmap.com
- **HIV i-base** – is an information and advocacy group led by people living with HIV committed to providing timely HIV treatment information to HIV-positive people and to health care professionals. www.i-base.info

Can I change the HIV treatment (medication) I am on?

There are a number of reasons why you or your doctor might suggest changing your HIV treatment.

Your doctor might suggest switching to a different combination of drugs if your routine blood tests show that the treatment is not working as it should. Your doctor will then give you information about alternative treatment options.

You might also want to switch treatment because it is causing unpleasant side effects. Talk to your doctor about the side effects you are experiencing and the impact these have on your everyday wellbeing, and ask if there are any alternative treatment combinations which you could try.

For more information:

- **HIV i-base** have produced a guide for people living with HIV on changing treatment. <http://i-base.info/guides/changing>
- **NAM** have factsheets on changing treatment due to side-effects <http://www.aidsmap.com/Changing-treatment-due-to-side-effects/page/1236872/> and drug resistance. <http://www.aidsmap.com/Changing-treatment-because-of-resistance/page/1044519/>

How do I collect my HIV medication?

You can collect your HIV medication in person at the pharmacy in your HIV clinic or the pharmacy in the hospital in which your clinic is based.

You can also choose to have your medication delivered through a 'home delivery' service (also called 'local delivery'). Despite the name, some delivery companies will deliver to work places, local post offices and local branches of high street pharmacies, as well as your home. All deliveries will be unmarked so it will not be possible to know from the packaging or van that the delivery is HIV medication.

Why does my HIV clinic always ask about my 'adherence'?

Adherence is a term doctors and nurses use to talk about how well you are managing to take your medication as prescribed – at the right time of day, every day, and following any specific instructions (e.g. taking with food). Good adherence (at least 95%) is essential if HIV medication is to work effectively. If you don't take your medication as prescribed you can become 'resistant' to that drug, meaning it will no longer be effective at managing your HIV. This limits your treatment options for the future. Drug resistance happens when the HIV virus in your body changes so that those specific drugs are no longer effective. Drug resistance can be transmitted along with the HIV virus.

You will be asked at each clinic visit about how you are adhering to your medication. If you are finding it difficult you should be offered support.

Adherence is particularly challenging when you are having problems with your mental or emotional wellbeing, so your clinic should also be asking you about this side of your health and referring you on to support as needed (also see the Other Doctors I See pages) . You can also ask for support with adherence yourself at any point.

Should I sign up for clinical trials?

Clinical trials and other research into HIV treatment and care are very important for increasing our understanding of HIV and how it affects people, and knowing the best ways to prevent and treat it. Volunteering to join a trial can also be a good opportunity for individual patients to get access to new HIV medications or find out more about aspects of your health which are not covered in your usual clinic visits.

HIV clinical trials must follow strict ethical guidelines and participants are given dedicated support during the study.

Your doctor might tell you about opportunities to take part in clinical trials, or there may be posters in your clinic. If you are interested in taking part in trials you can tell your doctor.

If you want to know more about research into new HIV treatments, you can join the UK CAB HIV treatment advocates network. <http://www.ukcab.net/>

Participating in a clinical trial is not for everyone, and you should not feel obliged to take part. Trial participation is always voluntary and should not affect your normal care if you refuse. You will be asked to sign a consent form for many studies, outlining any potential risks and what will be asked of you. You can change your mind and withdraw your consent at any stage even if you have agreed already to take part.

What say do I have in the medication I am prescribed?

BHIVA provides guidelines to help your HIV doctor decide which medication to prescribe for you.¹ **E** Your doctor should provide you information about it including any possible side-effects.¹ **E** You can ask them at any point if you have any concerns about your medication or are finding it hard to take it as prescribed (see HIV Treatment and Care for more on HIV medication).

For any non-HIV health problems, you have the right to any clinically appropriate medication or other treatment which has been recommended by NICE in a technology appraisal <http://www.nice.org.uk/newsroom/nicestatistics/TADecisions.jsp?domedia=1&mid=CB611E43-19B9-E0B5-D471DEC569F73B12>, which your doctor agrees is right for your case.² **R** NICE is the National Institute for Health and Care Excellence. NICE considers all the evidence about the possible medications or treatments for a health condition and then produces technology appraisals. <http://www.nice.org.uk/newsroom/nicestatistics/TADecisions.jsp?domedia=1&mid=CB611E43-19B9-E0B5-D471DEC569F73B12> (Remember that HIV medication is not covered by NICE).

You can also talk to your doctor if you have any concerns about the medication you are already being prescribed.

[1] BHIVA Guidelines for the Treatment of Adults with Antiretroviral Therapy 2012 http://www.bhiva.org/TreatmentofHIV1_2012.aspx

[2] Handbook to NHS Constitution, March 2013.

<http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Pages/Overview.aspx>

Do I have to pay for my prescriptions?

To collect any medications your GP prescribes, go to your local high street pharmacy. You may have to pay a prescription charge for these.¹ **R** The current prescription charge is £7.85. If you need to pick up prescriptions a lot (more than 15 a year), you may find it better value to buy a Prescription Prepayment Certificate. <http://www.nhs.uk/NHSEngland/Healthcosts/Pages/Prescriptioncosts.aspx>

There are also exemptions to prescription charges. You are entitled to free prescriptions if you are^{1,2} **R**:

- getting income support, income-based Jobseekers Allowance or income-based Employment and Support Allowance
- over 60; under 16; or aged between 16 and 18 and in full-time education.
 - pregnant or have had a baby in the past 12 months, and have a MatEx certificate <http://www.nhsbsa.nhs.uk/1126.aspx>
 - living with a medical condition or disability which entitles you to a MedEx certificate <http://www.nhsbsa.nhs.uk/1126.aspx>
- an asylum seeker receiving section 95 or section 4 support

(Remember that prescription charges are not the same as the NHS charges for treatment which some migrants are asked to pay, which must cover the whole cost of treatment.)

[1] <http://www.nhs.uk/NHSEngland/Healthcosts/Pages/Prescriptioncosts.aspx>

[2] www.ukba.homeoffice.gov.uk/asylum/support/health