

# Treatment Questions and Answers

by Elijah Amooti & Simon Collins



## **Why has no cure for HIV been found and will there be one?**

HIV is a very difficult virus to beat – but we do at least now have very effective treatments – and these have all been developed over the last 20 years. One of the reasons the drugs don't eradicate HIV, is because a lot of infected immune cells are resting or asleep. The drugs can't work when they are sleeping – and they can sleep for 70 years. Different scientists are looking at whether there are ways to wake up all those cells. Other researchers are looking at drugs that can work on the sleeping cells. With all this research, science will find a way to improve treatment – and there may even be a cure one day. There are lots of reasons to be optimistic.



## **Is there any difference in the way white and black people respond to treatment and if so what are the differences?**

In general there are very few differences between the way different racial groups respond to treatment. Sometimes differences relate to the type of viruses that people are infected with. This is called the HIV sub-type. Even then, most differences are small and may be related to risk of developing resistance. There are some genetic differences that are linked to race though. One of these is that efavirenz may be metabolized more slowly by Africans compared to Caucasian people. Because levels of the drugs are higher, this could mean a higher risk for efavirenz-related side effects. It also means that if you discontinue efavirenz for any reason, you need to be especially careful so as to not risk getting resistance. A few other HIV drugs (including AZT) can change make fingernails darker if you are Black, and FTC can cause a rash on the hands of Black people but not White people – though both of these pigment changes don't do your health any harm, they can be disconcerting, and so people often choose to alternative treatments.



## **I want to know more about side effects?**

There are many sources of information. Ask your doctor or one of the nurses at your clinic. i-Base and NAM are two community organisations that produce free booklets and leaflets, and that also put information onto the internet. Ask your friends, or workers at your local HIV group for more information or see the adverts in this issue of African Eye.



## **I want to know how worse it can get?**

Whatever is causing you to be so upset at the moment, it is important that you get to speak to someone who can help. It may be you are talking about a difficult reaction to our HIV diagnosis – in which case counselling with a health advisory can help. If your difficulties are related to poor health, or difficulty with side effects, then you need to talk to your doctor or nurse at your clinic.



## **Is there a difference between HIV and AIDS?**

Yes. HIV is a virus that damages your immune system. AIDS is the name for the effect that the virus has on your health – for when your immune system has been more severely damaged by the virus and the infections that you are then more at risk from. Some guidelines (in the USA) define include a CD4 count below 200 cells/mm<sup>3</sup> as a definition of AIDS. HIV stands for Human Immunodeficiency Virus. AIDS stands for Acquired Immune Deficiency Syndrome.



## **Can you say something about the ability to speak out openly with my doctors?**

Your doctor really wants to work with you. He or she will be used to all sorts of questions

from many different situations. Developing confidence with your doctor can take time but it should get better. Some simple things can help though. Plan what you want to talk about beforehand, and take a list in to the appointment to use. Go to the appointment with a friend, partner or family member. Your doctor is very happy for you to have someone with you at your appointment. This can help focus the meeting, and also give you someone to talk about afterwards with what the doctor said. If things are very difficult talk to one of the nurses. You can always ask to see a different doctor if there are more complicated reasons why you can't talk to your doctor.



## **I would like to know more about salvage therapy.**

Salvage therapy is the name given to rescue treatment if you have developed resistance to all the main classes of HIV drugs. It is a specialized subject – but very important to know about if you are in this situation. I-Base have a non-technical treatment guide that goes into detail about the options for someone in this situation. If you would like a free copy, ask at your treatment centre or call 0808 800 6013.



## **How do I explain my hallucinations to my family when I have not disclosed?**

It would be better to try to deal with the hallucinations first. Are you taking efavirenz? If so, it sounds like your doctor should change this for another drug as it sounds like the side effects are too strong. It is easy to switch to another treatment, and then you can take more time deciding how to talk to your family about HIV. Hallucinations are not a normal part of life. You need to speak to someone about this.



**Why is the CD4 count different in everyone?**

The CD4 count is different because everyone has a slightly different immune system. The range for an HIV-negative person can be anything from 500 to 1600 cells/mm<sup>3</sup>, but some people are outside even this range. There are difficulties with the sensitivity of the CD4 test too, so that you could test the same sample twice and may get slightly different results. Also so that if you took several blood samples at different times of the day, you will get different results. With CD4 count you really think of it as an approximate test and look for any changes in the trend.



**I have many things to ask but I don't know how to explain in English.**

First talk about your questions with someone who speaks your first language so that someone knows what your concerns are. If you have family or friends here one of them may speak better English and be able to come to your doctor with you. Ask at your support groups whether anyone attends from your country. If you need help, ask your clinic for an interpreter, and use the time to explain things until you understand them. The internet may have written resources in other languages that you prefer to use – see if your support group or treatment worker can find anything,



**How do I deal with recurrent shingles?**

Shingles is a very painful rash of small blisters that usually affect one band of the body's nervous system ie one leg, or a band around the chest. It is caused by Varicella Zoster Virus (VZV) which is in the herpes family of viruses. Ask your doctor about using a daily treatment with acyclovir. As well as being a treatment for shingles, it can help suppress the chance of future outbreaks of shingles. If your CD4 count is low,

then modifying or changing your HIV treatment to improve your CD4 count may also reduce the risk of future shingles.



**I need information on vaccines for hepatitis A and B**

This is something to ask your clinic about. Both vaccines are easy to get free on the NHS, and they are particularly recommended for HIV-positive people. If you have had these vaccinations in the past, your doctor can test whether they are still working, or whether you need a booster. Every HIV-positive person should have been tested for hepatitis A, B, and C so this should be on your hospital notes. If you have not been tested, then ask. Both vaccines are recommended to protect against future infections. The response to the vaccinations are better with a higher CD4 count.

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**If you would like to speak to an HIV-positive treatment advocate about any question relating to HIV and treatment, call the i-Base freephone Treatment Phonenumber on 0808 800 6013 on Mon-Wed from 12.00 – 4.00pm. You can also email questions to: [Info@i-base.org.uk](mailto:Info@i-base.org.uk)**

In each edition we will focus on different aspects of treatment for HIV, related illnesses and other social issues affecting African Communities living with and affected by HIV/AIDS.

If you have any suggestions please do write to:

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