

Talking Treatments

Taking pills twice a day is a reminder of what I've got! Iza

Treatments have made me feel well again and I've returned to work. Tony

Taking them means that you're not going to die. Margaret

When positive heterosexuals call the Pozhet Freecall line 1800 812 404 they talk about everything to do with living with HIV. On many occasions both men and women have discussed using treatments. Here are some of their frequently asked questions.

Note: Treatments can be called Combination Therapy or HAART (Highly Active Retroviral Therapy). Most HIV positive people call their treatments 'pills' or 'combo'.

Treatments – are they a good thing or a bad thing?

Many people say that the good thing about taking treatments is that it gives them every chance to live a longer healthy life. Treatments have stopped HIV becoming a death sentence for them and they now have the chance to continue with their lives and even start a new relationship or explore new work opportunities. Surveys of positive people on treatments have shown that many are hopeful for a better future, because by taking treatments, fewer people are getting sick. Today HIV is seen as a manageable medical condition.



Some people say that taking treatments is a bad thing because they find it difficult to swallow pills and take blood tests, and they feel anxious most of the time about their blood results. Taking treatments also reminds them that they are HIV positive and sometimes they don't want to think about this. They may also get stressed if they forget to take their pills on time. Some are concerned about the long-term effects of taking treatments and some feel that the side effects from treatments seem to be worse than the HIV itself.

It's a good idea before starting treatments to give yourself enough time to talk about all of this with your doctor, your family, friends, and other HIV positive people in a support group.

How many treatments are available? What if they don't work?

There are more than 15 pills. Their colour, shape and size all vary. They work against HIV in a number of different ways. Most people usually take a combination of three different kinds of pills, but sometimes more are needed. There are even some pills that can be taken once a day.



Even if you follow all the rules - take the right amount of pills, eat the right foods - it is still possible that some drugs won't work. This can be because the HIV in your body gets used to the drug you are using and builds up a resistance to it.

You may also have to try several combinations to find out what works best and is easier for you to take. However the more times you change your treatments the less drugs you will have to choose from.

How do I take them and for how long?



Some pills are taken with food and others are taken without food. You usually take pills twice or sometimes three times a day. Taking the right dose at the right time is important. Making sure that you do this will give your treatments a chance to work very well.

Many positive people have come to terms with the idea that they may be taking treatments for a very long time. This is because they do not want the virus to damage their immune system. Some people choose to stop their drugs for short periods of time. If you are thinking of doing this, talk with your doctor about the best way to go about it.

How much do they cost? Where do you get them?

Very few places provide free medicine - usually you have to pay. HIV drugs are subsidised through special arrangements with the Commonwealth government. In a few places the drugs are available for free but generally they cost roughly \$20 per prescription (2003 prices). If you are not working or you are on a low income you may be eligible for a Health Care Card which allows you to get the drugs more cheaply.

Your HIV pills are specialist drugs and you need to pick them up at a hospital pharmacy or specialist sexual health centre.

Will treatments stop me from doing things like driving a car, going to work or playing sports?

When you first start taking your treatments you may have some short-term side effects, but in most cases positive people can keep on being active and doing normal things. Some people who have been diagnosed late with an AIDS-related illness, have started treatments and gone on to make a good recovery.

Treatment side effects - what is this?



HIV is a very complicated virus, so the drugs needed to treat it are powerful. Because of this they may cause side effects. Some side effects are things like: diarrhoea, feeling depressed, nausea or having headaches. For some people these can be temporary and may last only a few weeks when they first start new drugs. Some people have on-going side effects while others experience long-term effects which can develop after they have been on treatments for a number of years.

- Over a period of time some people may develop problems, eg body fat changes or high cholesterol, which require them to change pills or have more visits to the doctor.
- On rare occasions it's possible for new drugs to cause potentially serious problems when they are first used, so if you get a rash or any kind of allergic reaction, see a doctor straight away.

Not all treatments are exactly the same and not all people taking a particular drug will have the same side effects. Other people's experiences with treatments are useful to hear about but don't assume what happens to them will happen to you. Some people may have mild side effects while others may have no side effects at all.

Whatever side effects you are experiencing, it's best to find out from your doctor if there are ways to reduce them before you stop the treatments. Don't suffer in silence. It's important to talk with your doctor to see if they can help to reduce or get rid of the side effects. Many side effects can be dealt with so you do not have to 'put up with it'. For example, a simple change of diet can help with diarrhoea. Ask for help! You may need to change your combination therapy, or work out if the side effects are due to your lifestyle or you may need to consider other things that are going on in your life.

What is viral load? Why is it important?

Viral load is the medical term used to describe the amount of HIV present in your bloodstream. This may range from a small amount to a large amount. Knowing how much HIV is present in your blood shows how well your immune system is going to deal with the virus.



You find out what your viral load is by having a simple blood test. The lower your viral load result the better. When it is low it means that the virus is replicating so slowly that there will be little, if any, damage to your CD4/T-cells and your immune system.

Lots of people with HIV say it's important to have an undetectable viral load. This means that the viral load is so low that the test is not able to detect the virus in your blood, but it doesn't mean that you don't have HIV. Current tests can't measure that you have got rid of the virus completely from your body. Undetectable means that HIV is present but in very small amounts.

You don't have to have an undetectable viral load to have an adequate immune system. Some positive people have test results that show low or moderate levels of virus and they are still well.

What are CD4 or T-cells? Why are they important? Will my T-cell count go up when I start taking treatments?



CD4 cells, also called T4 or just T-cells, are a very important part of your immune system. They help to fight infections and keep your immune system healthy. HIV particularly targets, infects and destroys T-cells. The more HIV there is in the blood, the greater the damage that can happen to your T-cells.

Most people starting new treatments for the first time notice some rise in their T-cells within 12 weeks. However it can take up to 12 months before you get the best results. Some positive people's T-cells don't go up as high as others do. Everyone's results are different.

A general guide to T-cell levels is as follows:

- Above 500 T-cells. This is the normal range for adults. More than 500 T-cells means there is little or no immune damage.
- 350 to 500 T-cells. This means that it's not likely you will get sick.
- 250 to 350 T-cells. This means there is some immune damage.
- Less than 250 T-cells. You should be considering starting treatments to keep yourself well.

Viral load and T-cells blood results can change from time to time so you have to look at them over a longer period of time to see how well they are working together. In general, more T-cells are a marker of a stronger immune system but people with low T-cells and low viral load can still manage well.

Remember: One bad result doesn't mean a disaster!

Can I eat normal foods with my treatments?



With HIV you need to get adequate nutrition, eat well and maintain weight. Avoid fad or cleansing diets, which could cause problems and may be harmful.

For treatments to work against HIV in your body you will have to take your drugs at the right time and, if necessary, with or without food, depending on the type of pills. Sometimes HIV drugs cause changes that mean you need to modify your diet, eg if you get high cholesterol your doctor and dietician will help you with this.

Can I use complementary therapies with treatments?

Since they were first diagnosed, many positive people have supplemented their care from their HIV doctors with care and support from a wide range of natural therapy practitioners. Some people still take steps to improve their diet or take herbal medicines or natural therapies while they are taking their treatments.

Be aware that some complementary therapies can interact badly with your treatments. They may affect your blood results and cause problems with the way your treatments work. It's a good idea to tell your doctor what else you are using so that you can get advice on what works well with your treatments.

Can I use other prescription medicines with my treatments?

Yes, mostly. However it's very important to tell your HIV doctor about any other prescription medicines you are using. Your HIV doctor won't always know what other things you have been given from your family doctor. In a few cases there could be a clash between different types of medicines and you could end up with side effects.

What about treatments if I'm pregnant?

It is possible for a positive woman to have a healthy baby using HIV treatments. Treatments can be taken in pregnancy and will dramatically reduce the chance of the baby being HIV positive.

More than 50 HIV positive women have given birth to HIV negative babies in Australia while using treatments with no evidence that the treatments harm babies during childbirth. However, some types of HIV treatments are not used in pregnancy, so speak with your doctor about this first.

Are there other types of drugs you might be taking besides treatments?



Some other drugs used to help positive people are:

- drugs like Bactrim, which is used as a general antibiotic to prevent HIV illness.
- other drugs that are used to treat illnesses and infections when they occur.
- drugs to manage side effects like high cholesterol and diarrhoea.

Who can I talk to about treatments?

Besides talking to an HIV doctor there are several good places you can contact when you are trying to find the answer to a question about using treatments.



Pozhet (Positive Heterosexuals). Freecall (Aust) 1800 812 404

The Treatments and Vitamins information service available through ACON.
Ph (02) 9206 2013 (Sydney) or Freecall 1800 816 518

Your closest dietician, social worker, counsellor or HIV clinic.

Ring: NSW HIV/AIDS Information Line. Ph (02) 9332 9700 (Sydney)
Freecall 1800 451 600



HIV+ HETEROSEXUALS
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helping ourselves

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