

Taking medication for HIV:

A factsheet for parents/carers looking after children

Introduction

Medication used to treat HIV is called Highly Active Antiretroviral Therapy (HAART). HAART usually includes a combination of 3 or more anti-HIV drugs that work best when taken together and everyday. The aim is to reduce the amount of virus in the blood, so that the immune system recovers and the CD4 count (fighter cells) increase. Skipping a dose or taking it late can have several possible consequences:

- The viral load (amount of virus in the body) can increase and the CD4 count (fighter cells) decrease. This can put your child at risk of becoming unwell
- The virus can become “**resistant**” to the treatment. The way a medicine is taken is important in helping it to fight infections. If a dose is missed or not taken properly, the treatment your child is taking may not work against the virus anymore and new drugs are needed. This is a real problem for those who live with HIV and for those who treat it.

What is adherence to treatment?

Being adherent to treatment means that you are always taking a medicine at the right dose, the right way (with or without food), at the right time for it to work, and without missing or stopping a dose.

Taking medicines for HIV can be difficult. Your child might feel tired taking many tablets several times a day, and your busy life and your child daily activities (school, playtime, holidays) may not fit with the medicine schedule. This might stop you from remembering to give the medicine to your child.

Taking medicines in front of other people can also be a problem especially if friends or family do not know why your child has to take it.

The medicine may have “side effects” that can temporarily make your child feel worse. But it is important to keep in mind that only good adherence to treatment will help keep the amount of virus in the blood very low or ‘asleep’.

What does “side-effect” mean?

Side effects are unwanted (sometimes harmful) effects of the drugs. There is a small chance your child could get side effects when taking anti-HIV medicines. This usually means something like a headache, upset stomach, rash or diarrhoea. Any side effect of a medicine may make your child not want to take it; and can also make it more difficult to start or keep taking medicines to control the virus. It is very important to tell your doctor or nurse as soon as your child experiences any side effects from the medicines.

What can be done about side effects?

- If side effects from anti-HIV drugs occur they usually improve over time. Although it helps to know what to expect not everyone gets the same side effects from a medicine, some people don't have any. Discuss your concerns with your child's doctor, nurse or pharmacist. Do not stop your child's treatment before talking to them
- Your child's doctor can prescribe some other medicine to take with the anti-HIV drugs that will stop or reduce side effects from happening
- Your child's 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 your child still experiences side effects.

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

Other medicines may interfere by making anti-HIV treatment too strong or too weak.

- Tell your child's doctor, nurse or pharmacist if your child is taking any other medicine; even the one you buy over-the-counter at the chemist and grocery store (e.g. herbal medicines or vitamins)
- Alcohol and other drugs may also affect the way anti-HIV medicines work
- Record any episodes of vomiting and how long after taking anti-HIV drugs it occurs
- Give another dose of the anti-HIV drug if your child vomits within 30 min after taking the medicine or if you have seen the tablet or capsule coming out
- Record any missed doses with date and time and inform your doctor or nurse at your child's next visit to the clinic
- If your child forgets to take the medicine, administer it as soon as you remember. Do not double the dose if it is time to take the next dose. If it is too late, you might want to give the next dose earlier
- Some medicines need 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). Follow these instructions and ask your doctor or nurse if you are not sure. Keep a

snack and bottle of water with you when going out. It is also advisable to keep an extra dose of medicine with you when going out.

Hot tips to help you remember to take your anti-HIV treatment

- Before starting treatment, inform your child's doctor or nurse of daily activities or routine, mealtimes, sleeping pattern.
- Discuss the treatment, known side effects, number of pills, food requirements, how many times a day, ability to swallow tablets/capsules, size of tablet
- Ask your doctor or nurse if your child needs help with pill swallowing.
- Make a plan for medicines and daily eating times that will work for you and your child. Your doctor, nurse or pharmacist can help you do this
- Use reminders (e.g. alarm clock, mobile phone, timer, chart, diary, notes around the house) to help you remember
- Use sticker or reminder charts and involve your child in managing the treatment
- For liquid medicines, ask pharmacy to colour code the bottles with matching oral syringes (where available). This helps make giving the right dose easier. Put the same colour for the medicine on the chart or checklist. You can also 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 dossett box/pill box to fill once a week and keep in a safe place. Ask your doctor, nurse or pharmacist to give you one. Fill the pillbox up a week in advance. Take a day box with you when going out
- Refer to written instructions on medicine containers to ensure your child is taking the right dose and the right number of times per day
- **Do not run out of medicines and plan ahead.** Contact your clinic at least one week in advance if you think you will not have enough medicines until your child's next clinic appointment
- In case of hospital admission, bring your child's medicines with you. Home medicines should not be used once in hospital unless the clinician on the hospital inpatient ward agrees this.

Hot tips to help your child take medicines

Consistency is key to success. Have a matter-of-fact attitude. You expect your child to take the medicine just as you expect him/her to put on a coat before going out in cold weather. Never ask your child if s/he wants to take their medicine. This is not optional; be firm in telling your child it is time for medicine.

- It really helps your child for you to show them how pleased you are that they have taken their medicines
- Make pill-taking part of daily routine (e.g. brushing teeth, washing face)
- Try to administer pills at same time and in same place (where possible)
- Give more control to the child (e.g. which tablet they want to take first)
- Use stories/songs (e.g. waterfall washes pebble away)
- Make the process a fun experience, be positive
- Do not hesitate to congratulate your child for managing taking the medicine. Positive feedback will encourage your child to show you how well s/he is doing next time
- Do not bargain or bribe the child
- It is important to be firm and consistent but avoid power battles, punishments and threats
- Avoid tricking the child with food (e.g. hiding the tablet)
- Use food to reduce taste and help with swallowing (e.g. jelly, milk, cold drink, ice cream, peanut butter). Involve your child in choosing the type of food s/he wants to hide the taste of the medicine in. Sucking an ice cube or a mint sweet before can disguise sharp taste of medicines
- Avoid thick liquids that could slow down the swallowing process
- Some tablets can be crushed or cut and mixed with food or liquids on the advice of your doctor, nurse or pharmacist. Ask your clinician or pharmacist if your child experiences problems due to the size of the tablet
- Medicine should always be given under adult supervision. Stay with the younger child until s/he has swallowed all the medicine. Occasionally, more independent older children may still require supervision from a distance
- It might also become necessary to provide an explanation, relevant to your child's age, to why they have to take their medicine
- If your child refuses to take the medicines, stay in the room with the child, alone and remain calm. Your child will be allowed to leave the room and go back to play only after taking the medicine.

How can I tell we have a problem with adherence to treatment?

If your answer is "yes" to any of the following questions, you should seek help by talking to your doctor or nurse.

- Do you forget to take your medicine or to give it to your child?
- Do you often forget to follow instructions about the way to take the medicines (e.g. with food)?
- Do you ever give or take the medicine at the wrong time or the wrong schedule?
- If your child complains, do you stop giving the medicine?

- 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. However, it may allow your child to remain healthy for a very long time.

References

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