

You and your medicine: A factsheet for young people about taking HIV medication

Introduction

The medicine used to treat HIV is called Highly Active Antiretroviral Therapy (HAART). HAART is usually a mixture of 3 or more anti-HIV drugs that only work properly when they are taken together and every day. These drugs lower the amount of virus in your blood, so that your immune system can recover and your CD4 count (fighter cells) can increase. Missing a dose or taking it late can mean:

- The amount of virus in your body (viral load) goes up and the CD4 count (your fighter cells) goes down. This can make you more likely to pick up infections, so you could become unwell

OR

- The virus can become '**resistant**' to the medicine. If you miss a dose, don't take the right amount or don't take it at the right time, the medicine may stop working against the virus and new drugs are needed. If this happens, you won't be able to take that medicine again and this could become a real problem as there are only a certain number of anti-HIV drugs.

Taking medicine at the right time and the right way

Your doctor or nurse may talk about you being 'adherent to treatment'. This just means that you are always taking a medicine at the right dose (amount), the right way (with or without food), and at the right time for the medicine to work properly.

Taking medicine for HIV can be difficult. You might feel tired taking many tablets several times a day, and your busy life (school, holidays, other daily activities) may not fit in with it. This might stop you or your parents from remembering to take the medicine.

Taking medicines in front of other people can also be a problem, especially if friends or family do not know why you have to take it and they may ask you questions.

The medicine may have side effects that can make you feel worse for a short time. But it is important to remember that taking them at the right time and the right way will help keep the amount of virus in the blood very low or 'asleep', so keep you feeling well.

What do 'side effects' mean?

Side effects are when the medicines you take have unwanted effects – so you might get a headache, upset stomach, rash or diarrhoea. This might make you not want to take it; and can also make it more difficult to start or keep taking medicine. It is very important to tell your doctor or nurse as soon as you get any side effects from the medicine you're taking as we may be able to help.

What can be done about side effects?

- Not everybody gets side effects and if they do, people can get different side effects to the same medication
- Many people find that the side effects go away after a few weeks once your body has got used to the new medicine. Talk to your doctor, nurse or pharmacist, but don't stop your treatment before talking to them
- Your doctor can give you some other medicine to take with the anti-HIV drugs that will help with the side effects – so talk to them
- Your doctor and nurse can also give you some tips to help you deal with side effects
- It is important to tell your doctor or nurse if any of the tips work or not and if you still have the side effects.

What else may stop anti-HIV treatment from working well?

- Other medicines can interfere with the anti-HIV medication. Make sure you tell your doctor, nurse or pharmacist if you are taking any other

medicine; even the ones you buy at the chemist and in shops (e.g. herbal medicines or vitamins)

- Alcohol and other drugs may also affect the way anti-HIV medicines work so let the doctor know if you are taking any of these.

Missing a dose

Sometimes you may forget to take the medicine or you may be sick.

- If you are sick within one hour of taking your anti-HIV drugs or you saw a tablet in your sick, take another dose. If it's more than one hour after you took your medicines, don't take another one
- If you are sick, write down when it happened and how long it was after taking anti-HIV medicines. Take this with you to your next clinic appointment and show your doctor or nurse
- If you miss taking your medicine – maybe you forgot or went out without it – write the date and time down and tell your doctor or nurse at your next visit to the clinic. Also read the section below (What if I forget?).

Always follow the instructions

- Some medicine needs to be taken with food, some before or after mealtimes. Some should be taken on an empty stomach (i.e. 1 hour before or 2 hours after eating). Make sure you know what you need to do with your medicine and ask your doctor or nurse if you're not sure
- Don't forget to take an extra dose of your medicine with you when going out in case you do not come back home on time for your next dose
- Keep a small snack and a bottle of water with you when going out in case you need to take your medicine.

Starting taking anti-HIV drugs

Before starting treatment, talk to your doctor or nurse about:

- What your normal day is like – when you get up, when you eat, when you go to bed
- The treatments and possible side effects
- What number of pills you will take?

- Do you need to eat with them or take them on an empty stomach?
- Are you happy taking tablets? If not, ask your doctor or nurse to help with this.

Top tips to help you remember to take your anti HIV treatment

- Make a plan to find out when the best time to take your medicines is – your doctor or nurse can help with this
- Use reminders like your mobile phone, a diary or notes around the house, to help you remember
- You could use sticker or reminder charts
- For liquid medicines, use a special marked dosing cup, measuring spoon or syringe. Do not use eating teaspoons or tablespoons to measure the medicine as they are all different sizes
- Use a pill box that you fill once a week and keep it in a safe place (ask your doctor, nurse or pharmacist to give you one)
- Have a day pillbox that you always have with you, so you don't forget when you're out (ask your doctor, nurse or pharmacist to give you one)
- Don't be afraid to get help – ask your parent or guardian, or your nurse or doctor.

What if I forget?

- If you forget to take your medicine, take it as soon as you remember BUT if its nearly time for your next dose don't take two doses at the same time – if you completely forget take your next tablet as normal and write down the one you missed and tell your doctor or nurse next time you see them.

Top tips to help you take your medicines

- Make pill taking part of daily routine like brushing your teeth and washing your face, taking your pill
- Try to take all your pills/medicines at same time, this will make it easier to remember
- Be positive! You can do it

- If it tastes bad or you don't like swallowing pills, take them with food like jelly, milk, cold drink, ice cream or peanut butter. Sucking an ice cube or a mint sweet before can take away the taste
- Don't swallow tablets with thick drinks like milkshakes, as it makes them go down slower
- Some tablets can be crushed or cut and mixed with food or liquids, but ask your doctor, pharmacist or nurse first.

It's important you do not run out of medicines, so you need to plan ahead. A week before your medicines run out you need to contact your clinic if you think you won't have enough until your next appointment.

If you have to go into hospital because you are unwell, bring your medicines with you in case you have to stay.

How can I tell I need support with taking my medicine at the right time and the right way?

If you answer "yes" to any of these questions, you should talk to your doctor or nurse.

- Do you sometimes forget to take your medicine?
- Do you sometimes forget to take the medicines the right way (like with food)?
- Do you ever take the medicine at the wrong time?
- If you have a problem with taking your medicines, do you just stop taking it?
- Do you forget to get more medicine when you are about to run out?

Taking Highly Active Antiretroviral Therapy will not cure the HIV infection. BUT it will help you to stay healthy for a very long time. Your doctor and nurse know that it can sometimes be difficult to take anti-retroviral medicines every day, so please ask them for help if you are having problems.