



Your treatment options in England

This leaflet was written by and for people living with HIV. It explains how decisions about prescribing HIV medications are made in NHS England regions. On page 2 there are contact details for further information on HIV treatment, and for your local clinic and support services. **Remember, you are not alone!**

What is HIV treatment?

- HIV treatment is usually a combination of three or more different drugs – called a ‘regimen’.
- There are many regimen options – some may suit you better than others – that are easy to take and with very few side-effects.
- Your medication may come in a single pill (called a fixed dose combination or FDC) or a small number of pills.
- They have strange names but it is useful to memorise or make a note of them in-case you need to tell someone, like another doctor or your GP.
- Since the mid-1990s these drugs have allowed people with HIV to lead a normal life like anyone else with a long-term managed health condition.
- HIV treatment only works if you take the medication as prescribed – this is called ‘adherence’.

How are decisions about my HIV treatment made?

- Your HIV team (nurse, doctor and pharmacist) has access to a range of HIV medications and different regimens. They will give you all the advice, support and guidance you need to help you decide on a treatment option that is right for you.
- Deciding on the best treatment option is based on what suits you in terms of lifestyle, possible side effects, other health issues and other medications.
- Sometimes you may need to change your HIV medication. Your HIV team will explain why this might be beneficial and what the alternatives are.

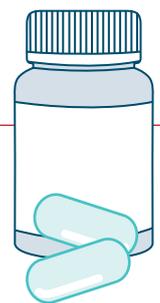
What is a ‘generic’ drug?

When a drug company makes a new drug, it is controlled under a patent for 20 years. Once the patent runs out, other drug companies can make the drug at a lower cost. These are called ‘generic’ drugs.

The NHS always tries to use generic drugs. This is normal for many health conditions. If your medication changes to a generic form it is nothing to worry about – the drug is the same, even if the pill and the packaging look different.

What does my HIV team need to know?

- **How you are feeling:** An HIV diagnosis can trigger difficult feelings and you may benefit from extra support. Some HIV drugs can also affect the way you feel. If you have suffered from anxiety or depression in the past, tell your HIV team so that they can take that into account.
- **Working life:** Shift work or irregular working times may affect your treatment options. For example, some drugs can make you dizzy, others you have to take with a meal.
- **Family life:** Tell your team what is going on in your life, for example, childcare, domestic violence, or living alone with no family. You may benefit from extra support.
- **Other medications and recreational drugs:** Tell your doctor what other medications and vitamin and herbal supplements you are taking, for example, for menopause, anti-depressants, statins, hormone treatment, methadone. These can affect how well HIV treatment works. Recreational drugs can also interact with some HIV drugs so it is best to be up front with your doctor.
- **Sharing health information:** Your HIV clinic can not legally share your health information without your permission. However, your healthcare will be easier to manage if your GP knows, for example, when prescribing for other conditions. Tell your team if you want your health information shared.
- **Side effects:** Talk to your HIV team if you think something might be a side effect. Another medication might suit you better. Find out who to talk to at your clinic and how to contact them.



What are side effects?

When you start taking HIV medication, your body can take a while to adjust. Some changes may not seem important, but **always** report anything unusual to your HIV team.

Talk to your doctor about switching to another regimen if the side effects do not go away or interfere in your day-to-day life. **Do not suffer in silence.**

Talk to your team about **anything** that makes adherence to your HIV medication difficult! They can offer advice and help with referrals for support.

Where can I get advice and support?

- You can get free online advice through community forums like myHIV or helplines (see below). All these services are confidential and helplines are anonymous.
- Find out if there are any local support services where you can get one-to-one support and advice or go to a support group and meet with other people living with HIV. This is called 'peer' support. It is comforting to meet with or speak to someone who knows what you're going through.
- Speak to your HIV team – they can also refer you to local services.

It is your right to receive respectful and non-judgemental care from your HIV team.

I have so many questions!

Below are the kind of questions we have all asked. Remember, you are not alone! Talk to your HIV team and HIV support services.

- What will happen when I start my medication?
- Who can I speak to if I'm finding it hard? Is what I am experiencing normal?
- Should I put up with side effects? What does switching to a new medication mean?
- What monitoring tests will I have? What do all the numbers for viral load and CD4 mean?
- What does being 'undetectable' mean?
- How do other people living with HIV remember to take their daily medication?
- How do I ask for counselling? If I can't cope, where do I get help?
- What services does the GP and the HIV clinic provide?
- How can I check for any drug interactions?
- Who can share information about my HIV status?
- Who should I disclose my HIV status to? Family, work and friends? And when?
- When will my children be old enough to understand my HIV status?
- How can I have sex without passing on HIV?
- How can I avoid getting other sexually transmitted infections?
- What happens if I want to have a baby?
- I want to help other people living with HIV, where do I start?

Further information

HIV i-base

Information on HIV treatment, online questions and answers, news and updates, helpline, free patient guides (ask your clinic or local support group to order them).

www.i-base.info

questions@i-base.org.uk

Confidential free helpline for treatment advice: 0808 800 6013

Terrence Higgins Trust myHIV

Online counselling and advice, live chat with online community forum, peer support.

www.tht.org.uk/myhiv

Confidential free helpline: 0808 802 1221

NAM Aidsmap

HIV-related information, including patient guides – *Taking Your HIV Treatment* and *Your Next Steps* are especially useful.

www.aidsmap.com

Positively UK

Training, advocacy, advice and support by and for people living with HIV. They run the national peer mentoring programme.

www.positivelyuk.org

Tel: 020 7713 0444

UK-CAB

HIV treatment advocacy network, free to join, online community forum, training and meetings on HIV topics.

www.ukcab.net

In my area

My clinic:

.....

Contact person/s at my clinic:

.....

.....

Tel:

Local support services:

.....

.....

.....

.....

.....

.....