

AIDS

A GAY MAN'S GUIDE

AN EASY-TO-READ INTRODUCTION TO THE ILLNESSES
CAUSED BY HIV/AIDS AND ANTI-HIV TREATMENT DRUGS



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AIDS – A GAY MAN'S GUIDE is a companion booklet to HIV – A GAY MAN'S GUIDE. It outlines the most common health problems caused by HIV infection and by HIV treatment drugs.

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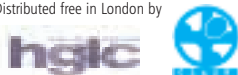


LONDON GAY MEN'S
HIV Prevention Partnership



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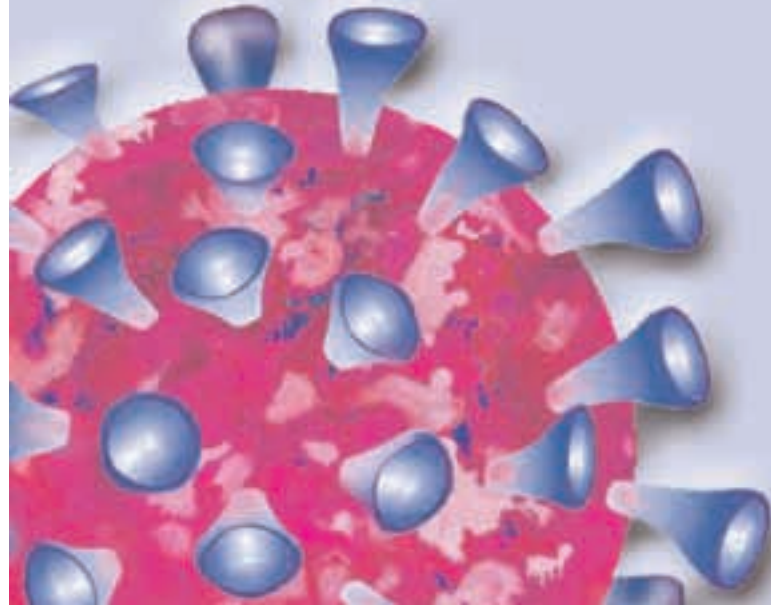
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AIDS

THE BASICS



HIV-positive men can lead happy lives, despite the shit we have to put up with. But it is important to stress that HIV is an illness that does affect your life and your confidence. It's no picnic.



WHAT IS AIDS?

AIDS is an incurable, life-threatening medical condition caused by HIV, the Human Immunodeficiency Virus.

AIDS stands for **A**cquired **I**mmune **D**eficiency **S**yndrome.

When someone becomes infected with HIV, the virus begins to damage their **IMMUNE SYSTEM**, their body's defence against disease. A person is said to have developed AIDS when their immune system is so badly damaged by HIV that it can no longer fight off a whole range of diseases with which it would normally cope.

The illnesses which affect people with AIDS are often referred to as **OPPORTUNISTIC INFECTIONS** because HIV, by weakening the immune system, gives them the opportunity to take hold. People with AIDS can get infections of the lungs, brain, eyes and other organs, and frequently suffer debilitating weight loss, diarrhoea, and a type of skin cancer called Kaposi's sarcoma.

HOW MANY PEOPLE HAVE HIV IN THIS COUNTRY?

An estimated 41,200 people are living with HIV infection in Britain today. More than half of them – 25,000 – are gay or bisexual men, a quarter of whom do not know that they are **HIV-POSITIVE**.

HOW MANY PEOPLE HAVE AIDS IN THIS COUNTRY?

Over 4,500 people are living with AIDS in the UK today, more than half of whom are gay or bisexual men. In the past 20 years, more than 20,000 people have been diagnosed with AIDS in the UK. More than

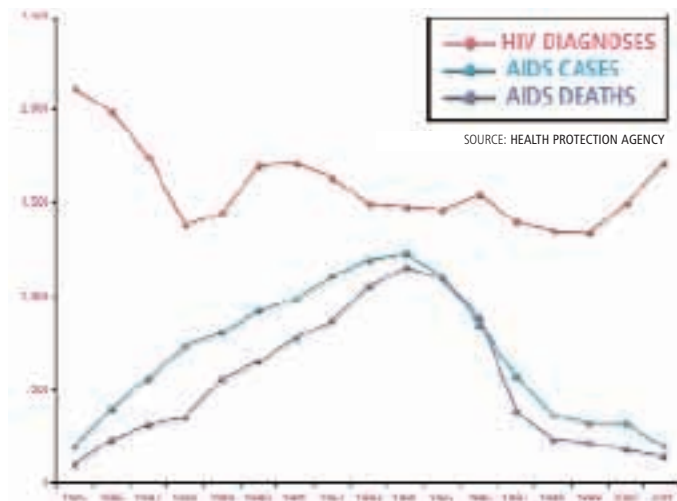
12,000 of them were gay and bisexual men, of whom 9,500 (80%) have died.

IS THERE A TEST FOR AIDS?

NO. There is only a test for HIV, the virus which can cause AIDS.

IS THERE A CURE FOR AIDS?

NO. But there are drugs which can help to keep people with HIV from getting ill and/or developing AIDS. The drugs do not get rid of HIV from a person's body; they only limit the damage caused by the virus.



HIV, AIDS AND GAY MEN IN THE UK 1985-2001

The numbers of gay men in the UK who have been diagnosed HIV-positive, been diagnosed with AIDS and died of an AIDS-related illness 1985-2001

For detailed information about taking the HIV test, see our booklets *HIV – A Gay Man’s Guide*, *HIV and Me* and *Keep It Up*. They are available free in most gay venues in London or by calling 020 7530 3596.

IF I BECOME HIV-POSITIVE, WILL I GET ILL STRAIGHT AWAY?

NO. It can be many years before an HIV-positive person falls ill, which is why so many people are unaware that they are HIV-positive.

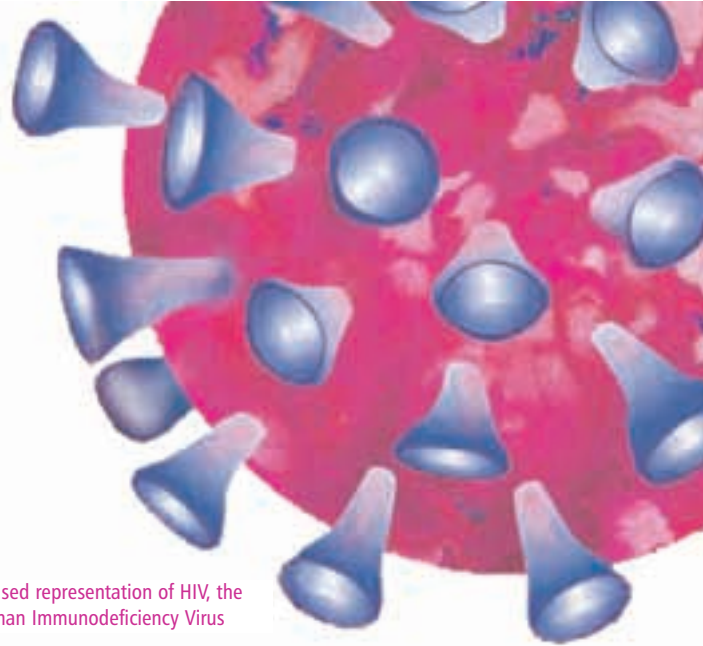
The new anti-HIV drugs, which have only been widely available since the mid-1990s, are keeping HIV-positive people free from illness for longer than ever before.

IF I HAVE HIV AND I GET ILL, DOES THAT MEAN I’VE GOT AIDS?

NOT NECESSARILY. People with HIV do get ill from time to time, as do we all. Many stay well for a long time. And even when HIV does start to make people ill, they may not actually have AIDS.

Since 1994, there has been an 87% drop in new AIDS diagnoses among gay men. Currently, fewer than 200 gay men develop AIDS each year in Britain, and most of them can look forward to many years of good health.

The number of people who die from AIDS in the UK has also fallen dramatically. These days, fewer than 200 gay men die each year from AIDS in this country. And even that number is likely to fall still further, as new and more effective drugs become available.



Stylised representation of HIV, the Human Immunodeficiency Virus

Of the 25,000 gay men living with HIV in the UK today, more than a third are **ASYMPTOMATIC** – they have no symptoms of HIV infection. Around the same number are **SYMPTOMATIC** – they have symptoms of HIV infection but they are not so ill that they have AIDS. And about a quarter have AIDS.

IF I’M UNLIKELY TO DEVELOP AIDS, DOES IT MATTER IF I BECOME HIV-POSITIVE?

YES. Even if it’s successfully kept under control by medication, so that you don’t develop AIDS, HIV can

AIDS

THE SCIENCE

make you ill. The virus can cause extreme weight loss, a condition known as **HIV WASTING**. In some cases, it can damage the brain, leading to **HIV DEMENTIA**.

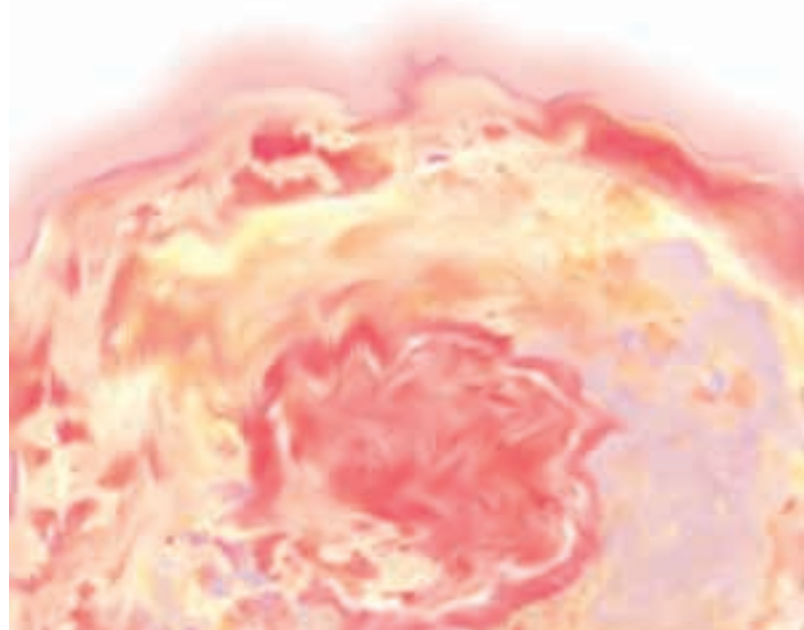
Living with HIV, despite the recent advances in treatment, is not easy. Almost three-quarters of HIV-positive gay men say that they have experienced **MENTAL HEALTH** problems, including anxiety and depression.

HIV-positive people still suffer from prejudice and discrimination – at work, at home, on holiday. People have lost their jobs, been ostracised by their families and refused entry to other countries.

At the same time, taking anti-HIV medication is far from pleasant. The drugs are very strong and can cause a wide range of side-effects, including nausea, diarrhoea and headaches.

Anti-HIV drugs have been widely prescribed in this country for less than ten years, so it is too early to say whether their long-term use is safe. There is already some evidence that they may cause liver damage in some people, for example.

So, although the outlook for HIV-positive people is better than it's ever been, HIV is still something to be avoided. For more on how HIV is passed on, how you can avoid it and for information about taking the HIV test, see the companion booklet to this, *HIV – A Gay Man's Guide* (available free in most gay venues in London or by calling 020 7530 3596).



HOW DOES HIV CAUSE AIDS?

HIV attacks the immune system, the body's defence against disease. As the immune system becomes weaker, so the body loses its ability to fight disease.

WHAT IS THE IMMUNE SYSTEM?

The immune system is highly complex, and it would take a much bigger book than this to do it justice. However, to understand how AIDS is caused, you can think of the immune system like this...

Blood is made up of **PLASMA**, which is the liquid part, and **BLOOD CELLS**, which float in the plasma. There are two main types of blood cell: **RED BLOOD CELLS**, which carry oxygen around the body; and **WHITE BLOOD CELLS**, which hunt down and destroy infections.

There are several different types of white blood cell, each of which has a different job to do.

Some, known as **ANTIBODIES**, track down and latch on to foreign invaders, such as viruses, in the bloodstream. Others attack and destroy the invaders. And a third type of white blood cell co-ordinates the whole process, directing the killer cells to the site of the infection, ordering up reinforcements and then winding everything down once the infection is overcome.

It is this third type of white blood cell – the **CD4** or **HELPER-T CELL** – which is targeted by HIV.



Stylised representation of an HIV antibody, a type of white blood cell which hunts down the virus in the bloodstream

HOW DOES HIV DAMAGE CD4 IMMUNE CELLS?

What happens is that HIV gets hold of a CD4 cell and gets inside it. The virus then takes over the cell's control mechanism and instructs it to start making copies of HIV. Eventually, these new copies of the virus burst out of the infected CD4 cell, usually destroying it in the process.

The copies of HIV then get hold of other CD4 cells and the process is repeated. The body makes new CD4 cells every day, but HIV reproduces so rapidly that it can destroy CD4 cells faster than the body can reproduce them.

Eventually, an HIV-positive person will have more and more copies of HIV in their blood and fewer and fewer CD4 cells.

An average, healthy HIV-negative person has between 500 and 1,500 CD4 cells in one cubic millimetre of their blood. An HIV-positive person who has developed an AIDS-defining illness (see page 19) will most likely have fewer than 200. HIV, in other words, can destroy almost 90% of the CD4 cells in a person's blood.

The number of CD4 cells in one cubic millimetre of a person's blood is known as their **CD4 COUNT**. As we will see, the CD4 count is useful in determining how well or how ill an HIV-positive person is.

WHY DOESN'T HIV CAUSE AIDS STRAIGHT AWAY?

Because **THE BODY FIGHTS BACK**.

When someone is infected with HIV, the virus starts to spread around their body, infecting CD4 cells and making copies of itself. Every time the immune system tracks down one lot of virus, there will be another lot somewhere else, reproducing. HIV manages to stay one step ahead of the immune system.

But for a long time, there will be a kind of stand-off between HIV and the immune system. The virus will manage to avoid being completely wiped out, but it won't damage the immune system so much that it ceases to function properly.

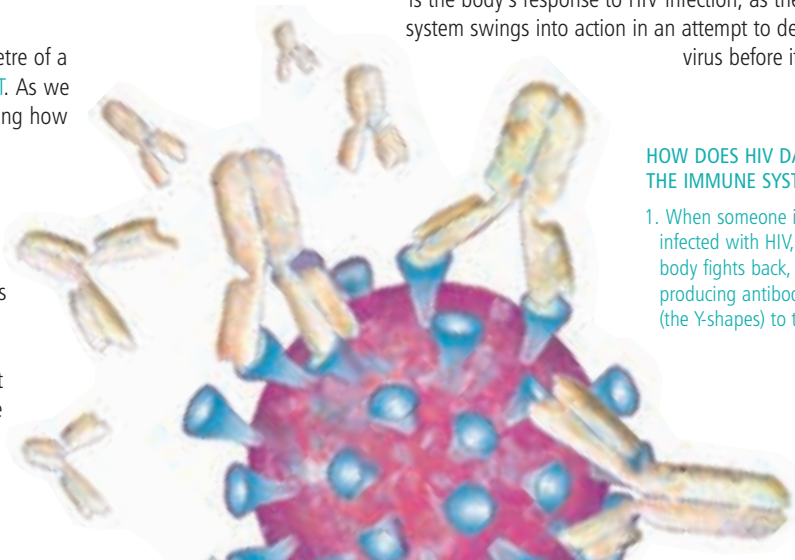
Gradually, though, over several years, the virus will begin to get the upper hand. And unless treatment with anti-HIV drugs is started, AIDS is inevitable – usually within ten years of infection.

WHAT ILLNESSES AFFECT HIV-POSITIVE PEOPLE?

When a person is first infected with HIV, they may experience a flu-like illness, which is known as **SERO-CONVERSION ILLNESS**. Sero-conversion illness is the body's response to HIV infection, as the immune system swings into action in an attempt to destroy the virus before it spreads.

HOW DOES HIV DAMAGE THE IMMUNE SYSTEM?

1. When someone is first infected with HIV, their body fights back, producing antibodies (the Y-shapes) to the virus.



Most commonly, when someone has sero-conversion illness, they will run a fever and feel tired and achy. In many cases, people newly infected with HIV also have swollen lymph glands (the glands in the neck, armpits and groin).

For a small number of people, sero-conversion illness can be a lot more serious and unpleasant, but, in most cases, all these symptoms will pass in a few days or weeks. And because they are so like the symptoms of a cold or the flu, many people don't think anything of it.

Once they've got over their sero-conversion illness (if, indeed, they noticed it), HIV-positive people can stay well for several years. This is known as **CATEGORY A** or **ASYMPTOMATIC** (without symptoms) **HIV INFECTION**.

It is not possible to put an exact timescale on all of this. The speed with which someone's HIV infection progresses depends on a number of things, including their lifestyle, if and when they started

taking anti-HIV drugs, how well their body responds to the drugs, and so on.

And when we say that people with asymptomatic HIV infection can stay well for some years, we should point out that we don't mean they never get ill at all. What we mean is that during this stage of their illness, they won't develop any illnesses as a result of HIV.

But, of course, HIV-positive people do get minor illnesses, such as coughs, colds and stomach bugs, just like everyone else.

Once an HIV-positive person does develop an illness which is a result of damage to the immune system caused by HIV, they are considered to have **CATEGORY B** or **SYMPTOMATIC** (with symptoms) **HIV INFECTION**.

This doesn't mean that they're going to be ill forever. People who have been living with HIV for many years typically experience periods of illness, sometimes quite severe illness, followed by long periods of being perfectly well.

WHAT ILLNESSES DO PEOPLE WITH SYMPTOMATIC HIV INFECTION SUFFER FROM?

When someone's immune system isn't working properly, they can become infected with viruses or bacteria which take the opportunity of the weakened immune system to take hold. These **OPPORTUNISTIC INFECTIONS** are the most common cause of illness in HIV-positive people.

HOW DOES HIV DAMAGE THE IMMUNE SYSTEM?

2. In the bloodstream, HIV (blue and green) latches on to a CD4 cell (orange), part of the immune system.

One of the most common opportunistic infections amongst people with HIV infection is **THRUSH** or **CANDIDIASIS**. We all have candida, a type of yeast, inside our bodies. In people with healthy immune systems, it causes few problems. Occasionally, if somebody is run down, for instance, they may get an outbreak of thrush (under their foreskin, for example). But apart from that, it does no harm.

However, if, for whatever reason, a person's immune system is weakened, thrush can attack more often and become more serious. Many HIV-positive people, at the symptomatic stage of their illness, develop thrush – of the mouth, throat, anus or penis.

Typical symptoms include a thick white sticky coating on the tongue, which can resemble lots of little balls of cotton wool, and pain in the mouth. A white discharge from the penis is not uncommon.

When candidiasis becomes particularly severe, infecting the oesophagus (the tube leading from the mouth to the stomach, otherwise known as the gullet), then it becomes an AIDS-defining condition (see below). Oesophageal candidiasis causes chest pain and difficulty swallowing.

HOW DOES HIV DAMAGE THE IMMUNE SYSTEM?

3. HIV penetrates the CD4 cell and starts to take it over.



The immune system helps to keep the whole body in balance and functioning properly. When it is weakened, there is a risk that some bodily processes will run out of control, which leads to a greatly increased risk of developing a whole range of **CANCERS**, including cancers of the lung, anus, testicles and penis.

These cancers are one of the causes of death of HIV-positive people. Another is **LIVER DISEASE**, caused most commonly by co-infection with the Hepatitis B or Hepatitis C viruses.

Doctors in London are also concerned that a significant number of HIV-positive men commit suicide. **DEPRESSION**, as we've already said, is very common amongst people with HIV infection.

WHAT ILLNESSES DO PEOPLE WITH AIDS SUFFER FROM?

When someone is diagnosed as having AIDS, it is because they have developed one of 25 or so **AIDS-DEFINING ILLNESSES**.

The most common AIDS-defining illnesses are:

- **PCP (Pneumocystis carinii pneumonia)**, a type of lung infection. The symptoms are extreme shortness of breath, particularly when doing any kind of physical activity, a persistent dry cough, fever, diarrhoea and a general feeling of being very unwell. Just climbing the stairs can make you feel like you are about to pass out. Someone with PCP may also have chest

HOW DOES HIV DAMAGE THE IMMUNE SYSTEM?

4. The CD4 cell has been turned into an HIV factory, churning out copies of the virus.



pain or tightness in the chest. PCP was the main cause of death amongst HIV-positive gay men in Britain in the 1990s.

- **CMV (Cytomegalovirus)**, a viral infection which damages the retina at the back of the eye, leading to blurred vision and even blindness. It can also lead to diarrhoea, stomach pain, weight loss, fever and ulcers in the mouth, throat and anus.
- **KS (Kaposi's sarcoma)**, a cancer which usually affects the skin, causing purpley-red blotches which can become swollen and painful. KS can also affect the gut, the lymph nodes and the lungs. It was the

main cause of death amongst HIV-positive gay men in the UK in the 1980s.

- **MAI (Mycobacterium avium intracellulare)**, a bacterial infection which can cause severe anaemia, chronic diarrhoea, weight loss, night sweats (extreme sweating while asleep, causing the bedclothes to become drenched), chills, loss of appetite and weakness.
- **TB (Tuberculosis)**, a bacterial infection which damages the lungs and brain. A severe chesty cough is a common symptom of TB, with people commonly coughing up blood. Shortness of breath, fever, weight loss, night sweats and extreme tiredness are other symptoms, though these may have a variety of causes in HIV-positive people.

CAN THESE ILLNESSES BE PREVENTED?

As we've seen, fewer and fewer people are developing AIDS in Britain today because of the success of the new anti-HIV drugs. Doctors also give HIV-positive people drugs to prevent them getting any of the AIDS-defining illnesses.

These preventative treatments are known as **PROPHYLAXIS** and include antibiotics to prevent someone getting PCP, for example.

This kind of preventative treatment is usually given when someone's CD4 count falls below 200 or when they have already had a bout of one of the AIDS-defining illnesses.

What happens is that prophylactic drugs – for example, the antibiotic Septrin – are taken for several months in addition to anti-HIV drugs.

The combination of prophylactic drugs and anti-HIV medication is responsible for the dramatic decline in the number of AIDS cases in this country.

In fact, some doctors don't talk about AIDS any more. Instead, they refer to patients as having **CATEGORY C, SEVERE** or **LATE-STAGE HIV INFECTION**.

It wasn't so long ago that a **CD4 COUNT** of less than 200 was a pretty sure-fire indication that a person had, or was about to develop, AIDS. These days, many people whose CD4 count has fallen that low have a good chance of staying healthy and avoiding the AIDS-defining illnesses.

In the United States, just to complicate the issue, an HIV-positive person whose CD4 count falls below 200 will automatically be diagnosed as having AIDS, whether or not they have an AIDS-defining illness. In this country, however, it is only when someone develops an AIDS-defining illness that they are said to have AIDS.

HOW DOES HIV DAMAGE THE IMMUNE SYSTEM?

5. The new copies of HIV break out of the CD4 cell, destroying it in the process. Eventually, after some years, HIV overwhelms the immune system.

WHAT IS THE CD4 COUNT?

It is a measure of the concentration of CD4 cells in a person's blood.

It is important to note that the CD4 cells circulating in a person's blood are only a tiny fraction (around 2%) of the CD4 cells in their whole body. CD4 cells spend a lot of their time in body tissues (such as the lymph nodes).

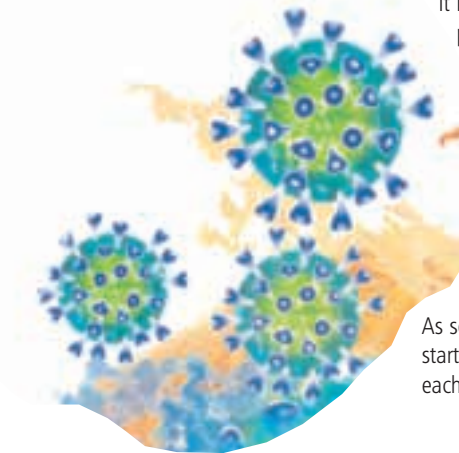
Doctors like to test the blood of HIV-positive people every three to six months, to keep an eye on their CD4 count and their **VIRAL LOAD** (see below). It is quite common for the count to fluctuate, to go up and down. This is not necessarily a cause for concern.

WHAT IS THE VIRAL LOAD?

It is a measure of the concentration of HIV in a person's blood.

When we say that someone is infected with HIV, we don't mean that they only have one virus particle or copy in their entire body. An HIV-positive person will have hundreds, thousands, millions or even billions of individual copies of HIV in their body at any one time.

As soon as HIV gets inside someone's body, it will start making copies of itself. The individual copies will each go off and attempt to infect CD4 cells, taking



them over and turning them into factories for the production of HIV.

Immediately after infection, a person's viral load may be quite high. But as the body's immune response fires up, it may fall. In the long term, and without treatment, an HIV-positive person can expect their viral load to increase steadily.

The aim of treatment is to get viral load down as far (and as fast) as possible and keep it there. Doctors will consider treatment to be successful if, after a few months, a person's viral load becomes **UNDETECTABLE**.

That doesn't mean that the virus has been completely got rid of. It simply means that there is so little of it in the blood that it cannot be detected by the standard viral load tests.

IF MY VIRAL LOAD IS LOW, DOES THAT MEAN THAT I CANNOT PASS HIV ON TO SOMEONE ELSE?

NO. The viral load test measures the amount of HIV in your blood. It does not measure the amount of HIV in your semen. In most men whose HIV is under control, a low or undetectable blood viral load is usually an indication that their seminal load – the amount of virus in their cum – will also be low.

However, this isn't always the case. Seminal viral load can remain high for some time after blood viral load has fallen to undetectable levels. And seminal viral load can sometimes increase much

more quickly than blood viral load.

In fact, there is considerable evidence that blood viral load and seminal viral load are independent of one another. In other words, an undetectable blood viral load does not necessarily guarantee an undetectable seminal load.

Even if the two did always go hand-in-hand, so that undetectable blood viral load meant undetectable seminal viral load, that wouldn't mean that you were uninfected. You would still have HIV in your semen; that means you could still pass it on if you don't use condoms when you fuck.

That's why it is not safe to assume that you can abandon condoms whenever your viral load is at an undetectable level.

At the same time, viral load can rebound very quickly. If you get a sexually transmitted infection, such as gonorrhoea for example, or if you get the flu or if your anti-HIV drugs stop working, your viral load can quickly go through the roof, from undetectable to stratospheric levels.

CAN THE CD4 COUNT AND VIRAL LOAD BE USED TO PREDICT WHEN SOMEONE WILL DEVELOP AIDS?

To a large extent, **YES**. CD4 count is the best predictor. A rising CD4 count or one which is high and stable are both indicators that a person is at low risk of getting ill or developing AIDS.

A falling CD4 count is not such good news. One scientific study suggested that for every fall of 100 in an HIV-positive person's CD4 count, the risk of that person developing AIDS doubles.

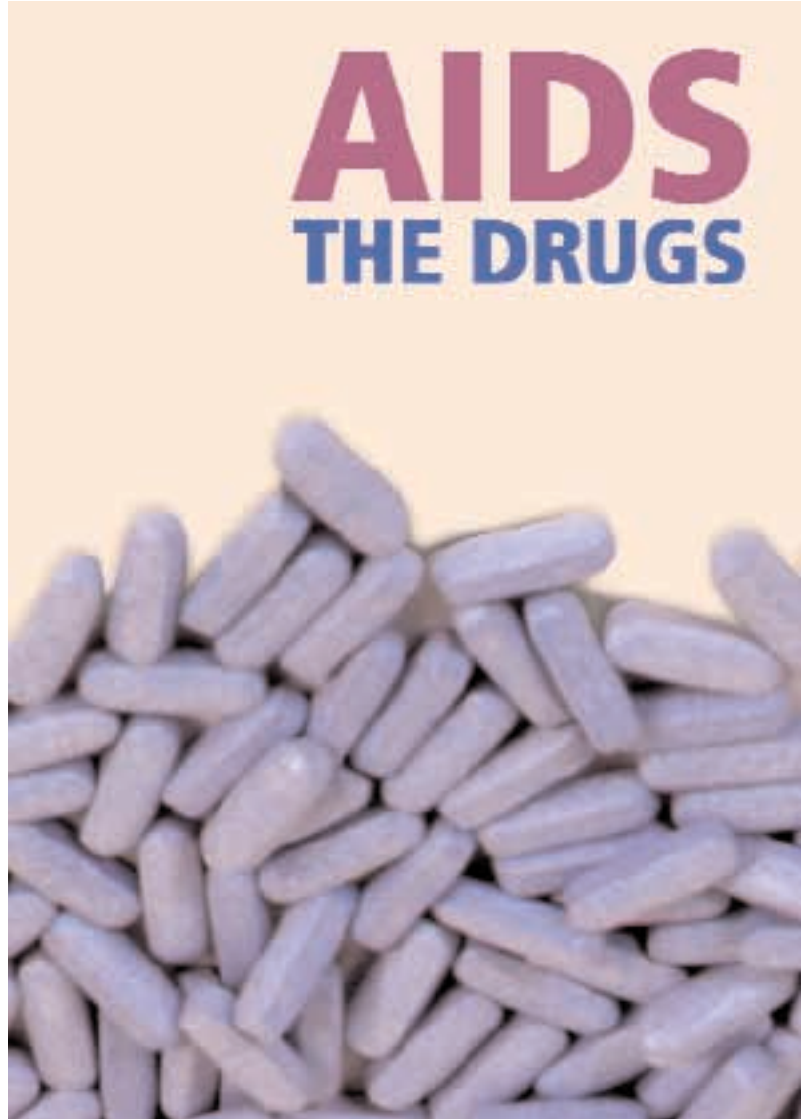
Remember, CD4 counts go up and down, even in HIV-negative people. That's why doctors test the blood of HIV-positive people at regular intervals – so that they can establish a trend over time rather than get hung up over one particular result.

The same is true for viral load – there may be blips, where it suddenly goes up, only to fall away rapidly soon after. If someone falls ill, for example, their viral load will probably increase, only to decline as they get better. So there is no figure – no absolute level of viral load or CD4 count – which means that a person has or is about to get AIDS.

The way to look at it is like this: if, over a period of time, someone's CD4 count is rising and their viral load is falling, then their risk of getting ill or developing AIDS is low. If it's the other way round – falling CD4 count and rising viral load – then they are at greater risk of getting AIDS.

But AIDS is no longer the inevitable outcome of HIV infection. People with relatively low CD4 counts are staying healthy, thanks to the new drugs, when, only a few years ago, they would have fallen ill.

AIDS THE DRUGS



CAN ANTI-HIV DRUGS STOP SOMEONE GETTING AIDS?

YES. And, perhaps, no...

As we've already seen, fewer and fewer HIV-positive people are being diagnosed each year with AIDS in the UK and more and more are staying well for longer. This is because of the widespread use of anti-HIV drugs.

There is no doubt that these drugs can delay the onset of HIV disease and AIDS. What we don't know, because it's too early to tell, is whether the drugs can keep AIDS at bay forever.

New drugs are becoming available all the time, so the longer that people with HIV stay healthy, the better. There is always a chance that new treatments will be developed which will keep HIV-positive people from ever getting AIDS.

HOW DO THE DRUGS WORK?

BY SLOWING HIV DOWN.

To put it simply, the anti-HIV drugs interfere with the process by which HIV reproduces itself. This helps to offset the advantage HIV has over the immune system and gives the body a chance to catch up.

As the rate of viral reproduction slows, so the damage caused to the immune system diminishes. This gives the body the opportunity to repair the damage to the immune system and to get on top of the virus by destroying it as fast as it reproduces (if not faster).

The result of this is that the concentration of CD4 cells in the blood increases while the concentration of virus decreases. Or, to put it another way, the **CD4 COUNT** goes up and the **VIRAL LOAD** goes down.

“ I started to notice that I was getting a lot of wasting on my face, and, as my health was improving, I was exercising more but I was still losing weight on my arms and legs. So we changed the combination twice to deal with that.

The other time I changed my combination was when I changed from indinavir to efavirenz. But it made me feel really groggy and after a while I couldn't get up in the mornings. So in the end I came off efavirenz.

I've never had any other side-effects from the drugs – no rashes or nausea. Whenever I've changed my combination, all I've had is a massive rush of energy, which is very nice.

GARRY BROUGH

WHAT IS COMBINATION THERAPY?

In the past ten years or so, an increasing number of powerful anti-HIV drugs have become available. Scientists have discovered that the drugs are most effective if several are taken at once.

Taking a **COMBINATION** of two or three different anti-HIV drugs is also known as **HAART** (Highly Active Anti-Retroviral Therapy) or, sometimes, just **ART** (Anti-Retroviral Therapy). It is so called because HIV is a type of virus known as a **RETROVIRUS**, after the

way it reproduces itself (for more on this, see *HIV – A Gay Man’s Guide*).

The different anti-HIV drugs used in combination therapy each interfere with a different stage in the life cycle of HIV. So taking them together like this greatly increases their impact on the virus and gives the immune system the maximum breathing space.



WHEN SOMEONE STARTS ON COMBINATION THERAPY, DOES THAT MEAN THEY’VE GOT AIDS?

NO. One of the main reasons for starting combination therapy is to avoid AIDS. So most doctors will advise their HIV-positive patients to start on combination therapy when it has become clear that HIV is causing significant damage to their immune system, but before they start getting ill.

WHEN SOMEONE IS DIAGNOSED HIV-POSITIVE, DO THEY START TAKING ANTI-HIV DRUGS STRAIGHT AWAY?

NOT USUALLY, NO. It all depends on when they were infected.

If someone has a positive HIV test result soon after becoming infected with the virus, they will almost certainly not be advised to start on combination therapy.

This is because, as we’ve already said, HIV takes a long time before it starts causing major damage to someone’s immune system.

When someone is first infected with HIV, they usually have a very high viral load and their CD4 count may well start to fall. However, as their immune system starts to fight back (resulting in sero-conversion illness), their viral load is quickly pegged back and their CD4 count stages a recovery.

In the early years of their HIV infection, following sero-conversion, an HIV-positive person is likely to be perfectly well. They will have a low viral load and a CD4 count within the normal range for a healthy person.

As long as this remains true, it is very unlikely that combination therapy will be recommended. Indeed, something like two-thirds of HIV-positive people in the UK are not taking any form of anti-HIV medication.

SO WHEN DO HIV-POSITIVE PEOPLE START TAKING COMBINATION THERAPY?

In general, when their CD4 count falls below 350.

This isn't a hard-and-fast rule. If someone's CD4 count drops below 350 but they haven't had any HIV-related illness and seem otherwise healthy, their doctor may not put them on combination therapy.

However, if someone is in the symptomatic stage of HIV infection – meaning that they have had at least one HIV-related illness – and their CD4 count falls below 350, then they are almost certain to be recommended to start combination therapy.

If someone's CD4 count falls below 200, whether they are symptomatic or not, they will certainly be prescribed anti-HIV medication.

It's at around these levels of CD4 count that prophylaxis comes into the picture, too.

Below 350, and, almost definitely, below 200, doctors will consider prescribing drugs to prevent the lung infection PCP and some of the other common AIDS-defining illnesses.

HOW LONG DOES IT TAKE FOR AN HIV-POSITIVE PERSON'S CD4 COUNT TO FALL BELOW 200?

The majority of HIV-positive people will live healthily and well for many years, without taking any anti-HIV medication. But there will come a time when their

doctors will recommend that they start combination therapy in order to boost their immune system and to suppress HIV.

For a minority of HIV-positive gay men, the picture is different. Up to a third of gay men who are diagnosed HIV-positive are already at quite an advanced stage of HIV infection. That is to say, they have been positive for many years without knowing it.

By the time these men find out that they are HIV-positive, their immune system has already suffered considerable damage. In such cases, they may be recommended to start combination therapy very soon after getting their positive test result.

WHAT DOES COMBINATION THERAPY INVOLVE?

Taking a number of tablets several times a day, at the same time every day for the rest of your life. Expect to take at least half a dozen tablets a day.

This can take some getting used to. Some of the drugs have to be taken with food, others on an empty stomach. It can be awkward adjusting to this new daily routine.

IS IT IMPORTANT TO KEEP TAKING THE TABLETS?

YES. Combination therapy is most effective if the drugs are taken at the time and in the manner prescribed.

That is to say, at the same time every day, with or without food, according to the drug in question.

The reason for this is that it is important to maintain the levels of anti-HIV drugs in the blood so that the virus is kept firmly under control at all times.

When viral load becomes undetectable, that means there is very little HIV floating around free in a person's bloodstream.

However, HIV can also lie dormant inside CD4 cells, waiting for the opportunity to become active.

WHAT ARE THE SIDE-EFFECTS OF COMBINATION THERAPY?

MANY AND VARIED.

The most common side-effects are nausea, headaches, tiredness, dizziness and diarrhoea.

It is almost inevitable that someone will experience one (or more) of these side-effects when they start on combination therapy. That's the bad news.

The good news is that many of these side-effects do tend to fade away after a few weeks. And if they don't, it may be possible to switch to another combination of tablets – if, for example, someone discovers they are allergic to one particular drug.

In the longer term, other side-effects can start to emerge. These include:

- **REDUCED SEX DRIVE** – many HIV-positive gay men complain that their sex drive diminishes after they have been on combination therapy for a while.

☞ Things started to go wrong when I took nevirapine and d4T. The nevirapine turned me into a huge blister. With the d4T, I started having visual hallucinations and I'd hear things, a really psychotic experience. The dog was talking to me, frogs were hopping in and out of the television, the wallpaper was chasing itself round the room.

The only way I can describe the side-effects of lopinavir is that you suddenly morph into a 90-year-old man. You get very tired, you can't walk very well, you hobble about, you have absolutely no energy whatsoever. My liver flares up, I can't eat, sometimes I go yellow.

My kidneys leak because of ddl and hydroxyurea. The two drugs together have ruined my kidneys. I ended up in hospital about three years ago and nearly died from lactic acidosis.



WILLIAM MCGARVIE

- **ANAEMIA** – some anti-HIV drugs damage bone marrow cells, which make red blood cells. This can result in anaemia, a condition in which there are too few red blood cells in your bloodstream. Since red blood cells carry oxygen to your muscles and other tissues, anaemia can leave you feeling weak and tired, lacking in energy.
- **LIPODYSTROPHY** – some anti-HIV drugs can cause a redistribution of body fat. Typical symptoms include: wasting of the face, resulting in sunken cheeks; wasting of the arms, buttocks and legs; a swollen stomach; a hump of fat between the shoulders or at the back of the neck.

AIDS

THE REALITY

- **NEUROPATHY** or nerve damage can be caused by HIV itself and by anti-HIV drugs. Peripheral neuropathy is damage to the nerves in the extremities – most commonly, the feet, but also the hands – which results in numbness, tingling and, in some cases, severe pain. Damage to the nerves in the penis or groin can cause numbness, lack of sexual sensation and impotence.
- **LIVER DAMAGE** – amongst other things, the liver is responsible for processing drugs. Some anti-HIV drugs can cause inflammation of the liver. Liver failure is an increasing cause of death amongst people with long-term HIV infection who have been taking combination therapy.

I'VE HEARD THAT THE DRUGS CAN STOP WORKING. IS THAT TRUE?

YES.

In time, HIV can develop **RESISTANCE** to many of the drugs used in combination therapy. That means that the virus is no longer affected by the drugs.

However, this is a well-recognised problem, and is one of the reasons why doctors test the blood of their HIV-positive patients at regular intervals. If it does become clear that HIV is developing resistance to one drug or other, then another drug will be substituted for the one which isn't working.





GARRY BROUGH

AGE: 36

HIV DIAGNOSIS: 1991

AIDS DIAGNOSIS: 1994

“ About three-and-a-half years after being diagnosed HIV-positive, I had a flu-like illness for two weeks and what looked like a bruise appeared on my chest. I lost over two stone in ten days, I was bed-ridden and sweating and fluey and the bruise didn't go.

I asked my clinic doctor about it, as I had concerns that it might have been Kaposi's sarcoma (KS, see page 20), and he said, 'Yes, it does look like KS to me.' That was my AIDS diagnosis.

I'd already had pretty bad candida (see page 18) throughout, from top to bottom, and my CD4 count was below 200.

I got a couple more KS lesions round my ribcage and then it spread to my face, my mouth and my throat. At that point, I began radiotherapy. It was horrible. The entire inside of my mouth peeled. I couldn't eat. Oh, it was terrible.

Then about six months later, I was in the cinema and suddenly I felt as though someone had squashed one of my lungs. I could hardly breathe and I was in excruciating pain. It turned out that the KS had got to my lungs and I had a bleed in my lungs caused by it.

I started chemotherapy, which was the only option at the time. There wasn't any combination therapy then. The chemo stabilised it for a while, but whenever I went through a stressful period, my lungs would give out.

I had chemotherapy for two-and-a-half years all told. I was hospitalised a few times with it. By the third time, I decided to give up work because the stress was making it worse.

In May 1997, I went onto combination therapy. Within a month, my viral load was undetectable, but I only had a CD4 count of 10. So I then got PCP (see page 19).

They had to stop the chemotherapy because of the PCP treatment, which meant that the KS came back very aggressively and I got lesions on my face and all over my body.

At that point, it was touch and go. I was allergic to the Septrin they gave me for the PCP and they had to give me other drugs, which eventually worked. But before they did, I was on oxygen all the time because I couldn't breathe properly and they didn't have much hope for me.

However, by April 1998, the KS had fully gone into remission and I stopped the chemotherapy.

I haven't had anything since then, touch wood. The lesions have gone. I have some very slight

discoloration in a couple of spots, which look like very faint birthmarks.



Although I now have a CD4 count of over 600, I've had an AIDS diagnosis and there's no reversal of the diagnosis.

The difficult thing is the fear. Living with HIV was one thing and it was difficult, but there was always the thought that maybe it won't progress. I focused on living healthily and I was convinced I'd be fine.

But then I got the KS and it was the A-word. That was the worst. It was much, much worse than the HIV diagnosis. As much as I'd worked hard to break the idea that HIV equals death, I hadn't prepared myself for an actual AIDS diagnosis. So when it came, I thought, this is it.

I got a counsellor in while I was in hospital and I made a living will and did all that kind of thing, got my family to come and visit me. It was extremely heavy.

I've been spending the last couple of years retraining to go back into work. But I've put off finishing my training, because I'm afraid that the stresses and strains of working life might make me ill again, as they did before.

As much as I feel fit and healthy and great, my worry is: what if my immune system isn't up to the stresses of working again?



MOHAMED
AGE: 27
HIV DIAGNOSIS: 1998



I came to London in 1998 after civil war broke out in my country, Somalia. I was admitted to hospital soon after with an attack of malaria. The doctors said they wanted to run some tests and asked my permission to test me for HIV. I didn't know what HIV was. I knew about AIDS but I didn't realise it was connected with HIV. I said they could test me.

Two days later, the doctor came to tell me the results of the tests. I was told that the tests confirmed that I had malaria but that they had found something else: I was HIV-positive. I asked them what that meant. When they told me, I screamed.

I was told that I should start taking anti-HIV medication right away. I hadn't had sex since 1991, so I realised that I must have been positive at least since then. Consequently, my CD4 count was below 200 and my viral load was very high.

I started taking the drugs, but they made me feel very ill. I itched all over. It was so bad, I felt like taking a knife to my skin. I became very depressed and almost suicidal.

The doctors stopped the medication and I began to feel better. Since then, I haven't taken any anti-HIV drugs because I am worried about the side-effects.

However, I have been taking Septrin for four years, ever since I had PCP, without any problems.

I have been working with HIV-positive people from my community and it has helped me to come to terms with my own diagnosis. My boyfriend, who is HIV-negative, has also been very supportive.

However, I am not out as a gay man in my community, as it would cause problems.





WARREN SCOTT

AGE: 38

HIV DIAGNOSIS: 1984



I was diagnosed HIV-positive in 1984, though I had probably contracted it two or three years before that. It didn't really hit me until a couple of years after my diagnosis. At that point, I thought I didn't have long to live.

In the past twenty years or so, I've buried two partners and I've lost loads of friends to AIDS. But, after all these years, I've had no HIV-related illnesses. I've never taken any medication. My CD4 count is about 650, viral load is still undetectable.

They're using me as a guinea pig. At the moment, I'm part of a small group which is being studied to find out why we're not contracting anything.

When I was a teenager, I couldn't see living beyond my 20s and suddenly I'm almost middle-aged.



RAJ

AGE: 35

HIV DIAGNOSIS: 1999



I was diagnosed HIV-positive four years ago. There were four of us – friends, all young Indian boys – who all found out we were HIV-positive about the same time.

There are lots of men in our community who think it doesn't happen to Asian gay men. But it does. The four of us were all going out dancing every weekend and

taking E and having unsafe sex, so it wasn't a surprise. I think I had been positive for about six months. I had been having lots of colds and chest infections and diarrhoea and generally feeling unwell and stressed out.

My shit stank. There was this strong ammonia smell, a smell I had never smelt coming out of my body before. I knew something had happened that had never happened to me before.

All four of us went on medication straight away. My doctor said that in my case it was borderline whether I should or not. I decided to do it because I didn't want to change my lifestyle. I wanted to carry on going out and taking drugs, and I knew if I did that, I would not be healthy, I would be ill.

My viral load went down immediately. I do have to look after myself. But I've had it pretty easy.

My cheeks have totally started sinking in. That's a huge thing for me – how you look to the outside world. It makes me feel awful. It makes you feel that the whole world knows you have AIDS.

There is a treatment where they fill your cheeks with collagen, but there's a huge demand for it and you have to be very wasted before you can get it.

I've lost all the fat on my legs too and they're much more veiny. When you see older men with HIV in our community – their top half is all pumped up, but on the bottom half they have pigeon legs and a

protruding belly because of the fat redistribution – you just think, 'Is that what I'm going to become?'

The worst thing about being HIV-positive is dealing with other people. Dating is a big issue. I find myself keeping away from people because I think to myself, 'I'm sure he's negative, so I don't want to go there.' And if you're going to tell people you're positive, when do you tell them?

When I fell in love with my last boyfriend and he fell in love with me, I knew that if I told him I was positive, it would scare him off straight away. I wanted to wait till he knew what we might have together. If he doesn't know me, then he's got nothing to lose by leaving me. But if he does know me, then he has something to balance the illness against, something to put on the other side of the scale.

I think I'm probably in the top two per cent in having a positive outlook on living with HIV. Most men I meet have real health issues and some of them just find it the most depressing thing.

I went to a support group for the first time within days of being diagnosed – to get as much information as possible. That's really important. That's the best way. Speak to other people.

All of this is still relatively new. Positive men can lead happy lives, despite the shit we have to put up with, but it is important to stress that it is an illness that affects your life and your confidence. It's no picnic.





WILIAM

AGE: 33

HIV DIAGNOSIS: 2001

“ I came to London from Brazil in 2000. It was very cold and I fell ill, so I went home again. While I was there, I took the HIV test again – I used to take it every year.

This was in January 2001 – and this time the result was positive. Since I had got a negative result in 1999, I assume I was infected some time in 2000.

My CD4 count was only 58 and my viral load was 280,000, so my doctors in Brazil put me on anti-HIV medication immediately. The combination they put me on made me feel very nauseous. I had a lot of stomach upsets and I used to get nightmares.

Since coming back to London, I have been on a different combination. I don't have the side-effects I had before, though I do get tired very easily. I feel legless, as if my legs can't support me.

My CD4 count is now 280 and my viral load is 50,000 – they are both going in the right direction I haven't had any AIDS-defining illnesses, though I have had herpes.

Being diagnosed HIV-positive was a shock. I try not to think about it too much and keep my worries to myself.





WILLIAM MCGARVIE

AGE: 43

HIV DIAGNOSIS: 1984



I was officially diagnosed in 1984 but I think I was probably infected two or three years before that. So it's around 20 years.

As soon as the test became available, I went and paid to have it done by a GP, who patted me on the hand and said, 'Oh never mind, terribly sorry, you'll probably only live for a year or two at the most.'

The doctor gave me a leaflet and said to give it to a friend to get them to buy me some aftershave to cheer me up.

Some of the things that are difficult – losing so many friends, especially friends that I grew up with in my late teens, early 20s.

That's something that I miss because I have other friends who still have friends they've known since school or college. All my friends from years and years ago are dead.

I went through a period when I felt really guilty that I'd survived so far but all my friends were dead.

Being positive isn't easy, it's far from being easy. If someone thinks it is, they're sadly mistaken. It really is a rollercoaster ride. Sometimes you get to the top and you just drop. And then you go back up again. You have to try and deal with it the best way you can.

I haven't had any AIDS-defining illnesses, such as KS, PCP or CMV (see page 19-20). But I don't have any testosterone after being positive for so long, and I have to have testosterone implants every five months.



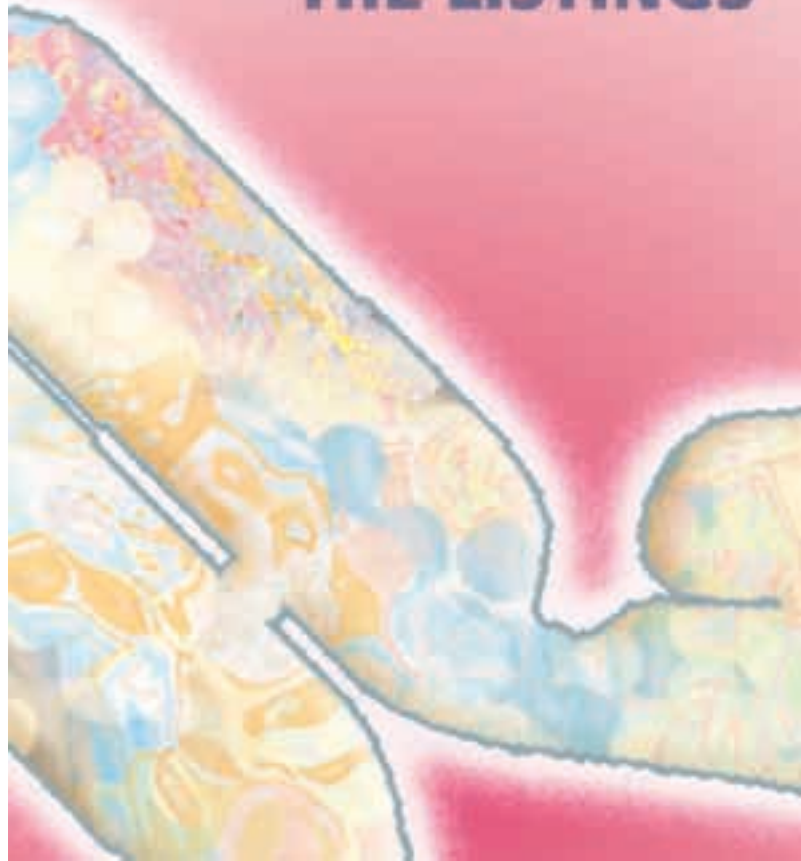
I also have HIV-related hypoparathyroidism, where my thyroid gland should produce this hormone but it doesn't. My body can't deal with or absorb calcium and I started getting dementia related to calcium deficiency.

My face went numb, I got these unbelievable headaches, didn't know where I was or what I was doing, and I thought things were happening that weren't.



AIDS

THE LISTINGS



HIV/AIDS TREATMENT CENTRES IN LONDON

You will be referred to a specialist HIV treatment clinic when you test HIV-positive. The doctors and other staff at the clinic will be able to answer any questions you have about your treatment. The clinic will also have an emergency telephone helpline which you can call at any time. If you are not happy with the treatment you are receiving, you are free to go and register with a different clinic.

INFORMATION ABOUT HIV/AIDS TREATMENTS

THE INFORMATION EXCHANGE

at the Chelsea and Westminster Hospital

020 8746 5929/5592

Mon-Thurs 1pm-5pm

www.hivgum.demon.co.uk/mw2/infoex/page1.html

POSITIVELINE 0800 1696806

Mon-Fri 11am-10pm, Sat & Sun 4-10pm

FOR INFORMATION ABOUT TREATMENTS ON THE WEB ...

www.aidsmap.com

www.ukcoalition.org

www.positivenation.co.uk

FOR INFORMATION ABOUT CLUB DRUGS & AIDS DRUGS

For information about mixing Ecstasy and other illegal drugs with HIV/AIDS treatment drugs, check out Positive About Drugs in the Health Library section of www.freedoms.org.uk.

See also, www.hiv-druginteractions.org

SUPPORT FOR HIV-POSITIVE GAY MEN

THT DIRECT 0845 1221 200

Mon-Fri 10am-10pm, Sat & Sun noon-6pm

THT Direct gives access to all of the support and information services provided by the Terrence Higgins Trust, including the Living Well with HIV project and the THT Gay Men's Support Group, which can be contacted direct on **020 7792 1200**

www.tht.org.uk

www.tht.org.uk/living.htm

UK COALITION OF PEOPLE LIVING WITH HIV AND AIDS

250 Kennington Lane SE11

020 7564 2180

Email: advocacy@ukcoalition.org

www.ukcoalition.org

POSITIVE FUTURES

c/o UK Coalition (as above)

020 7564 2188

Email: PFenquiries@ukcoalition.org

www.positivefutures.org

OASIS NORTH LONDON

Unit 2000, Regis Road, Kentish Town NW5

020 7485 2466 (24-hour ansaphone)

Email: cfo@dircon.co.uk

www.cfo.dircon.co.uk

POSITIVE PLACE

52 Deptford Broadway, SE8 4PH

020 8694 9988

www.thepositiveplace.org.uk

COMPLEMENTARY THERAPY TRUST

PO Box 32879, London N1 3QX

020 7704 1777

E-mail: info@comphealth.org.uk

www.comphealth.org.uk

GLOBE CENTRE

159 Mile End Road E1

020 7791 2855

Email: info@theglobecentre.co.uk

FOOD CHAIN

25 Bertram Street,
Dartmouth Park N19

020 7272 7272

Email: info@foodchain.org.uk
www.foodchain.org.uk

COUNSELLING & WORKSHOPS

Counselling is available from the Terrence Higgins Trust (THT), PACE, the Healthy Gay Living Counselling Service, London Friend and the East London Out Project. PACE and GMFA also offer workshops.

TERRENCE HIGGINS TRUST

52-54 Gray's Inn Rd WC1

020 7792 1200

www.tht.org.uk

PACE (Project for Advocacy, Counselling and Education)

34 Hartham Road N7

020 7700 1323

www.pacehealth.org.uk

HEALTHY GAY LIVING COUNSELLING SERVICE

020 7407 3550

EAST LONDON OUT PROJECT (ELOP)

56-60 Grove Road E17

020 8509 3898

LONDON FRIEND

86 Caledonian Road N1

020 7837 3337

(helpline daily, 7.30-10pm)

www.londonfriend.org.uk

NAZ PROJECT LONDON

(for Asian, Middle Eastern, South American and North African men)

020 8741 1879

www.naz.org.uk

GMFA (ACTION FOR GAY MEN'S HEALTH)

020 7738 6872

www.metromate.org.uk

TAKING THE HIV TEST

Blood tests for HIV are offered at all sexual health clinics. The results are usually available within one week. But at some clinics, you can take a test in the morning and get the result in the afternoon. Same-day testing is by appointment only. You will be offered advice and counselling before you decide to take your test. For details of all sexual health clinics and same-day HIV testing centres in London visit www.metromate.org.uk or www.freedoms.org.uk. For clinics outside London, visit www.aidsmap.com/search/orgsearch.asp or www.lovelife.uk.com.

Check out these websites, too:

www.metromate.org.uk

www.hgscotland.org.uk

www.hivgum.demon.co.uk

www.avert.org

www.ssha.info

THE 'YOU CHOOSE' SERVICE

A HIV-testing service for gay men in Soho at the Soho Centre for Health and Care (29-30 Soho Square W1 – entrance on Frith Street) runs every Wednesday evening from 5.30pm till 8pm. The results are available in just one hour. Check out www.youchoose.org.uk for details and information about the test. The one-hour results service is also available at the sexual health clinics in Chelsea and Westminster.

CONDOMS

You can buy condoms and lubricant in chemists, many supermarkets and in gay sex shops. For the widest range, gay shops and the internet are your best bet. For more details, see our booklet *Condoms - Everything A Gay Man Needs To Know* (available free in most gay venues or call **020 7530 3992** for a copy).

Freedoms (**020 7530 3941**) supplies free condoms and lube to gay bars, saunas and other venues in London. So if you find yourself out and about but out of condoms, Freedoms are there for you. Please don't take more packs than you need as supplies are limited.

Freedoms also now sells condoms and lube online at exceptionally low prices. Go to www.freedoms-shop.com.

FURTHER READING

Camden & Islington Gay Men's Team produces a range of information booklets for gay men. They are available free in gay venues in London or by phoning **020 7530 3596**. They are also available free to London-based organisations. The booklets can also be downloaded in Adobe Portable Document Format (pdf) from www.metromate.org.uk.



CONDOMS
EVERYTHING A GAY
MAN NEEDS TO KNOW



HIV
A GAY MAN'S GUIDE
A fully illustrated guide to the basic facts about HIV and AIDS. The companion booklet to this one.



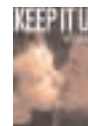
CRUISING FOR SEX
A guide to safer sex for gay men who have a lot of sexual partners.



HIV AND ME
The complete gay guide to the HIV test and living with the virus.



GOOD SEXUAL HEALTH
A GAY MAN'S GUIDE
A guide to sexually transmitted infections, how to treat them and how to avoid them.



KEEP IT UP
A gay man's guide to staying HIV-negative.



NEED HELP?
...ADVICE?
...INFORMATION?
A comprehensive credit-card sized listing of gay helplines, booklets, addresses and websites.