The START study – if you are a LTSP…

Is your CD4 above 500 without treatment?

Are you a long-term slow progressor?

This leaflet explains why HIV treatment might be a good idea at higher CD4 counts, even though this wasn't recommended in earlier years….

HIV and slow progression

If you are reading this may be one of the people who were lucky enough to have a strong immune response to HIV. Even ten years after infection, about 25% of people have a CD4 count over 350. For 5% of people their CD4 count is over 500 after 15 years without treatment.

This used to be called long-term non-progression (LTNP) but more recently it is called long-term slow progression (LTSP). This is because we now know that everyone's CD4 drops, however slowly.

This means that nearly everyone is likely to need treatment at some time.

Eating a healthy diet, resting well, reducing stress, only using alcohol and recreational drugs in moderation, and keeping your mind and body active all help long-term health. However, slower HIV progression is mainly explained by the immune system that you inherited through your genes.

Using treatment to keep high CD4s

Having a CD4 count over 500 is generally called a 'normal' CD4 count – ie similar to an HIV-negative person.

Reaching 500 is now a goal for people starting treatment. As treatment has become better and safer, the CD4 count for starting has increased from 200 to 350 and many guidelines include 500 for either some or all patients.

This is because the closer your CD4 count is to 500 when you start, the great the chance you will reach and maintain a level over 500 afterwards.

Recent research into CD4 recovery, especially with better treatments has led doctors to now recommend treatment earlier than they used to.

Now, similar research based on viral load is used to recommend earlier treatment. This includes people with CD4 counts above 500, even when viral load is low.

Using treatment to reduce inflammation

Most LTSPs can manage HIV for many years based on their CD4 count.

However, less than 1% of LTSPs also have an undetectable viral load. So the virus is usually there and generally slowly increasing.

Recent studies have shown that detectable levels of viral load may affect your long-term health–even at low levels of a few hundred copies/mL. When the virus is detectable, your immune system works harder because it is in a continual state of inflammation.

In large studies, this inflammation explained why people not on treatment with high CD4 counts had a higher risk of serious health complications that were not previously thought to be related to HIV. These included heart, liver and kidney disease and some cancers.

If you have been HIV-positive for many years, then the impact of this ongoing inflammation may be more serious than it is for someone who started treatment much earlier – because it has gone on for longer. This is why treatment may be important even if your CD4 count is high.

This recent research has changed the way most doctors now see the balance of the advantages and disadvantages of treatment.

The issue of inflammation is one of the reasons why the guidelines in the US and France now recommend treatment for anyone whose CD4 count is under 500, and why they include the option for treatment at any higher CD4 count. While UK guidelines still use 350 for most people, starting at higher counts is recommended with other health complications, such as hepatitis coinfection, heart disease and in older people (over 50 years).

The START study is looking to find out about the risks and benefits of earlier treatment. It will randomise people whose CD4 count is over 500 to either start treatment or wait until it drops to 350.

Randomising means that you cannot choose which group you join, but you can choose which drugs you use. This is up to you and your doctor. START will enable you use drugs that are not available to other people starting treatment. This includes the integrase inhibitor raltegravir.

Research is important to help understand why HIV-positive people, even with treatment, are still not expected to live as long as HIV-negative people.

The issue of HIV and aging is having a lot of attention too. Within a few years half of HIV-positive people in the UK will be over 50 years old. START has important sub-studies that look at these issues.

You will get good care whether or not you join this or other studies. In the START study, whichever group you join, you can get more frequent monitoring compared to routine clinic care, whether you are on treatment or not. You will also have the option to choose from a wider range of drugs, when you do come to start.

You need be happy whichever group you join, and see the advantages of being in each group. This is because the group you join will be decided randomly – like tossing a coin. This will make the final results more accurate and reliable.

If you would like more information and think you may be interested in this study, please speak to your doctor or health worker. Or contact the i-Base phoneline on the number below.

HIV i-Base is a treatment advocacy project based in London that has run a treatment phoneline by HIV-positive people for over 10 years. Free publications include the HIV Treatment Bulletin and a range of non-technical treatment guides.
The i-Base Treatment Phoneline is an anonymous and confidential phoneline on any aspect of HIV treatment: 0808 600 6013:12.00–4.00pm on Mon, Tues and Weds.