

Starting HIV Treatment

Who is this leaflet for?

This leaflet is for people living with HIV who will be starting medicines to treat HIV.

What is the aim of this leaflet?

This leaflet will give you information about HIV treatment and answer some frequently asked questions.

How does treatment work?

All HIV medicines try to prevent HIV infecting new cells in your body. This is done in different ways by different medicines and so a combination provides a powerful attack on HIV. The aim of the treatment is to have very low levels of HIV in your blood, this is described as an undetectable viral load.

What are the benefits of starting treatment?

The main benefit is that people live longer, healthier lives. The harmful effects of HIV on your immune system are reduced and you are able to fight off infections. When your viral load is undetectable you cannot infect another person (transmit) with HIV. This is known as U=U (undetectable = untransmissible)

When should I start treatment?

In the clinic we follow the guidelines from the British HIV Association which recommends that everyone with HIV should be offered treatment but you will be involved in the decision about when to start.

What should be discussed with me before I start treatment?

Before starting treatment you should have discussed with a member of the HIV team:

- why it is recommended that you start treatment and potential risks of delaying treatment
- how ready you feel to start treatment
- any concerns you have about starting treatment
- any problems you may have in taking your treatment

What are the side effects of these medicines?

There are short term and long term side effects for every medicine.

The most common short term side effects are because your body is getting used to a new medicine (for example diarrhoea, feeling sick, feeling tired, disturbed sleep). After a few weeks these effects usually go away. If you find you cannot tolerate these side effects or they don't go away please discuss it with a member of the HIV team.

HIV medicines can also cause longer term side effects like bone problems, heart disease, kidney or liver problems. Monitoring and testing for long term side effects is an important part of your clinic appointment and is done by having regular blood tests, urine tests and discussing any problems.

What medicines will I start on?

You will normally start on 3 medicines some of these may be combined into the same tablet. The choice of these 3 medicines depends on many different factors and is individualised for you. You will usually be given leaflets for the medicines the team is considering before you start on treatment.

What time of day should I take my medicines?

Depending on which medicines you start they may be taken once or twice a day. A member of the HIV team will explain your new medicines to you and discuss how they should be taken and the best times to take them that fit in with your daily life.

How will I get my medicines?

The hospital pharmacy will normally dispense your medicines ready to collect at your clinic appointment. Sometimes this is not possible and other arrangements will be made with you. Your HIV medicines will usually continue to be supplied by the hospital at your follow up appointments. Your other medicines will still be supplied by your GP.

It is also an option for a Community Pharmacy to supply your medicines along with your GP medicines and you can discuss this with the HIV pharmacist or pharmacy technician.

Are there any problems between HIV medicines and other medicines I am on?

- There can be problems, known as interactions, between your HIV medicines and other medicines you get from your GP, pharmacy, supermarket or herbal products and recreational drugs.
- These interactions can affect the amount of medicine in your body and how well it works or may cause you more side effects.
- It is important that you tell the HIV team what else you are taking so we can avoid any problems. We will also look up your medication record from your GP.

How long will I be on these medicines?

When you start on HIV medicines it is a lifelong treatment. It is not recommended to stop your medicines for a 'drug holiday' as this can lead to problems like resistance limiting what medicines can be used in the future. Stopping and starting medication has also been shown to be a problem for your general health.

What is resistance?

- HIV can develop resistance to the medicines used to treat it.
- This can mean that the medicines may no longer work for you.
- The most important way you can prevent getting resistance is to take your HIV treatment as explained to you, often called adherence to treatment.
- You will have had a resistance test before you start treatment as part of the assessment of what medicines you can start on.

What is adherence and why is it so important?

- Adherence is a description of how well you are taking the medicine compared to how it was explained to you.
- Missing doses, taking the wrong doses or taking the medicine the wrong way (for example taking it on an empty stomach when it should be with food) can lead to the HIV virus becoming resistant to these medicines and the treatment may stop working for you.

- The best results for HIV treatment are seen in people who are able to take their medicine every day.
- The safest approach is to aim to take ALL your doses as explained to you.
- You will be asked at your appointments how many doses you have missed so please be open about any problems you are having and tell the HIV team so we can help.

What should I do if I miss a dose or take a dose late or I am sick after taking a dose?

You need to take the next dose of your HIV medicine before the last one is completely out of your body. Taking your medicine late can cause as many problems as not taking your doses at all. However, most HIV medicines can be taken an hour or two early or late without any problems. For each of your medicines the information leaflet given to you by the pharmacy team or in the box will give you advice on how to take your tablets if you do miss a dose and what to do if you are sick after taking a dose.

What support will I get?

When you start on these medicines you will be given contact numbers and email address for the specialist nurses and pharmacy team who will be happy to discuss any questions you have or problems you are having with your medicines. Within the first 2 weeks of treatment a member of the team will usually contact you by phone or text to check how you are getting on with your medicines.

What can I do to help me remember to take my medicines?

There are a number of 'adherence tips' we can discuss with you to help you take your medicines correctly. These include:

- taking your medicines with something you do every day (for example brushing teeth, eating breakfast)
- set a mobile phone or watch alarm
- plan ahead if there are going to be any changes to your routine
- filling a pill box weekly or using a small pill box if you are going out
- using a text reminder service

Do I have to take the tablets with food?

The printed label and leaflet for each medicine will tell you if they need to be taken with or without food. It is important to follow these directions as it can affect how well your medicines work.

Can I drink alcohol with these medicines?

Some HIV medicines can make you drowsy so if you also drink alcohol you might feel even sleepier. Also alcohol can be a problem if it causes you to forget to take your medicines or makes you sick and you may have to take another dose.

Can I take recreational drugs with these medicines?

Some recreational drugs can interact with HIV medicines affecting the amount of HIV drug and recreational drug in your body. This can result in more side effects, resistance or can even be fatal. Recreational drugs can also affect your judgement and you may take risks you would not normally take which can lead to sexually transmitted infections and other problems. Please speak to a member of the HIV team so we can advise you how to minimise these risks.

How often will I be seen at the clinic when I start on treatment?

This will vary depending on the medicines you are on and how you are feeling. You will usually be given an appointment 4 weeks after starting treatment. If you have no problems with your medicines, the time between appointments will gradually increase to a maximum of 6 months.

Will my GP know that I am on these medicines?

When you start on medicines your GP practice will be informed (a letter is sent electronically) and we will request that your record is updated with the new medicines. Having the medicines on your GP record is important because it reduces the risk that you will be prescribed a medicine that may cause problems or interact with your HIV medicines. Also if you come into hospital or are seen at another clinic or GP Practice there is a full record of all the medicines that you are taking.

If I am admitted to hospital how will I get my medicines?

If you have to come to hospital to stay as an inpatient or you are having tests when you need to take a dose then **please try to bring your own medicines** with you which means you are much less likely to miss doses. If you do not bring your own medicines they will be ordered from the hospital pharmacy.

If I am travelling abroad how should I take my medicines?

Please let us know if you are going abroad at any time and we can advise you on how to adjust your medicines depending on time changes, if you need a letter to take with you and how to carry your tablets. We also have a leaflet available about 'HIV and Travelling' which you can pick up at clinic.

What if I run out of tablets?

At your clinic visit you will be given enough tablets to last until your next appointment. If you have to change an appointment or do not attend and are going to run out of tablets then you should contact the specialist nurses or pharmacy team. If you run out of medicines do not take old medicines that you may have in the house or to take medicines belonging to someone else.

Please ensure you give at least 5 working days notice to allow time to get further supplies organised and transported to a suitable place for you to collect them. You will be given enough medicines for 1 month and will need to be seen at the HIV clinic before we can supply you with any more medicines.

Contact the team

For appointments, medicines and general queries:

Email: tay-uhb.arv.service@nhs.net (The team check this email daily except weekends and public holidays and endeavour to respond within 48 hours)

Urgent enquires phone: 01382 496554 or text 07768058301

To cancel or change appointments:

East Block Clinic, Ninewells: 01382 740082

Outpatient Clinic, PRI: 01738 473752

Sexual Health Clinic, Ninewells: 01382 425542

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