

INFORMATION  
ON ADHERENCE  
AND HINTS TO  
HELP MANAGE  
YOUR HIV  
MEDICATIONS

Australian Federation of AIDS  
Organisations  
PO Box 51 Newtown NSW 2042  
[www.afao.org.au](http://www.afao.org.au)  
July 2009



## WHAT IS ADHERENCE?

Adherence to your HIV treatment regimen means taking all your medications at the right time, in the right doses and in the right way.

### Taking your HIV drugs properly involves the following:

- Taking all the drugs that make up your combinations in the right quantities.
- Taking your pills at the right times.
  - Taking your medication at the wrong time can cause a rise in viral load and this may lead to the development of drug resistance.
- Making sure you take your medication with or without food, according to instructions.
  - Some medicines need to be taken with or without food to ensure correct absorption in your body.
- Checking for interactions with other medications or drugs.
  - This includes medicines that your doctor may have prescribed for you, or that you have bought from a chemist, supermarket or health store. It is important to be aware that some recreational and illicit drugs can have potentially dangerous, and in some cases, life-threatening interactions with HIV medications.

## WHY IS ADHERENCE SO IMPORTANT?

- Adherence to your anti-HIV medications is the most important element under your control in the success of your HIV management.
- Missing doses can lead to the medications not working effectively. Missing doses is associated with increases in the levels of HIV in your blood and other parts of your body (viral load), a fall in your CD4 count, and an increased risk of HIV disease progression, leading to AIDS.
- Another important factor to consider is that missing doses, taking them late, or taking them in a way that results in your body absorbing too little of them, can all contribute to the development of drug resistance or cross-resistance (becoming resistant to similar classes of drugs). This can then limit your future treatment options.
- Developing resistance means that your treatments are likely to stop working and your chance of becoming ill because of HIV is increased as the amount of HIV in your blood increases and your CD4 count falls.
- If you do develop drug resistance, you may need to change your HIV treatments, which may result in having to take more drugs, some of which may be more difficult to take and have more or new side effects.
- Because adherence is so important, some doctors think that in some circumstances it is better for your health to stop treatment completely if you are unable to adhere properly.

## HOW MANY DOSES DO I NEED TO TAKE?

The best responses to HIV treatment are seen when adherence is 100%. Levels of adherence below 95% have been associated with poor suppression of viral load and a reduction in CD4 counts.

- If you are taking once-daily treatments, 95% adherence means missing no more than one dose per month.
- If you are taking twice-daily treatments, 95% adherence means missing no more than three doses per month.
- If you are taking treatments three times a day, 95% adherence means missing no more than four doses per month.

Many people with HIV do not manage to achieve such high levels of adherence. Nevertheless, try to miss as few doses of your medication as possible. Any fall in drug levels in your body will offer an opportunity for HIV strains that are less susceptible to the action of the drugs to develop.

## HELPING YOU TO ADHERE

A wide range of factors influence people's adherence to their medication, and the relative importance of these factors differs from person to person. This means that there is no one best solution for everyone. Instead, you will need to spend time with your doctor or health care team working out what kind of things help or prevent you from adhering. One approach is to divide these issues into broad categories, such as:

- You and your medication.
- What you think about your HIV treatment.
- Support.

## YOU AND YOUR MEDICATION

Everyone can go through difficult periods with regards to adherence to his or her medications. These are some of the things that may affect your adherence to HIV medication.

- **Being involved in treatment decisions**

By being involved in deciding when to start, and choosing which medications to take, you may be more likely to adhere well. Similarly, if you understand why you need to

take medication and the benefits of treatment and how these outweigh the risk of side effects, you are also more likely to adhere.

- **Depression and other mental health problems**

Mental health problems such as depression lead to poorer adherence. If you about to commence HIV antiretroviral treatment and are experiencing depression or are otherwise concerned about your mental health, and consequently do not feel that you are able to adhere to your treatment regimen properly, then it might be best to wait until you feel better able to cope.

Many people living with HIV experience periods of depression, so if you think that depression is having an effect on your adherence, it is important to speak with your doctor or other mental health professional to seek support and treatment.

- **Lack of money, housing problems, other problems**

Lack of money, housing problems or feeling isolated and alone may affect your ability to adhere. Not having enough money could mean that you are unable to eat properly or meet the cost of your medications. There are a number of organisations that can provide financial counselling and assistance to help you meet the cost of medications. As eligibility criteria may apply, check with your local AIDS council or PLWHA organisation for assistance.

Having housing problems, or living in poor quality housing has been shown to lead to lower levels of adherence, as has excessive or problematic drug and alcohol use. However, you should not assume that just because you have challenges in your life other than HIV, that you will not be able to take your medication properly. There is good evidence that receiving support from your doctor, AIDS council or PLWHA organisation, as well as family and friends, can help you to greatly improve your adherence to your medications, even if you are living in difficult circumstances.

# WHAT YOU THINK ABOUT YOUR HIV TREATMENT

People who understand why taking HIV treatments could benefit their health are more likely to achieve high levels of adherence.

If you are thinking about stopping your treatment because you do not think that it is working, or if you are concerned about side effects, you should first discuss these concerns with your doctor or other health professional (such as a treatments officer at the AIDS council) before taking any action.

## SUPPORT

### YOUR HEALTH CARE TEAM

You should feel confident in speaking to your doctor if you are having difficulties with your adherence to medications. Difficulties with adherence are not unique to people with HIV, so your doctor should be well versed in these issues and be well prepared in helping you find effective solutions to your adherence difficulties.

If you are having adherence problems, the sooner you seek help, the better. If for any reason you feel unable to discuss your concerns with your doctor, try speaking with a treatments officer or counsellor at your local AIDS council or PLWHA organisation. The pharmacist where you collect your medications may also be a good source of help.

### SUPPORT WHEN STARTING OR CHANGING TREATMENTS

When you first begin taking HIV treatments, thoroughly read through the printed information provided by your doctor and/or pharmacist. This can reinforce your understanding about how and when to take your treatments. AIDS councils and PLWHA organisations are also able to provide you with further information and assistance on your treatments, and on how to best manage them.

Side effects are a particular problem when starting new treatments; however, for most people, these significantly reduce in their severity or disappear altogether after a short period of time. These side effects may include lethargy, nausea, diarrhoea, bad or disturbing dreams, or feeling 'spaced out'. It can help to know in advance if your

treatment is likely to cause side effects that may interfere with your daily life and responsibilities, so that you can make plans to help you cope with and manage them.

### When you start or change treatments, make sure you understand:

- Why you have been given the medication.
- How often and at what intervals (or frequency) you need to take it.
- How much of it you should take.
- If there are any dietary restrictions you need to consider when taking it.
- If there are any side effects that may occur, and how you may be able to manage them.
- Where you can get help and advice.

Because taking treatments is a life-long commitment — at least with our current levels of understanding and technology in HIV management — you may find that you need support and assistance with adherence on an ongoing or on an occasional basis. You should feel confident in being able to freely discuss adherence issues with your doctor, treatments officer or counsellor at any time.

### OTHER SOURCES OF SUPPORT

There are a range of other support services available to assist you with adherence and provide you with support:

- Mental health specialists such as psychiatrists, psychologists, mental health nurses and counsellors can provide treatment and support if you feel that your state of mind is giving you problems with adhering.
- Pharmacists can discuss how you should be taking your medication and provide information on possible interactions with other drugs and treatments.
- Dieticians can provide advice on eating the right amount and type of food so that your medications are properly absorbed. They can also give you advice about how to minimise side effects such as nausea and diarrhoea.
- Social workers can help you find practical solutions to problems, such as those with housing and financial difficulties.

# YOUR MEDICATIONS AND ADHERENCE

## TREATMENTS AND YOUR LIFESTYLE

You are most likely to take your HIV medications when they fit in with your existing lifestyle. Consequently, treatments-related decisions should be made on an individual basis, taking account of your unique circumstances. This should include a history of your past treatment experiences, but also your needs and preferences about how often you take your medication, the chances of getting side effects, and the potential for harmful interactions with other medications.

Looking at your lifestyle needs before you start treatment may mean that you are less likely to encounter adherence problems later on.

## LATE DOSES

Taking your medication late can be as bad as missing doses completely, allowing HIV to become resistant to some or all of the drugs you are taking.

The safest approach is to aim to take all your doses at the right time and in the right way. Nevertheless, most people will, at some time or another, probably take their medicines late. If this happens very occasionally it will probably make no difference to the success of your medication. However, if you are regularly late in taking your medication it could allow HIV in your body to quickly become resistant to the intended effects of your medication.

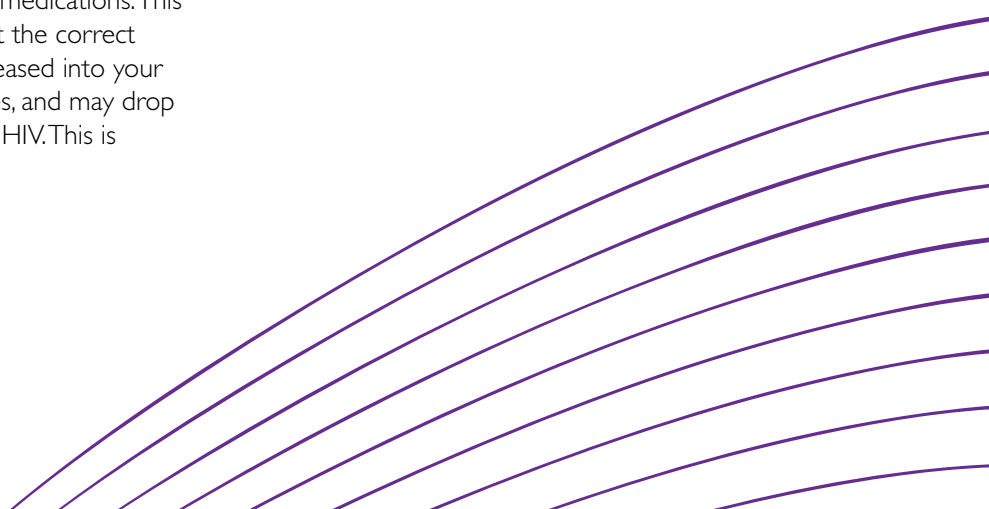
Some medications, such as the protease inhibitors nelfinavir (Viracept) and indinavir (Crixivan), are processed more quickly by the body than other HIV medications. This means it is very important to take them at the correct time as the amount of the drug that is released into your body will gradually diminish between doses, and may drop to a level that is not sufficient to suppress HIV. This is called a drug's 'half life'.

For other drugs, such as efavirenz (Stocrin) and lopinavir/ritonavir (Kaletra), it may be possible to take your drugs an hour or two late (or early) and for it to have minimal risk for the success of your medication.

Do not assume that because somebody else is able to take their medication late, even if they are taking the same drugs as you, that you will be able to do the same. The speed and effectiveness with which individual people process medicines can vary considerably.

If the way you lead your life means that you find it difficult to stick to very strict schedules then talk to your doctor about the possibility of switching to a combination that requires less rigorous timing.

Having a big night out, travelling overseas or domestically, or doing anything that interrupts your normal routine may cause difficulties in taking your medication at the correct time. If you know that your normal dosing routine may be interrupted, try to make a plan that ensures that you take your medication as close as possible to the correct time. For example: take your pills with you when you go out or travel away from home; have a bottle of water; a bar of chocolate or some other easy-to-carry and easy-to-eat food at hand if you need to take your medication with food. Planning ahead in this way means that you are able to take your treatments without disrupting either what you are doing or your medication routine.



## ADHERENCE TIPS

Simple forgetfulness is a common reason for missing doses of anti-HIV drugs. If you forget to take your medication don't be too hard on yourself. Try to learn from the experience and remember what it was that caused you to forget. If you are missing doses regularly, discuss this with your doctor. It may be possible to make your dosing schedule easier, or change to a more suitable combination of drugs. Where this is not an option, simply talking through your concerns and difficulties with your health care team or GP may provide you with the support you need to manage your treatments better in the future.

There are plenty of ways to help you remember to take your drugs on time. You could experiment with some of these:

- Take your drugs at the same time each day.
- Have supplies of your drugs at places you know you'll be (at you partner's house, work, etc.).
- Take your medications with you wherever you go.
- When travelling, be aware of the different time zones you might be crossing and adjust your dosing times accordingly. (This can be done by talking to your doctor before you leave.)
- Portable alarmed pillboxes (i.e. with a timer that you can set to beep each time you need to take a pill) are available from your local AIDS council or doctor.
- Get a dosette box — this is a box which lets you set out your pills for the week in labelled sections so you can easily see what you have taken and what you need to take next. These are available from chemists or AIDS councils.
- Keep a calendar or diary in a prominent place (at home and at work) where you can tick off each time you take your pills.
- Establish a routine which associates pill-taking with meals (where appropriate).
- Get an electronic diary to remind you to take the drugs
- Prepare for holidays by getting a stock of drugs in advance.
- Find out from other people with HIV what they do to help remember their pills.

## GLOSSARY

### Adherence

The act of taking a treatment exactly as prescribed.

### Antiretroviral

A substance that acts against retroviruses such as HIV.

### CD4

A molecule on the surface of some cells of the immune system onto which HIV can bind. The CD4 cell count roughly reflects the state of the immune system.

### Cross-resistance

The mechanism by which HIV that has developed resistance to one drug, may also be resistant to other similar drugs.

### Disease progression

The worsening of a disease.

### Dose

Measured amount of a drug to be taken at one time.

### Genotype

The genetic makeup of an organism.

### Protease inhibitor

Family of antiretroviral drugs which target the protease enzyme. Includes nelfinavir (Viracept) and indinavir (Crixivan).

### Regimen

A drug treatment combination and the way it is taken.

### Resistance

HIV drug resistance occurs when the virus develops genetic mutations that make it less sensitive to the effects of one or more antiretroviral drugs.

### Viral load

Measurement of the amount of virus per millilitre of blood. HIV viral load indicates the extent to which HIV is reproducing in the body.