

Autumn 2009

POSITIVELY WOMEN

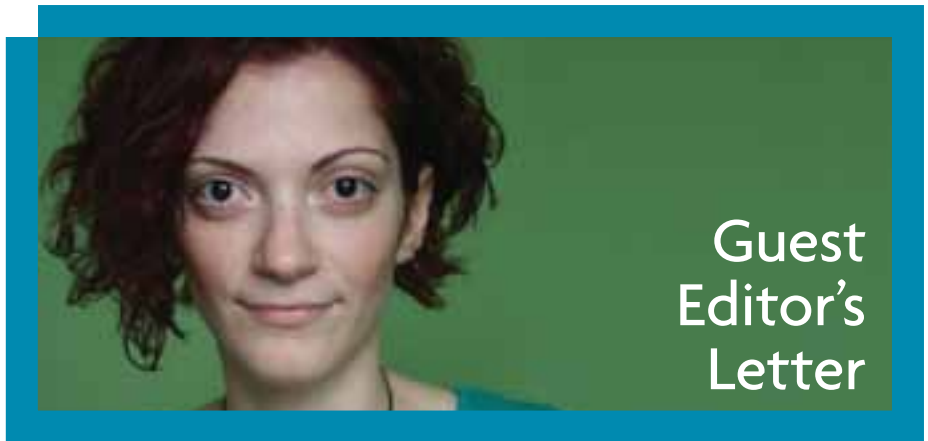


Me: My Body, My Treatments

The only magazine for positive women written by positive women

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Dear Readers,

It was after Freddie Mercury's death when I first became aware of HIV and I remember I felt an inexplicable sadness. That was in 1991, and little did I know that only a few years later, I would be diagnosed with the same virus...

In 1996, HIV combination therapy was licensed in Europe. In 1999, I was put on treatment myself and was told that I might live up to 10 years. In 2001, in the developing world, generic drugs became available and in 2008, there were three million people on anti-retrovirals. Less than one month ago, I was filled with hope at the promising news that an investigational HIV vaccine could possibly cut the risk of infection, according to researchers.

In my article for the next issue, I will describe a different aspect of treatment: my ordeal of dealing with the Romanian healthcare system and the contrast with what I have experienced recently in getting treated in London. When I first came to England, a little over one year ago, I had no idea that this was going to be my new home; it wasn't planned, but my health was so bad that I had to stay and get my medical care here. I was fortunate enough to have some wonderful people in my life who have always encouraged me to believe that I could be treated better and that my life was not less valuable because of my

status. As a result of my experience, I've come to understand that treatment means not only being handed a prescription and swallowing tablets, it is also about people's support, comprehension and sensitivity towards the diverse range of issues that come with HIV.

In writing this editorial, I reflected on my life post-diagnosis, and yes, since the early 80s, when HIV meant GRID (Gay Related Immune Deficiency) and life expectancy used to be dramatically poor, great advancements have been achieved and I am confident that vital progress will continue. HIV drug therapy has helped me LIVE and that's something I am truly thankful for, but I cannot ignore those who didn't have the privilege of living in developed countries, nor disregard their frustration and uncertainty generated by lack or discontinuity of HIV treatment, reduced medical care and support systems, absence of accurate information, and of any form of equal opportunities and human rights. Until I see these issues actually resolved, we've still got a long way to go...

Before I let you enjoy this issue I am pleased to announce that Positively Women have been nominated have been shortlisted for the Guardian Charity Awards 2009. The winners will be announced in December!

Anca

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Living Well: With or without drug therapy

I have been diagnosed HIV positive for 18 years and still enjoy good physical health, despite my advancing years. I credit this to a consciousness to look after myself in terms of lifestyle; healthy eating, enough sleep and a varied exercise routine. All combined have maintained my physique, youthfulness, and energy levels.

For 10 years, I chose to live with the virus, engage with it, without any medical intervention other than being regularly monitored for CD4 and viral load counts. These were important years where I learnt how the virus expressed itself in me.

Symptoms such as swollen lymph glands or night sweats could subside but quickly returned if I got too stressed out or drank too much alcohol. These were pivotal experiences in determining to look after myself well. My body acclimatised to co-existing with the virus. I developed a strong sense and respect for equilibrium, stability, and consistency – it often escaped me in the huge variables of my personal and emotional life but the concept always remained that it was possible to achieve optimum health.

After the birth of my second child, I decided to go on combination therapy permanently. I had a short experience with it around the birth of my first child with no adverse side effects. My viral load very quickly became undetectable and my CD4 over the years has steadily climbed. In terms of adherence that proved quite straightforward, but definitely improved when I changed from a combination that I had to take twice a day to one that I only required once a day. Most importantly, I experience no discernible side-effects

I think of my drug therapy as my health insurance policy, I really don't think in terms of being ill, even a common cold is a rarity. I

know my immune system is functioning and supported. Moreover, I do a lot to boost my system. I regularly take nutritional supplements, but my practice of yoga has impacted most beneficially. The communication it enables in terms of mind, body and spirit has helped me to heal and develop. Over the years, I have also utilised many other therapies to help alleviate the imbalances that naturally occur: homeopathy, craniosacral therapy and shiatsu. In so doing, I've acquired a mixed bag of knowledge and self help skills that I draw upon as and when necessary.

However, I attribute the greatest part of my health to a 'positive mental attitude'. My experiences with depression and low self-esteem led me to find the teachings to challenge this state and learn a more self-accepting and less judgemental vocabulary to face life with.

I believe it is possible to live well with this virus, without the use of drug therapy. This statement in no way seeks to undermine the life and death reality that access to drug therapy represents for some people in the world. I appreciate I have the luxury of having the choice and free access to comprehensive treatment, for which I'm unreservedly thankful. Yet I feel it's important to assert that one's health and vitality is something, particularly for positive people, to be actively undertaken and to warn against complacency.

I attribute the greatest part of my health to a positive mental attitude; a confidence that I could live with this virus with or without drugs. Treatment may suppress the virus but an individual has to create their own vitality.

Janine

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Positively Women promotes visibility and the involvement of women living with HIV and is proud to have an HIV positive woman on the front cover. This month it's Anca, if you would like to be our cover model please contact us by emailing Lucy at losman@positivelywomen.org.uk

Access All Areas

In the mid eighties, I became aware of a terrible and new infection that devastated people by suppressing the immune system. An infection that there was no vaccine against and for which there was no treatment or cure. I had seen the adverts with icebergs and gravestones and the leaflet that came through the door. Then there were the pictures of people wasting away and I felt sad, it was such a tragedy, but it was something distant and unrelated to me or any of my experiences.

Around this time, I went back to college to study and took a job in a nursing home to pay my way through. There I met Evelyn. Evelyn had had multiple strokes and she could no longer move. She watched out of her world in silence with seemingly blank, watery and unblinking eyes. She was unable to move or speak. Her skin was as thin as tissue paper, her hair was so wispy, and fine you could see her skull through the thin down. Youth was long since gone and what was once a tall elegant frame was now skeletal. The muscle wastage caused her ageing skin to sag and swivel around her bones. No movement could be made without help or pain. She could not feed herself or walk, she could not smile or laugh or shout, she could not rub her watery eyes or scratch if she had an itch.

I was with Evelyn when she died. I saw her last look out at this world and saw her take her last breath. I helped to lay out her ravaged body. She was the first person I had looked after who had died, but she would not be the last. Death goes along with working with the old and infirm in nursing homes.

I did not expect that in my early 20s I would see such wasting devastation outside work, but my own HIV diagnosis was just around the proverbial corner and with it would come meetings with people of my own age whose bodies and lives were just as fragile as Evelyn's.

Not long after my own diagnosis I met Eric, a gay man who was also diagnosed with HIV. We quickly became friends, spending lots of time together. He had an Old English sheepdog called Bucket who wore a scarf. We would go out on trips in his Ford Anglia car and I stayed at his place a lot of the time. He introduced me to gay clubs and showed me a scene I had no idea existed. He also took me along to Body Positive in Leeds, here I met other men who had been diagnosed with HIV and some who had AIDS-related conditions.

When I was first diagnosed, I bombarded myself with images of what this could mean. I looked at a book called the *A-Z of AIDS* peering in horror at the photos of related conditions and telling myself 'you're not going to get that'. I also borrowed a copy of The National AIDS Manual (NAM) and went through it, looking at all the weird names of things that can happen when you have no immune system. Hundreds of different AIDS-related diseases and conditions with accompanying acronyms, to shorten their long and complicated names.

I felt I needed to know something about the things that were now affecting my newly found peer group. I watched as time went on and many of the men became frail and wizened. I saw medicine's unsuccessful attempts to preserve their weakening bodies. I saw a myriad of drugs to treat innumerable conditions and I remember thinking, 'I am not sure I could do that.'

I had a number of people lined up to help me to die if I got to the point of no return. Laburnum pods under the tongue, a pillow over the face and a massive overdose of morphine were on offer from three different people if I ever got to that stage. Luckily, I have never had to test their commitment, or my own, to the plan. I remained healthy enjoying university and getting involved in HIV awareness programmes.



In my final year of university, I spent three months in Tanzania and Uganda. I visited HIV projects and went to meet other people living with the virus. At the time, there were no treatments but we all knew that when they did come along I would have access to them and they probably wouldn't. A harsh and despicable reality hit me very hard – if this was the privilege I had gained by being born in the UK, I wasn't sure I wanted it.

On my return to the UK, Eric was diagnosed with CMV retinitis and his sight started to go in one eye. He wore a patch with diamonds and emeralds. Over the next few months, he became increasingly ill and had a constant drug regime to keep up with. He developed toxoplasmosis and became paralysed down one side. Exhaustion and depression sucked at his energy and he struggled to live a life reliant on others. He went on a drug trial that corresponded with him being sicker than ever. I saw him fading and privately blamed the drugs rather than the disease.

By that point, even if a cure had miraculously come along the next day, I thought his body would not recover. Of course, for Eric the drugs were his only chance of survival, no matter how many he had to take. He knew he was being used as a guinea pig – he wanted to be – and not just for himself. He said that no matter what happened to him, others would hopefully benefit.

One day, we sat in his kitchen after he had yet another fall. His speech was slurred and he struggled to stay upright in the chair. I played him some music that I wanted him to hear. We were both tearful and he told me what I already knew – that he had had enough.

He died two days later. It was the week I was due to move to London to a new job at Positively Women (PW). I arrived at his house just after he died but we had already said our goodbyes. I helped to lay out his body. His skin was loose around his bones and seemed older than his 32 years. His body was an empty husk where a once vibrant, gregarious man had lived. I delayed my start date at PW to help with the funeral, for which he was (typically) an hour late. The driver had accidentally taken him to the wrong church! The Eric I knew would have howled with laughter, so it felt quite fitting.

I remained well. I felt optimistic about life but not about HIV treatments. Over the years, I had a few peculiar ailments but there was no evidence to suggest they were related to HIV. They included hidradenitis suppurativa. The symptoms were painful interconnecting clusters of chronic abscesses and boils in my groin, sometimes as large as a snooker ball, sometimes as small as a bean, but often leaving wounds that would not heal. Once it was diagnosed, I took a cocktail of drugs over a

ten-year period; some of them were toxic and had unpleasant side-effects. Nothing seemed to work.

My consultant discussed starting HIV treatments as a possible way to suppress the condition, but I wasn't keen. I had built a psychological barrier about starting them and harboured deep-rooted anxieties and guilt about having access to drugs. I asked myself, why should I have them when Eric and the people I met in Africa could not? I also worried I would sabotage my long-term prospects by not taking them properly. Then I remembered how Eric had been a willing guinea pig so others would benefit. Eventually, I realised that it would be a greater sabotage of my life and the memory of Eric and others like him, not to take them.

Until there is universal access to treatments, each tablet will be both a wonderful life-saving tonic and a very bitter pill to swallow.

So, I started treatments a couple of years ago. Now, I'm on one tablet, once a day. How far things have come, I think, since Eric's time. It would perhaps be easy to convince myself that HIV is no longer a big deal. However, the lack of universal access to treatment, care and support and the continuing stigma and discrimination means that there is still a very long way to go before all people living with HIV enjoy the rights that I have.

And so I find myself at yet another crossroads in my life, trying to work out the direction to go that will bring me the greatest sense of satisfaction and pride in my life and work.

Of course, without access to treatments it is unlikely I would find myself in such a dilemma. Being in my forties and living with HIV for nearly 20 years and still making decisions about the future is a privilege.

For me – although I am grateful for treatments – something makes every pill a symbol of the inequality that exists. Lives are still seemingly given more value because of where they are born. Each tablet is coated with memories, going back years: Friends withering and the smell of dehydration. It is also laced with thoughts of and for the millions of peers that I will never meet.

Until there is universal access to treatments, each tablet will be both a wonderful life-saving tonic and a very bitter pill to swallow.

Julie

HAART versus HEART

Over recent years, there have been massive improvements in the treatment of HIV disease. This has come about not only through the advent of new drugs, but also the understanding from both medical personnel and individuals of the importance of individualisation of therapy with proactive switching of drugs to prevent issues of adherence or toxicity developing. There are multiple choices of treatment available which can control HIV replication and choice of therapy should be based not only on the effectiveness of the regimen but also on known toxicities associated with the drugs and the ability of the patient to comply with the dosing regimen. However, with the long-term durability of the efficacy of these agents, new toxicities have come to light. These have included side-effects affecting major organs of the body, including the kidney, liver and the heart.

Over the last two years, increasing information has come to light that individuals living with HIV both on and off treatment may be more likely to develop cardiovascular disease including strokes, heart attacks and blockages of arteries of the legs leading to poor circulation. Perhaps the most worrisome of these is the possible effect of some drugs on increasing the risk of heart attack.

Background

HIV has always been known as a pro-inflammatory condition, and the inflammation associated with uncontrolled HIV disease has been associated with the development of disease of the kidneys, heart and liver. Therefore in any consideration of the effect of HIV drugs on heart disease, this must be balanced by the fact that an uncontrolled HIV disease itself may be associated with this condition. The improvements in the ability to control HIV disease, even in individuals who are multi-class resistant, means that all individuals should expect their HIV to be able to be controlled. However, there has also been data that individual drugs may be associated with an increased risk of heart disease. This risk must be taken into consideration with other risk factors, some which may be associated with HIV disease or its therapy. Other risk factors for heart

disease are non-modifiable; as we get older and having a strong family history of heart disease all mean that the risk of cardiovascular disease is higher.

However, there are other factors that are modifiable; these include exercise, diet, cigarette smoking, which is increased in the HIV positive population and hypertension. Hyperglycaemia and insulin resistance, which may lead to diabetes, are associated with some anti-retroviral agents as is hyperlipidemia. As anti-retroviral drugs may be associated with diabetes, hyperlipidaemia and possibly hypertension, the additional risk of myocardial infarction with the drug per se may be very important. However any increased risk of myocardial infarction needs to be balanced with other toxicities and effectiveness of alternative agents.

What drugs may be associated?

The DAD study has collected data from individuals throughout Europe and followed them up over time. This consists of a large group of individuals who are on multiple different therapies and thus allows possible associations of drugs with specific diseases to be examined. The early results from this cohort showed that protease inhibitors (PIs) were more associated with the risk of myocardial infarction (MI) than non-nucleoside reverse transcriptase inhibitors (NNRTIs), although this was mostly explained by the higher lipids with the PIs.

More recently, further analysis of this data has allowed individual drugs to be associated with possible risk. The most recent data has shown an association of abacavir and didanosine in the nucleoside class, and lopinavir and indinavir in the PI class to be associated with an increased risk of cardiac disease. There was no associated risk with other nucleoside analogues including tenofovir, and no association with the other PIs studied, although the most widely prescribed PIs at the present time, atazanavir and darunavir, have not been studied yet within this cohort, as there has not been sufficient time of follow-up. The risk with abacavir has been confirmed in four other studies, although four

cohorts have shown no associated risk. In one study which showed no associated risk there was a suggestion that the reason more heart attacks were seen with abacavir was because individuals with renal dysfunction, another risk for MI, were more likely to receive this drug. Interestingly, in one study showing a risk, the risk with abacavir only occurred during the first year of treatment. The risk of abacavir in the DAD study was approximately 1.8 i.e. there was 80% increase chance of heart attack with this drug. If true, this would be equivalent to the risk seen in someone who smoked 20 cigarettes a day. In the case of the PI lopinavir, the risk is slightly different, whilst with abacavir this is a risk which does not alter over time; the risk with lopinavir appears to increase with longer time of drug. It is important to realise that this risk is independent of the hyperlipidemia which may occur in individuals receiving these drugs.

So what to do?

Individuals with HIV should be encouraged to perceive their life span as being that of the general population. As such, they should live a life similar to that of the general population. This means that they should make great efforts to give up smoking, should exercise and have a good diet. In addition, they should be encouraged to have their blood pressure checked frequently, to have their lipids well controlled, and also undergo tests for diabetes. Most clinics will now carry out these tests on a routine basis. In addition, some clinics may start testing the HIV population for cardiac risk using non-invasive modalities such as brachial reactivity. Whether these can be utilised for the whole HIV population is a question of both resource and cost.

Individuals need to weigh up the pros and cons of the therapy they are on, and discuss with their physicians whether it is in their best interest to switch drugs. It is important to realise that with some drugs we do not know what the cardiovascular risk is, and all drugs have toxicities associated with them.

In my clinic, I would encourage individuals to switch from abacavir where it is feasible. This is

principally in individuals who have commenced a regime involving abacavir, and have the option to switch to tenofovir without a high risk of toxicity. However, in other individuals abacavir may be the best drug, and has certainly been shown to be effective as part of antiretroviral therapy. So once more, it is a question of deep discussion of the pros and cons of treatments and individualisation of therapy. Similarly with kaletra, individuals should be given the option of switching to one of the newer PIs such as atazanavir or darunavir. However, it should be noted that we have no cardiac outcome with these drugs although they do have a lower risk of hyperlipidemia, and have the added advantages of being able to be dosed once daily and have less diarrhoea as a side-effect.

However, it is important that we do not demonise these drugs. All drugs have side-effects, and if one were to look at the side-effect profile of even the safest drugs used in HIV, probably no-one would ever take them. It is always a case of balance, a balance between the efficacy of the drugs, the known toxicities and possible toxicities in the future. It is likely that most individuals during their lifetime will need to switch drugs for one reason or another, and it is important that at each clinic visit, the suitability of the regimen that the individual is receiving is discussed.

Dr Mark Nelson

Consultant Physician, Chelsea and Westminster Hospital, London



Treatment Timeline: Silvia

I was started on HIV treatment in 1998, just over a year after finding out I was HIV positive. I was still in Italy at the time and finding it extremely hard to come to terms with my diagnosis.

Treatment was pretty new then and in Italy there wasn't any information available for patients. All I knew about treatment was an article I found in a magazine I was reading in the dentist's waiting room. The article was an interview with Magic Johnson on a new 'miracle' cure for HIV. There was a picture which showed ten different bottles of drugs. I kept the article folded in a secret drawer and I would take it out from time to time and look at it with a sense of disbelief. Was it true that HIV could be treated? Would I be given the drugs? The rumours from the hospital corridors were that only 'deserving' patients – patients who could be expected to be compliant with this very expensive and complex medical regimen – would have access to it.

My CD4 count was rapidly declining and so the doctor informed me that I had to start treatment as soon as possible. I wasn't asked how I felt about it, or given any explanation on what was the aim of treatment, if it would have worked for me and how. I had no knowledge about the virus. I vaguely understood that CD4 were important for the immune system and I had never even heard of viral load counts or anything else. I was very anxious about this mysterious treatment. When I dared to ask my doctor about possible side-effects, he shouted at me, annoyed: 'Just fucking [*sic*] take it!'

His tone and attitude were telling me (or at least this was what I heard in my head): 'You probably deserve to have this awful illness, you should be grateful we even bother to give you medication. How do you dare ask all those questions?'

I don't know if it was the nerves, or the appalling communication skills of my doctor, I felt really confused, when I arrived home with all those boxes of pills, which I couldn't pronounce the names of. I had to hide the pills in fear somebody from my family would see them.

Anyway, I started taking the medications. It was a lot of pills. When I went to the first check up appointment, after a couple of weeks, I was feeling really awful, nauseous, and tired. I told the doctor: 'I feel terrible, it is a lot of pills: I take three of these two of those and then this one on an empty stomach and...'

The doctor looked at me horrified: 'You are doing it ALL wrong! You have mixed the pills up!'

He called other consultants into the room, sent for a nurse. Everybody started running around looking really worried and freaked out. Apparently, I had overdosed some medications and not taken enough of another. It was a surprise to everybody that I didn't have a really severe reaction.

I started crying, in fear, terrified. I hadn't even told anybody about starting treatment. I couldn't stop the tears flowing.

The doctor start shouting at me 'What did you do????! This is really dangerous, you know?' He asked a nurse to take my blood test immediately. I started crying, in fear, terrified. I hadn't even told anybody about starting treatment. I couldn't stop the tears flowing. While the nurse was taking my blood she was trying to console me, telling how much she wished they would find a cure. She seemed the only human person there. I couldn't stop crying. The doctor started telling me: 'But, what is the matter with you?! I'll make a referral to psychiatric department.' Somehow I managed to tell him, through the tears, that I didn't need to go to a psychiatrist: I was just scared. He decided to stop the treatment for a few weeks, and when I was started again later on they wrote everything down on a piece of paper for me. This time I took them right. It was hard, 18 pills a day, some with food some without food. I had to wake up in the middle of the night to swallow some of them. Nobody had explained anything about

the importance of never missing doses, in order not to develop resistance to the medications. So I just took them when I could remember. Sometimes I would miss two or three doses in a row.

The saying: 'Knowledge is power' is particularly appropriate when applied to HIV. Learning more about the virus and what I can do to counteract it has really helped me in feeling I have some control over HIV.

I had minor side-effects, mainly a tingling feeling in my mouth, always thirsty, my skin was dry and flaky, and my lips chapped, I developed in-growing toenails. But I was lucky, those were all minor and they stopped when I changed treatment. I was just really fortunate that in spite of taking Indinavir and d4t I never had any lipodystrophy, which would have stayed even when I switched treatment.

When I moved to London the year after, I was told for the first time that I had an undetectable viral load and what it meant. It seemed like a dream. I started to understand how treatment worked, reading magazines and booklets I found in hospital. By going to support groups at Positively Women I learnt from others how to take the pills, little tricks not to forget doses. I also learnt it was my right to discuss my treatment with the doctor and negotiate something that suited my lifestyle better. Thanks to the support of treatment advocates, I asked my new doctor to change my treatment. She was initially resistant: her point was my 'numbers' were OK. She told me: 'I cannot change your treatment because it is working.' 'It is working for who?' I asked.

I explained that taking 18 pills a day was impossible and I kept missing doses. After a lot of insistence from me I was finally moved to Nevirapine and Combivir, four pills twice a day. It was an incredible change. At last I was able to go out without

massive pill boxes rattling in my bag. I stopped worrying about constantly missing doses and feeling I was my worst enemy because of my incapacity to take the treatment right.

I have been on treatment for almost 12 years now, and I have also become a treatment advocate. I try to support other women to learn as much as possible about treatment, so that they can be in control of their health. The treatment I am taking now is really working for me, it is only once a day, and I have absolutely no side-effects. It is almost a miracle and I feel lucky to have now a doctor who really listens to my concerns and will always discuss all aspects of my care with me.

The saying: 'Knowledge is power' is particularly appropriate when applied to HIV. Learning more about the virus and what I can do to counteract it has really helped me in feeling I have some control over HIV. I know the medical system has not overtaken my body and my life. Supporting others to gain more understanding of HIV and ARVs has also helped me increase my self-esteem and the feeling I am a valuable member of the community of PLHIV.

If you are interested in becoming a treatment advocate or just want to know more about treatment, go to *i-Base* (www.i-base.info). They organise great training, all run by people living with HIV who have developed an in-depth knowledge about treatment and also know how to make things easy for those of us who don't feel too confident about reading medical research. Even if you don't want to become a treatment advocate, or you don't live in the UK, *i-Base* has a great website where you can ask questions online and download lots of booklets and resources, completely free for people with HIV.

Silvia



HIV and Your Liver

Why do I need to know about my liver?

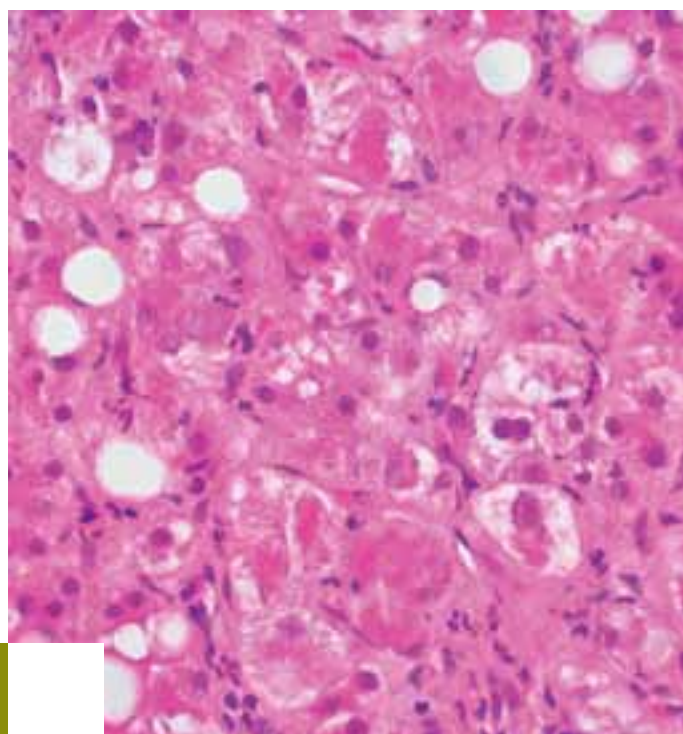
Your liver is important. It filters your blood, removing poisonous (toxic) substances from food, medicine and body waste. It produces a substance called bile which helps to digest your food. It processes (metabolises) nutrients from food, releasing energy into your bloodstream and storing vitamins and minerals. Your liver also produces proteins needed by your immune system to fight infection.

Many HIV drugs, as well as other medicines, are broken down (metabolised) by your liver. Unfortunately, when this happens some of these drugs can damage the liver and this can affect how well your liver works.

What are the benefits of knowing what condition my liver is in?

Liver disease can progress very slowly, often taking many years. People living with HIV who also have hepatitis B or C (co-infected) may experience faster liver disease progression than people infected only with hepatitis. Often people do not have any symptoms until liver damage is advanced.

Over time your liver can become scarred. This process is called fibrosis and may lead to liver cirrhosis, a serious condition where the liver is very damaged. The sooner you know what condition your liver is in, the sooner something can be done about it and any underlying causes can be treated.



A healthy liver is important for your health, your immune system and to make sure your HIV treatment has the best chance of working effectively.

How can I prevent liver problems?

If your anti-retrovirals (HIV medicines) are causing liver damage, you may be able to switch to other drugs. You should not stop taking your current HIV medicines without speaking to your doctor first.

You should try to keep the amount of alcohol you drink within recommended safe limits. If you take recreational drugs you need to be aware that they may also damage your liver.

To help prevent co-infection with hepatitis B or C, you should avoid contact with blood or needles and use condoms for anal and vaginal sex. This will reduce your risk of exposure to either virus. Having unprotected sex and having many different sexual partners can increase your risk of co-infection. Some sexual practices, including more extreme forms of sex, could also put you at risk.

If you are co-infected with hepatitis (B or C) make sure you are monitored regularly and take any medicine that has been prescribed.

Obesity is another risk factor for the development of liver damage. It is important to eat a healthy, balanced diet and to maintain a healthy body weight through exercise. Ask your doctor or nurse for advice: they may refer you to a dietician.

What are the risk factors for liver disease?

Factors that can affect your liver include:

- Prescription drugs
- Over the counter drugs
- Frequent use of antibiotics
- Some dietary supplements (e.g. Kava Kava)
- High doses of vitamin A
- AIDS-related opportunistic infections (e.g. tuberculosis, cytomegalovirus and cryptosporidiosis)
- Hepatitis A, B, C, D or E
- Obesity
- Heavy alcohol use
- Recreational drug use

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What types of liver disease exist?

There are many types of liver disease. Possibly the best known are hepatitis B and C, both are viral infections. If they are left untreated they can damage your liver and this can lead to end-stage liver disease, the need for a liver transplant and even death.

Other types include fatty liver disease (which is linked to obesity) and liver cancer (which may develop as a result of cirrhosis).

How is liver disease detected?

Blood tests known as liver function tests (LFTs) are a good way of finding out if you have liver damage. They measure the levels of certain enzymes in your blood. High levels could indicate liver damage.

There are blood tests to check if you have hepatitis B or C and some other liver diseases.

A liver biopsy can check how healthy your liver is. A machine called a Fibroscan can detect stiffness in the liver. The stiffer the liver, the more likely scarring is present.

Can liver disease be treated?

There are treatments for liver disease. If you have any form of liver disease you should at least reduce the amount of alcohol you drink: it is best to cut out alcohol completely.

Hepatitis B can be treated with oral drugs (antivirals) or interferon-alfa injections to control the virus.

Hepatitis C can be treated with a course of medicine for 24 or 48 weeks.

Fatty liver disease (obesity-related) can be controlled with a well-balanced diet to assist weight loss.

Questions to ask your doctor

- Have I been tested for hepatitis B or C?
- Can I receive the hepatitis A or B vaccine?
- Do I need (or am I having) my liver function tested?
- How can I look after my liver?
- Am I receiving the most appropriate treatment?

HIV and Your Body Secretariat

Would you like to help other positive women?

Would you like to volunteer at Positively Women?

Have you got one day or evening a week spare to volunteer your time?

Positively Women is currently looking for new Case Work Volunteers

As a case work volunteer your role would be to:

- 1 Assess needs of new clients, set goals and draw up an action plan
- 2 Facilitate the running of support groups around London
- 3 Provide clients with available information on women, HIV and related issues

You need:

- Good at communication skills with people from all backgrounds
- An HIV diagnosis of at least two years
- Good knowledge of HIV and related issues
- Ability to listen well, and respond appropriately, to needs and requests of service users
- Experience of group facilitation
- IT, Administrative and organisational abilities
- Ability to work as part of a team
- A willingness to disclose status to service users, within PW, and the HIV sector
- Ability to deal with stress and be emotionally resilient

In exchange Positively Women offers:

- Relevant training to meet the responsibilities of this role
- Work towards NVQ level 3 in advice and guidance.
- A chance to develop your skills
- Supervision and feedback on progress
- Travel and other out-of-pocket expenses

If you are interested in volunteering please contact Sarah Fraser on 020 7713 0444 or email sfraser@positivelywomen.org.uk

The New Female Condom:

Frequently Asked Questions

What is FC2 Female Condom?

FC2 Female Condom is a thin, soft, loose-fitting sheath made from synthetic rubber which is worn inside the vagina. There is a flexible ring at each end. The inner ring at the closed end of the sheath is used to insert the condom inside the vagina and to hold it in place during intercourse. The rolled outer ring at the open end of the sheath remains outside the vagina and covers part of the external genitalia.

FC2 Female Condom is inserted into the vagina before sex. It holds the man's sperm after ejaculation thus preventing unintended pregnancy. It also acts as a barrier to sexually transmitted infections (STIs), including HIV, because it completely lines the vagina.

What are the advantages of FC2 Female Condom?

- FC2 Female Condom gives women control and choice over their own sexual health.
- Women can protect themselves with FC2 Female Condom when their partner does not want to use a male condom.
- FC2 Female Condom is hypo allergenic and is safe to use with people who are allergic to rubber latex.
- FC2 Female Condom can be inserted before intercourse thus not interrupting sexual spontaneity.
- FC2 Female Condom is not dependent on the penis being erect for insertion and does not require immediate withdrawal after ejaculation.
- FC2 Female Condom is not tight or constricting.
- FC2 is highly lubricated and the material warms to body temperature so sex feels natural.

Why do we need FC2 Female Condom?

Women and men can initiate the use of FC2, so it provides them with an additional choice to protect themselves from STIs, HIV and unintended pregnancies. It is not intended as a replacement for the male condom but rather as an additional option for both women and men.

Is FC2 Female Condom Safe?

Yes. Extensive testing has shown that FC2 Female Condom is a safe and effective method for preventing unintended pregnancy and STIs, including HIV.



Is FC2 Female Condom easy to use?

Yes. You can try several positions to insert FC2 Female Condom and decide which one works best for you.

Try inserting FC2 Female Condom while standing, sitting, squatting or lying down. Some women also involve their partners in insertion and find this is enjoyable for both of them. Most women find FC2 Female Condom easier to insert with practice. Research has shown that new users who try it three to five times become confident using it. Inconsistent users may take longer to master FC2 use.

When can I insert FC2 Female Condom?

FC2 Female Condom can be inserted in advance of sexual intercourse and does not need to be taken out immediately after intercourse.

Is it true that FC2 Female Condom can provide pleasure during intercourse?

Many men and women feel closer with FC2 Female Condom than with a male condom due to the fact that FC2 is made from a material that conducts heat and makes sex feel natural.

What type of lubricant can be used with FC2 Female Condom?

FC2 Female Condom comes pre-lubricated with a non-spermicidal, silicone based lubricant. Oil-based or water-based lubricants can be added on the inside and outside of FC2 Female Condom or on the penis.

(Please note that with a male condom only water-based lubricants can be used because male condoms are made from a different material called latex).

Will FC2 Female Condom be noisy during sex?

There may be a little noise particularly if the condom is not properly lubricated. If you experience noise during sex and it bothers you, you can add extra lubricant. Inserting FC2 Female Condom a few minutes before intercourse also helps to reduce noise. Some women have found FC2 Female Condom quieter than the first generation FC Female Condom (FC1).

How does the inner ring feel during sex?

Many women and men report that the inner ring enhances pleasure for them during intercourse. If the inner ring is causing discomfort, try repositioning or reinserting FC2 Female Condom.

These are some of the FAQs for more information, please contact: info@supportworldwide.org or visit www.supportworldwide.org

“We were a little apprehensive about it at first – I felt a little embarrassed and clumsy inserting it, although, once it was in, it felt fine and we forgot about it, for the rest of what was, a highly pleasurable afternoon, thank you!”

“I like the female condom as I often have issues with negotiating safe sex with my partner. With the female condom I can take control and I feel more confident.”

“My experience has been a good one. Me and my husband can feel more sensation when we use the female condom. My husband is not positive and he feels more comfortable if I use a female condom...”

The Female Condom



FIND YOUR FREE FC2 on the cover of this issue of Positively Women

The new Female condom is

- more affordable
- safe and effective

The Female Condom gives women control and choice over their own sexual health.

Let us know what you think!

www.femalehealth.com
www.postalcondoms.co.uk

HIV and the Cervix

An estimated 471,000 new cases of cervical cancer are diagnosed each year in the world with 80% of these occurring in developing countries.

The NHS cervical screening programme was set up in the UK in 1988 in order to reduce the number of women who develop invasive cervical cancer and the number of women who die from it. Regular screening of all women at risk allows conditions that might otherwise develop into invasive cancer to be identified and treated.

Many HIV positive women are not aware that they require more frequent cervical screening than HIV negative women. This guide endeavours to explain the reasons why it is so important not to keep postponing that smear test.

Cervical abnormalities and HIV infection

An abnormal change to the cells of the cervix is termed cervical dysplasia. Cervical dysplasia is a transformation of cells on the surface of the cervix and the most common cause is the sexually transmitted human papillomavirus (HPV). In

the main the virus will be dealt with by a woman's immune system and the cells will go back to normal without treatment. However, in a small proportion of women, cervical dysplasia can, if left untreated, develop into more serious abnormalities and potentially cervical cancer. In HIV negative women, this progression can take 10 years or more, but if a woman has a low immune system then she will be less able to clear HPV and more likely to develop cervical dysplasia. Also unfortunately, for women with HIV, a weakened immune system allows the progression from cervical dysplasia to cancer to happen faster. This is the reason that current UK guidance is that women with HIV infection should be screened every year for cervical abnormalities as opposed to every three years in HIV negative women.

What causes changes to the cervix?

Abnormalities of the cells of the cervix are caused almost entirely by infection with HPV. Although approximately 100 different types of HPV have been identified, HPV-16 and HPV-18 cause the majority of all cases of cervical cancer. The cells of the body have naturally occurring cancer-suppressing proteins to prevent abnormal cells developing. HPV-16 and 18 are able to inactivate these proteins, which leads to the development of cervical dysplasia.

How are abnormalities of the cervix diagnosed?

Cervical screening is not a test for cancer. It is a method of preventing cancer by detecting and treating early abnormalities, which, if left untreated, could lead to cancer in a woman's cervix.

The test involves the insertion of a speculum into the vagina by a doctor or nurse. A small brush is then used to take a sample of the cells on the surface of the cervix. This can be a little uncomfortable, but is not painful. It takes about five minutes. Many people refer to the procedure as a smear test as the sample of cells used to be smeared onto a slide to be looked at under a microscope. Most clinics now use liquid based cytology (LBC) where the sample of cells is placed in a sterile pot of liquid and then sent to a laboratory for analysis.

The test is looking for cervical cells that have been transformed by HPV into abnormal cells that have the potential to become cancerous. If the laboratory detects these cells, they will advise your clinic to refer you for colposcopy. At colposcopy, a specialist doctor or nurse takes a magnified look at the cervix. If abnormalities are seen at colposcopy, then a biopsy is usually



Smear Tests

– Dealing with the discomfort

taken. Examination of the biopsy allows the changes to be graded as cervical intraepithelial neoplasia 1-3 (CIN 1-3), where CIN 1 is the least severe, and CIN 3 most severe. It is this CIN that may develop firstly into a local pre-cancer within the cervix and then into invasive cancer that can spread to other tissues.

Can you develop cervical cancer even if your screening tests are normal?

No test is perfect. A cervical screening test is good at picking up some precancerous changes. However, some types of cervical cancer do not show up on the screening test. Some women with cervical cancer have vaginal bleeding between periods or bleeding after sex, a change in the vaginal discharge, or pelvic pain. Women with any of these symptoms should tell their doctor. Even if the most recent cervical screening test was normal the doctor may want to have a look at the cervix.

What treatment will be offered?

Treatment depends on the stage of the cervical changes. Sometimes it is only necessary to repeat the screening test again after six months to ensure there has been no further change. If CIN is diagnosed at colposcopy then the abnormal areas of the cervix may be frozen with liquid nitrogen or the cells burnt off with a laser. Other treatments include simple surgical techniques to remove deeper layers of abnormal tissue within the cervix under local anaesthetic.

If pre-cancer of the cervix is diagnosed, then a hysterectomy (operation to remove the cervix and womb) is recommended and if the cancer becomes invasive the woman will also need radiotherapy and chemotherapy.

Advice

Have a cervical cancer screening test when you are diagnosed with HIV then once every year. It is very important that HIV positive women keep up-to-date with their cervical screening tests and attend the treatment advised by their clinic. Cervical abnormalities can worsen quickly in those with impaired immune systems. With correct screening and treatment, almost all cervical cancer can be prevented.

Dr Andy Williams and Dr Katherine Coyne both of Homerton University Hospital

Like many of you out there, for years I dreaded going for my annual smear test. It usually meant that by the time I was called in for my appointment I would be feeling very tense. This was mainly due to the fact that I did not cherish the whole business of the nurse poking about down below trying to insert the speculum as it often took ages before she could get it in just right. I guess the fact that I felt tense did not help matters and, try as I might, I just could not relax enough.

The idea of a stranger, albeit a qualified and friendly one, poking about my nether regions trying to insert a metal instrument is just not my idea of fun. However much the nurse tried to make me relax by chatting away about everyday stuff and reassuring me, I simply just could not relax. And so as far back as I can remember, I came to regard the smear test as an annual necessary evil!

One day though, after much prodding, I asked the nurse if they had a smaller speculum, which she duly produced and tried again without much success. Then, as I was lying there trying to pretend that nothing was going on 'down below', an idea struck me. I asked the nurse if I could insert it myself. She said; 'Of course', gave me the instrument, stepped out and waited behind the curtain and left me to my own devices. As soon as she did that, I felt completely relaxed and proceeded to 'do-it-myself'.

Wonders of wonders, because I wasn't so tense anymore, I found that I was able to insert it without much difficulty. I was done within seconds, called the nurse back in and she was able to take the sample and within minutes my appointment was over. What a relief that was! I have been doing this now for the past few years and I now find that my annual visit to the clinic for my smear test isn't such an ordeal any more!

This approach has certainly made things a lot easier for me. I am much more relaxed about my visits and the nurse is happy as she is able to take the sample she needs, without much difficulty.

So, next time you are due for a smear test, try a bit of 'D-I-Y' and see how it goes. Good luck!

Angelina

HIV and Breast Cancer:

I felt a lump and thought nothing of it. I did not want to panic; I just prayed the whole night that it would not be what I feared.

hannah webster

I can't remember how I reacted or felt when I was diagnosed with HIV, maybe I kind of expected things to be like that after the death of my husband. It was terrible knowing my daughter was also infected, but my life continued and everything fell into place. I had moved to the UK eight years ago, struggled like everybody else for the first year, but things just fell into place and I got a good job, worked hard and bought my own house. HIV did not define me as it was something invisible, I was never ill, continued eating healthily, exercising and having regular check ups. My hospital has, I think, the most supportive doctor and staff. I started medication in 2006 and just felt as good as any other time of my life. I am an activist, politics keep me ticking, and without it, I find the world boring.

The worst time of my life came nearly three years ago. I had come from being actively involved in a women's campaign in London, Trafalgar Square. I lay down in my bed and just tried to massage myself, as I felt achy from all the chanting, walking and standing. My hand guided itself to one of my breasts, which are non-existent; I call them my poached-egg breasts. I felt a lump and thought nothing of it. I did not want to panic; I just prayed the whole night that it would not be what I feared. I went to see a nurse at my surgery who quickly summoned the doctor. Everything moved so fast. Within two weeks I was seen at the breast cancer hospital and tests were done. I don't know how time moved so fast, but it stood still on the day I got the results. When the doctor told me the news, I just could not hear, all I thought and saw was death. I don't have a single living relative and have only my kids now and I thought: how can that happen, what wrong have I done to deserve such punishment? The doctor pulled me back to reality and said if I had somebody, could they come as I seemed shell-shocked. Yes, what did he think? I was going to smile and say thank you for giving me results of another terminal disease. Things moved so fast at that time and the team of doctors at the breast cancer clinic had not had a patient with co-infection, so it was trial and error.

I felt comfortable telling my friends, other family members and colleagues about my breast cancer, but none of them knows about my HIV status; I have been diagnosed for over 10 years. What is it about HIV that we cannot discuss it, but we can talk about cancer as if it's no more than swine flu? I live in a secret world of HIV and I live in a public, open life with my breast cancer. It's the stigma, people feel sorry for you when you have cancer, but nobody feels sorry for you when you have HIV, they think you brought it on yourself.

My Encounter

I had the first operation to remove the lump and lymph nodes. I stopped working, luckily at work, I was fully paid while I was on sick leave. My children were in a state of shock, I was their only living parent. Again, devastating news, one of the lymph nodes was infected so they all had to be taken out. It was now time for my beloved poached-egg breast to go. Back to hospital, the team at the clinic were working together with my HIV doctor and monitoring my CD4 count or any infections. Chop – the poached-egg breast is gone, thrown to the dogs. I sat there in the theatre wondering where they put those breasts they cut. Are they frozen, archived for more tests? Will mine look like a breast at all or will it be the one thrown in the incinerator?

When I came home, I had one breast, one poached-egg breast and the other side was flat, flat as a pancake. I felt the loss, I felt unwomanly, I felt empty. HIV is in the blood, not visible, cancer of the breast is visible with scars and with no breast. I had to start chemotherapy, six doses of toxic chemicals. Well those who complain about their antiviral tablets, believe me, you are enjoying a dose of milkshake by comparison.

Chemotherapy is toxic, it smells, makes you sick and you feel it when it goes into your body. I nearly died, the chemicals played up in my body. I was in bed all the time, infection after infection. I never thought I'd be incontinent, but I could not feel anything in my body and did not know when I was going to pass urine. I could not eat and had a nutritionist come to the HIV clinic to give me supplements. I had thrush, diarrhoea, chest infections, my pubic hair started falling. This is how strong the chemotherapy concoction was. I had long hair and did not want to go through the trauma of seeing it fall out, so I cut it off.

I went through the chemotherapy half-dead, came out the other side and went for radiotherapy. Radiotherapy does not have the toxic feel of the chemotherapy, it's calming, but you are made to lie on the bed as if you are an animal awaiting slaughter. For all that time I forgot about my HIV, I was not a woman anymore, I was now a statistic, one-breasted woman, with a prosthesis. Every time I went for treatment, reviews or appointments, I made sure I looked beautiful, to reaffirm to myself that I was still a woman. After reading a book: *Why I Wore Lipstick To My Mastectomy*, I also had lipstick on. I remembered Winston Churchill said that: 'you can't deal with the most serious things in the world unless you understand the most amusing'. My poached-egg breast amused me and I made a joke out of it and laughing was my daily Prozac tablet.

I had a reconstruction, just to reaffirm to myself that I was still a woman. I endured a nine-hour operation just to have

another breast. I had drips all over my body in hospital and was continuously being viewed by a nurse with two eyes – one as a cancer patient and another as an HIV positive woman. All the time in hospital my HIV status was never an issue, they managed not to make it the light of my illness. Before I had a breast reconstruction, I had to seek a second opinion from the main London cancer hospital due to my HIV status. My surgeon was not sure if it would be okay to put silicon in my body and how it would work with somebody with HIV. They had never done it before, so they had to do a lot of research. Nonetheless it was done and it came out well. I acquired two enlarged breasts, and my two poached-egg breasts were gone. The other one which was not affected by the cancer was enlarged and now I am a proud owner of two round breasts.

When I came home, I had one breast, one poached-egg breast and the other side was flat, flat as a pancake. I felt the loss, I felt unwomanly, I felt empty.

I am still on anti-retrovirals and I take Tamoxifen and go for my reviews frequently, but I am celebrating life and thanking God. I wear my lipstick, high heels, go to work and although I have many scars, my skin colour changed and became darker due to the treatments. Sometimes I think I am lucky. I continue to do what I do best; my work, education, motherhood, writing a book, reading, travelling, and being a loving friend and an activist. If I had a choice between HIV and cancer, to be honest I would choose HIV and you might wonder why, but nobody can see it and I don't have any reminder of it on my body. I have the reminder of the cancer, the scars. HIV scares people, it defines your sexual life, it is in the blood and you have it but you can live longer by eating healthily, exercising, thinking positively and taking your medication. With cancer you have the worry of recurrence, secondary cancer, that's my dilemma now. My viral load never went down and I check it every year, but I am at the breast cancer clinic more than I am at the HIV clinic. I never let HIV define me. Cancer now defines me. I am ill all the time, something that doesn't happen with HIV. Happiness based on my circumstances is by its nature temporary, but if it is based on my inner character, it cannot be taken away.

Helen

The Girls are Back in Town

Living with a long-term condition brings with it many challenges. Managing it takes up a considerable amount of time and effort and often can be emotionally harrowing. I have found certain tools in my arsenal very useful for keeping on top of the situation. Good friends who are available at the drop of a hat with non-judgemental love and support, a great medical team, alternative therapies and last, but not least, retail therapy.

Although my finances have been very limited in the past few years, I have found shopping for two particular very close friends of mine very exciting. I like to call them DD1 and DD2. As you may have guessed I am referring to my new and improved cleavage.

Since I started my treatment, my chest has grown from a nice little 34C to a whopping 36DD. Imagine my surprise when I walked into a well known, expensive underwear shop (*La Senza*) and was told that I was not a 34 anything but in fact a 36DD. This presented me with a whole host of new problems such as what kind of bra to buy and where to find one that fits well. Contrary to popular belief, not all boobs are the same. Unfortunately, even those whose job it is to sell us these very important items do not seem to be aware of this fact. One sales assistant in *Marks and Spencer* told me that that if I was a 36DD then any 36DD bra should fit. Wrong! She even had the nerve to suggest that I did not know my bra size.

Different women's breasts fall in different ways and every woman needs to consider not just the size and shape but also how they

sit inside a bra. I, for one, do not want a bra that makes my boobs stick out five inches in front of my chest like two lighthouses. This may work very well on page 3 of *The Sun* but it is not practical for the real world. I need to accentuate the shape and size of what a friend recently referred to as a smashing pair of ****s (for **** substitute any four letter word meaning cleavage). It also needs to be a comfortable means of support.

It took me two hours to find three bras in my size that were not only the right size but also the right colour. After that, I spent another hour trying to find knickers to match. This is because as I get older and become more and more like my mother, I am concerned about the colour of my underwear. I will not be seen dead wearing anything but white or my skin colour under a white blouse. Call me old fashioned, but etiquette is important to me (I am such an old woman).

Thank heavens for the stores such as Primarni (*Primark*). They have taken account of the needs of the well endowed and have a range of reasonably priced, matching underwear in most sizes. This means that I can indulge my new passion for tight fitting stretchy-tops and dresses that show off my new figure. Many women have been forced to spend a fortune in order to get a decent sized cleavage. I got mine free. Hooray for ARVs. Roll on winter! I need to get new, brightly coloured, tight polo neck jumpers. I will let you know how it goes.

Mona



Putting ^{1st} Patients



Real faces, real stories, real lives

Gilead believes in supporting people living with HIV. That is why we have created a series of booklets to help patients make the most appropriate choices to maintain their health. If you would like to receive copies of these booklets, **please contact your healthcare professional.**

Treatment Timeline: Angelina

I was diagnosed about 15 years ago but did not start treatment. I remained relatively well for the first 10 years, with a steady CD4 count of 400, give or take a few, at each quarterly visit to the clinic for monitoring. I also maintained a low viral load. I had a few minor ailments including a bout of Bell's Palsy*, but none of these drastically changed my CD4 count or viral load.

Then, I suddenly fell ill with a pneumonia-like illness. My CD4 count dropped to nearly 200 and my viral load shot up. I lost the equivalent of two dress sizes in what seemed like a matter of weeks, from a size 14 to about a size 10. Something, I guess, that would be very welcome to someone on a diet, but quite a different matter altogether when you lose weight due to being ill!

My doctor at the time suggested that it was time to start treatment. It was a complete shock. After having done relatively well for so long without needing treatment, realising that I now needed it to stay alive was quite difficult to take in. I felt as if I had been diagnosed all over again.

Even though I had been supporting women for years about starting treatments and doctor/patient relationships, I found it extremely hard to deal with the reality of my own situation. A lot of my anxieties stemmed from the fact that I had over the years met many women who had experienced all sorts of side-effects from their medication, and if I am honest with myself,

I was filled with dread. On top of that, the realisation that I had reached a point where I clearly could not survive without medication just made things worse.

It took a while for it all to sink in and I am glad to say that I had a very good doctor [Dr Simon Portsmouth at the Wharfside Clinic], with whom I could talk easily about my fears and concerns about starting treatments, and who understood that I needed to do things at my pace. Although, of course I needed to take action sooner rather than later lest my situation got worse.

Once we'd had a detailed discussion about my options, we agreed on a regime that best suited me and I went home armed with my medication.

I carried my medication in my bag for ages, trying to psych myself up for that moment when I would take the step and pop them into my mouth.

I was working full-time, but I decided to take a few weeks off work as I wasn't in a fit state and I was also scared of how my body would react. Also I wanted to be sure that I allowed myself enough time to deal with the adjustment and to do that I felt I needed to concentrate on just one thing at a time. Luckily, I was working at Positively Women at the time and as they have excellent policies about employing HIV positive people, allowing me some time off work during this period was not an issue.

I saw a counsellor for a couple of weeks too, in preparation, as the whole thing was too difficult for me to deal with on my own. One of my colleagues, Silvia, who had been taking treatment for a number of years also provided me with the much needed support.

After having done relatively well for so long without needing treatment, realising that I now needed it to stay alive was quite difficult to take in. I felt as if I had been diagnosed all over again.

When I felt ready, I went for my appointment with the health advisor at the Wharfside Clinic – Chris – and he proceeded to talk me through what I needed to do. I remember him clearly explaining to me about resistance and the importance of adherence – using the visual example of a bin. To summarise, he said that I should imagine that my HIV was contained within a bin and that every time I took my medication on time, the lid stayed closed and the virus stayed put. But, every time I missed a dose, or did not take it on time, the lid opened a little bit and

some virus escaped into my system and started replicating. The idea being that my aim should be to keep that lid on the bin at all times. It was a simple explanation but one that stuck in my mind. I still see the picture of the bin he showed me all those years ago!

After arming myself with all the information and support that I needed, I set myself a date, took my pills and waited for the side-effects to take hold. Luckily for me, I did not encounter anything too severe, maybe it's because I'd psyched myself up so much! That's not to say that life has been a bed of roses in all that time, and I did join what my friends and I now refer to as the 'Kaletra Klub', ... but that's another story for another day. I have been on the same combination now for the past four years [touch wood], although I did change one of my medications to a different formulation that did not need to be stored in the fridge!

Angelina

* **Bell's Palsy** is a paralysis of cranial nerve VII (the facial nerve) resulting in inability to control facial muscles on the affected side. Several conditions can cause a facial paralysis, e.g., brain tumor, stroke, and Lyme disease. However, if no specific cause can be identified, the condition is known as Bell's Palsy

HIV and Your Kidneys

Why do I need to know about my kidneys?

HIV can affect your kidneys and sometimes leads to kidney disease. Some drugs may be harmful to your kidneys. Risk factors for cardiovascular disease, such as high cholesterol, smoking, high blood pressure or diabetes can also affect kidney function. Over time your kidneys can stop working well, which can occasionally lead to end-stage renal disease (ESRD) or kidney failure. If either of these occurs, you may need kidney dialysis or a kidney transplant.

Being aware of symptoms of kidney disease and taking steps to prevent it will help you stay healthier for longer.

What do my kidneys do?

The main role of your kidneys is to filter waste products and excess sodium and water from your blood. Your kidneys reabsorb what your body needs and the rest is excreted as urine. If you have kidney disease, your kidneys may not do this very well and waste can build up in your blood and make you feel ill. This can lead to high blood pressure, anaemia (a low amount of haemoglobin which carries oxygen in the blood), weak bones, nerve damage and increased risk of heart disease.

How can I prevent kidney problems?

There are steps you can take such as:

- Stop smoking
- Drink enough water
- Avoid drugs that are harmful to the kidneys
- Improve your heart by exercising and reducing cholesterol
- Get high blood pressure treated
- Lose weight if you are overweight

Limiting your protein intake may slow the progression of chronic kidney disease and limiting salt intake could help you avoid fluid retention and control high blood pressure.

If you have late stage kidney disease your doctor may recommend that you restrict the amount of fluids you drink. They may also suggest potassium restriction (avoiding bananas, nuts, potatoes etc.) because your kidneys would not be able to remove potassium.

What are the risk factors for kidney disease?

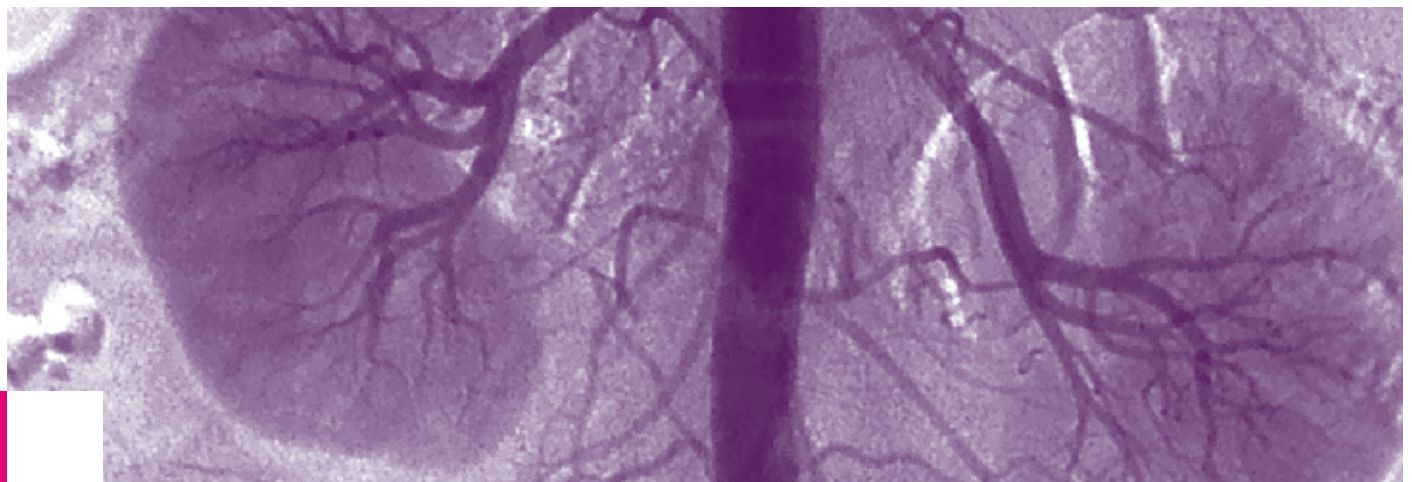
HIV is a risk factor, especially if you have a high viral load and are of African origin. You may have other risk factors, including diabetes (which can also be caused by HIV), high blood pressure, older age or take certain anti-retrovirals or other medicines (some anti-inflammatory/painkillers). Kidney problems related to HIV are called HIVAN (HIV-associated nephropathy).

What types of kidney damage exist?

Many things can damage your kidneys. The most common are ageing, diabetes and high blood pressure (along with other risk factors for heart disease). Drugs such as painkillers can lead to kidney failure. Depending on how the drugs work, the filter (glomerulum) and/or the reabsorption site (tubulus) can be damaged.

In rare cases you may have acute kidney failure, which means the kidney stops filtering completely. This can be caused by a poor blood supply to your kidneys, a severe bacterial infection or substances that are toxic to your kidneys (renal toxicity).

High blood pressure can damage the blood vessels in your kidneys. So can too much glucose in your blood (a problem



associated with diabetics and known as diabetic nephropathy). Some antiretrovirals can drive diabetes, particularly protease inhibitors. Other drugs are also known to cause renal toxicity in some patients, usually because they damage your kidney tubules.

How is kidney disease detected?

It can be hard to detect. If you urinate often or rarely, or it is an unusual colour, this may indicate that you have kidney problems. These symptoms usually only show up in late stage kidney disease.

A urine dipstick test can look for changes much earlier. You give a sample of urine and it is checked to see if it contains glucose, blood, protein, ketones, bilirubin and leucocytes. If certain substances are present that should not be in your urine, further tests can be carried out to find out the nature of the problem.

Can kidney disease be treated?

There is treatment available. Chronic kidney disease cannot be cured, but can be treated. The goals of treatment are to slow disease progression, treat the causes and any complications, and replace lost kidney function. It is important to avoid or reduce any nephrotoxic drugs (potentially harmful to your kidneys) you may be taking.

Treatments can be used to control blood glucose (if you are diabetic) and control high blood pressure (if you have hypertension). Dietary control is another essential component of disease management.

Complications of chronic kidney disease may also require treatment, such as fluid retention, anaemia, bone disease and acidosis (which can cause breakdown of proteins, inflammation and bone disease).

Questions to ask your doctor

- Have you checked my kidney (renal) function?
- Should I have a urine dipstick test?
- Do I need further tests (e.g. blood sample)?
- How can I look after my kidneys?
- Am I receiving the most appropriate treatment?

HIV and Your Body Secretariat

Body part word search

By Malika age 10

Words are diagonal, backward, across upwards and downwards

- Head
- arms
- neck
- shoulders
- legs
- hands
- fingers
- feet
- toes
- ankles
- breasts
- stomach
- bottoms

There is a mystery prize for the first correct answer pulled out of the hat.

To enter please return your completed word search to:

Freepost RLYJ-ULRT-CEEC, Positively Women,
347-349 City Road, London EC1V 1LR

N	A	Y	R	X	Z	F	T	B	D	M	Q	F
O	D	A	E	H	A	Z	C	F	F	G	I	I
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C	B	O	T	T	O	M	S	S	C	S	R	S
X	Q	K	U	S	P	H	C	A	M	O	T	S

Name: _____

Address: _____

Treatment Timeline: Carole

I am sitting at the table, about to start supper. I have lit some candles, and there is a bunch of flowers in a vase beside me. After struggling to prepare my spaghetti Bolognese in time, it is all ready, with minutes to spare, at the time that I am supposed to take my first pill 'with food.' I run to the bathroom to get the bottle of pills, and then unexpectedly struggle to open it. Here's a difficulty I hadn't anticipated! I laugh at the thought of having to delay everything because I can't open the child-proof bottle in time. But no, the top twists off and I can see the little blue pills inside. I sit down, take the first one as my watch ticks round to 7.30pm, and dig my fork into a spoonful of pasta.

That's it. Ta-da! No drum roll, no sudden feeling of anything at all. It might as well have been a Paracetamol. I carry on eating with a sense of anti-climax, and set my alarm for the next pill at 9.00pm. The next one is the one I'm more scared about. It's the infamous Sustiva that's supposed to give you vivid dreams, disturbed sleep or send you off into fits of depression or paranoia.

The minutes tick by, and then I take that one too, but not until after I've read the leaflet that comes with it to discover that I was supposed to take it two hours after my last meal. Oh no! That would spoil my plans because I also thought I was supposed to take it two hours before going to bed! To do both of these, I would have to eat at 7.00pm. I couldn't keep that up every day. Sometimes I don't get home from work until 6.30.

I take the pill anyway, at the time I planned, and go to bed feeling pretty nervous about what might happen next. Will I

have vivid and disturbing dreams, or even nightmares? Will I be able to sleep at all?

I slept soundly that night, and have slept soundly every night since. I have had no disturbing dreams or nightmares, and I have not felt paranoid or depressed. I had no other side-effects at all for the first week. No headaches, no sickness, no diarrhoea, nothing. I was amazed and relieved.

Then after about a week a friend at work asked me if my shingles was coming back. 'No' I said, startled, 'why?' 'Because you've got a rash all over the back of your neck' she said. A quick look in the mirror confirmed this, and I phoned the clinic. I was given an appointment for the next day, and by that time I was relieved to get some advice. The rash had spread all over my body. It was four more days before it slowly started to fade. It has gone completely now, but for a while I was worried about how long it would last and whether I would have to change my medication.

Right now I'm experiencing no side-effects at all and I'm hopeful I can stay on the same pills. Life has returned to normal.

So, the side-effects I was scared of didn't appear: instead I got a rash that I hadn't expected at all. Luckily, it has faded quite quickly and I'm feeling fine. But for a while I was scared and worried. On the positive side, it prompted me to re-discover the support that is still out there. The THT Helpline listened and talked to me for as long as I wanted. *i-Base* were great too. 'Chill, Carole' said the voice on the phone, 'you need to rest and give your body time'. I took the advice to heart. More importantly, I felt that I wasn't alone. It made all the difference.

And the doctor and nurse at the clinic gave me loads of time too. They called me in as soon as the rash appeared, and saw me every other day until it went.

Meanwhile, I'm learning how to make taking medication part of my ordinary life. I'm getting into a routine (just about!) of eating at the same time every night, and I've coped with taking the pills while eating out with friends or at the cinema. It's all OK.

Taking medication doesn't hang over me any more: I've done it. Maybe with the more sophisticated medication we're lucky to get now, side-effects are a rarity for everyone. I would say to any friend who is starting medication: 'Assume that you won't get any side-effects. Rest while your body copes with the new drugs. Keep in touch with your clinic and use the support that is out there: it really does help.'

Carole



Ouch!

My Feet Hurt...

Or so I thought that's what it was. You know? The severe, burning, aching pain in the feet and legs? Little did I know that it was actually neuropathy – a condition that can be brought on by the HIV virus. What I have read from the website is that it is a result of the degeneration of the nerves responsible for conducting impulses. One can recognise this by numbness and a sensation of pins and needles in the hands and feet. I also found out that there is a more severe type of neuropathy which is known as (something I can't pronounce!!) Acute or Chronic Inflammatory Demyelinating Polyneuropathy (AIDP/CIDP). What happens in AIDP/CIDP is that there is damage to the fatty membrane covering the nerve impulses. This kind of neuropathy involves inflammation and resembles the muscle deterioration often identified with long-term use of AZT.

It is sometimes the first manifestation of HIV infection, where the patient may not complain of pain, but fails to respond to standard reflex tests, such as vibrations or pin pricks on the toe pads. This kind of neuropathy may be associated with sero-conversion, in which case it can sometimes resolve spontaneously. It can serve as a sign of HIV infection and indicate that it might be time to consider anti-retroviral therapy. I thought to myself, 'oh, this is interesting' so I read a little more and also learned that there is a drug-induced, or toxic kind of neuropathy which can be very painful. Anti-retroviral drugs like DDI are commonly known to cause peripheral neuropathy.

As if that wasn't enough, the material I was reading went on to tell me that CMV (Cytomegalovirus) causes several neurological syndromes in AIDS, including Polyradiculopathy – a rapidly developing, ascending paralysis that affects both hands and feet and is difficult to treat.

When I got to this point, I thought I had read enough about the condition itself and all I wanted to know was how I could get rid of it or ease my discomfort. So I scrolled down and, lo and behold, there was a remedy – there is something that I can do, or anyone that suffers from neuropathy can do about it anyway. Having spoken to many of my veteran buddies who feel the same way I thought perhaps I could write a brief article about what I found out and say that the best way to deal with it is perhaps discuss the various options with your consultant and take it from there. There is hope after all and I can go back to wearing my heels as my feet don't hurt as much anymore.

Bex

*CMV is a common virus that infects most people at some time during their lives but rarely causes obvious illness. It is a member of the herpes virus family.



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Teeth'n'Smiles

People with HIV and dentists

People with HIV are still failing to access good dental care, even though it's in their interest. Do they assume dentists will still have issues treating them? And are they right?

A survey aired at this spring's British HIV Association Conference showed that only just over half of HIV positive patients in Edinburgh were currently registered with a dentist compared with 80% of HIV negative patients, and were disproportionately less likely to have seen a high street NHS dentist, as opposed to a private one or a hospital dental clinic, in the last year.

A survey in Hammersmith and Fulham Primary Care Trust found the same. Silvia Petretti of Positively Women was involved in this and says: 'Only 65% of people with HIV in the PCT were registered with a dentist, only 45% percent would tell their dentists about their HIV status, and 55% thought that their HIV status prevented them accessing services.'

Why? Are NHS dentists refusing to see people with HIV and referring them to specialist dental services? Or are people with HIV afraid to access dental treatment?

What is clear is that people with HIV should see a dentist regularly. Oral HIV symptoms used to be one of the most characteristic first signs of AIDS – and still are in the late-diagnosed. At CD4 counts below 150, oral thrush (Candida) and the similar-looking viral infection oral hairy leucoplakia appear. Below 100 CD4s, patients turn up with Kaposi's sarcoma lesions and persistent mouth ulcers. Below 50, and they start getting gum disease so severe their teeth fall out. The same survey found that one in eight people with HIV, but none of the negative ones had seen a dentist last time because it was an emergency.

Happily in the HIV treatment era, these manifestations of AIDS are rarer. Some conditions that are more common in people with HIV have not got rarer, though, and dentists may be the best practitioners to pick up on these and spot signs of trouble.

The human papilloma virus (HPV) for instance, is well known to cause cervical cancer. But oral HPV infections are also a lot more common in people with HIV. Oral HPV-related warts may feel like bumps inside the mouth, especially on the inner surface of the lips. They can become cancerous: HPV causes 20-25% of cases of oral cancer. Oral warts have become more than twice as common in people with HIV since the introduction of anti-retroviral drugs (ARVs): one in five has them now, versus one in ten in 1990. A visit to the dentist could result in a cancer being spotted that could be missed by your regular doctor.

Oral cancer is rare. But tooth decay and gum disease aren't, and are more common in people with HIV. Neither is likely to kill you; but failing to visit the dentist can result in a lot of pain, loss of teeth, and damage to your self-esteem and social acceptability. Who wants to be scared to smile or have bad breath?

One condition more common in people with HIV is xerostomia, which means dry mouth; the salivary glands produce less saliva than they should. One in nine HIV positive people has xerostomia compared with one in 25 HIV negative people. It's more common in people with low CD4 counts but also more common in people taking HIV therapy, and has been associated with drugs ranging from DDL in 1992 to protease inhibitors in 2009. It can also be caused by the 'speedy' recreational drugs such as cocaine and amphetamines.

Xerostomia is important because saliva has natural antibacterial agents in it, and also washes food particles and associated bacteria away from crevices where they do mischief, so people with xerostomia experience an often dramatic increase in tooth decay.

Carrying a bottle of water round with you and use of sugar-free gum and sipping sugar-free drinks can help. You can help with gum disease and tooth decay by regular and attentive teeth cleaning using a high fluoride toothpaste and flossing too.

Where you can't, it's the job of the dentists and their indispensable assistant, the hygienist, to do it for you. Dentistry is as much about preventing gum disease and tooth decay as it is about treating it.

'Dr Steve', a dentist from the English Home Counties, thinks that both patients and dentists should stop seeing HIV as a big issue that prevents proper dental treatment. He should know. Steve is HIV positive himself (hence the pseudonym).

'The principal dental problem in HIV positive and negative people alike is gum disease,' he says. 'And the main cause of



that is plaque.' Plaque is the soup of bacteria that live inside the mouth. If it's not cleaned off properly and gets into the crevice between tooth and gum, it starts eroding the gums. They recede – leaving teeth vulnerable to loosening and exposing softer parts of the tooth to decay.

Erosion can also happen out of sight, between the inside of the gum and the tooth root. This can create abscesses and even if you don't get those, the bacteria inside can attack the tooth root and erode the bones of the jaw

'That bone loss can't be reversed,' says Dr Steve. 'Without supporting bone, your teeth are like buildings without foundations and will fall out anyway.'

If a dentist rejects you because of HIV, or if they insist on extra conditions such as double-gloving, you have the winning hand. The General Dental Council Good Practice Standards are quite explicit and they could face a charge of professional misconduct.

If people cleaned and flossed properly, he says, people would rarely have to see dentists. 'But you need to do it regularly and be shown how to do it properly, not just with a toothbrush but with floss and an interdental brush' (one of those tiny ones that cleans in between teeth).

'HIV positive patients should regularly attend for dental health supervision', he adds. 'Check-up frequency can be anything between six months and two years depending on the standard of oral health achieved.'

Diet, of course, is important, and we all know we should avoid eating sweets. 'But,' Steve adds, 'the hidden sugar in items like ketchup is just as important.'

So what about the issue of access to dentists? Are patients mistaken in thinking they'll be turned away?

The General Dental Council guidelines say: 'It is unethical for a dentist to refuse to treat a patient solely on the grounds that the person has a blood-borne virus or any other transmissible disease or infection.'

Despite this, as the Scottish and Hammersmith surveys show, people with HIV are still reluctant to see dentists. We asked readers about recent experiences with dentists and got back a mixture of replies.

Outright refusal of treatment was rare, but it did happen. More often, there was a suspicion that the dentist was avoiding taking the patient. In the patients we talked to, only ever being

seen as the last patient of the day was the most frequent complaint, and the most common reason patients felt, rightly or wrongly, that they were seen as a 'problem'.

Do dentists really worry about taking on HIV positive patients? Or are patients too ready to regard normal practice and precautions as discrimination?

One of the few studies that asked dentists what they really thought of patients with HIV was conducted in north-west England six years ago. When 15 practitioners were quizzed closely, only seven of the 15 (45%) said that they would accept an HIV positive patient 'without hesitation'. Of the others, five would 'accept with some hesitation' HIV positive patients, while three (20%) would refer them elsewhere.

Of the hesitant ones, some stressed the 'disproportionate time involvement' of dealing with patients with HIV. This was due to the belief that they needed to take extra precautions, and they expressed rather contradictory attitudes towards infection control. One said that he knew extra precautions were not 'strictly necessary, but I want to take them'.

Dr Steve says: 'If a dentist rejects you because of HIV, or if they insist on extra conditions such as double-gloving, you have the winning hand. The General Dental Council Good Practice Standards are quite explicit and they could face a charge of professional misconduct.'

Remember if you are rejected once, it may be because of NHS pressures, not because of your HIV as such.

Faced with attitudes such as these in both patients and practitioners, not to mention the general shortage of dentists willing to provide NHS care, one way is to contact your local Community Dental Service: local dental clinics in which dentists who are receiving an NHS salary provide first-line service on the NHS.

In Lothian in Scotland, for instance, Dr Chris Cunningham, co-author of the BHIVA study already referred to, works for what is there called the Salaried Primary Care Dental Service.

'Only a small minority of our patients have had problems getting a dentist specifically because they have HIV. A larger number can't find an NHS dentist for the same reasons as anyone else – there aren't enough of them.'

'For a while we have only been accepting new referrals for people with CD4 counts less than 200 or with specific oral problems but as a result of our study we are reconsidering whether we should accept asymptomatic HIV positive



Me: My Body, My Treatments

individuals. We'll offer a course of treatment, get you dentally fit, and our advice is then to go and find a regular NHS dentist.'

In other parts of the UK, however, Salaried Primary Care Dental Services are seeing fewer and fewer patients with HIV as their reason for referral. A spokesman for the Lambeth, Southwark and Lewisham Community Dental Service, for instance, said: 'To get referred now, you need to have additional needs other than HIV: maybe a low CD4 count, complex dental problems, or issues such as mental health. Having said that, our criteria also include 'people who may not otherwise seek or receive dental care.'

To find out your nearest Community Dental Service, contact your local Primary Care Trust. If you have special needs, specialist dental clinics also exist in a number of hospitals that also have HIV clinics.

Another answer is to go private. But if you haven't had dental care for a long time, it may be a good idea to seek out an NHS dentist first. They should restore you to basic dental health and save you money.

Unless you are on certain benefits such as Income Support (not Incapacity Benefit), in which case you get free treatment, NHS dentists in England and Wales will charge you one of three fees (in Scotland, basic checkups are free.):

- £16.50 for a basic checkup, X-rays and cleaning
- £45.60 for drilling and anything up to 20 fillings
- £198.00 for crowns, inlays or anything outsourced such as dental lab work.

Dental checkups are free during pregnancy.

If you go private you may get a better and quicker service, but this is likely to cost you a lot of money. Steve gives as typical private charges for an out-of-London clinic – London practices may cost a lot more:

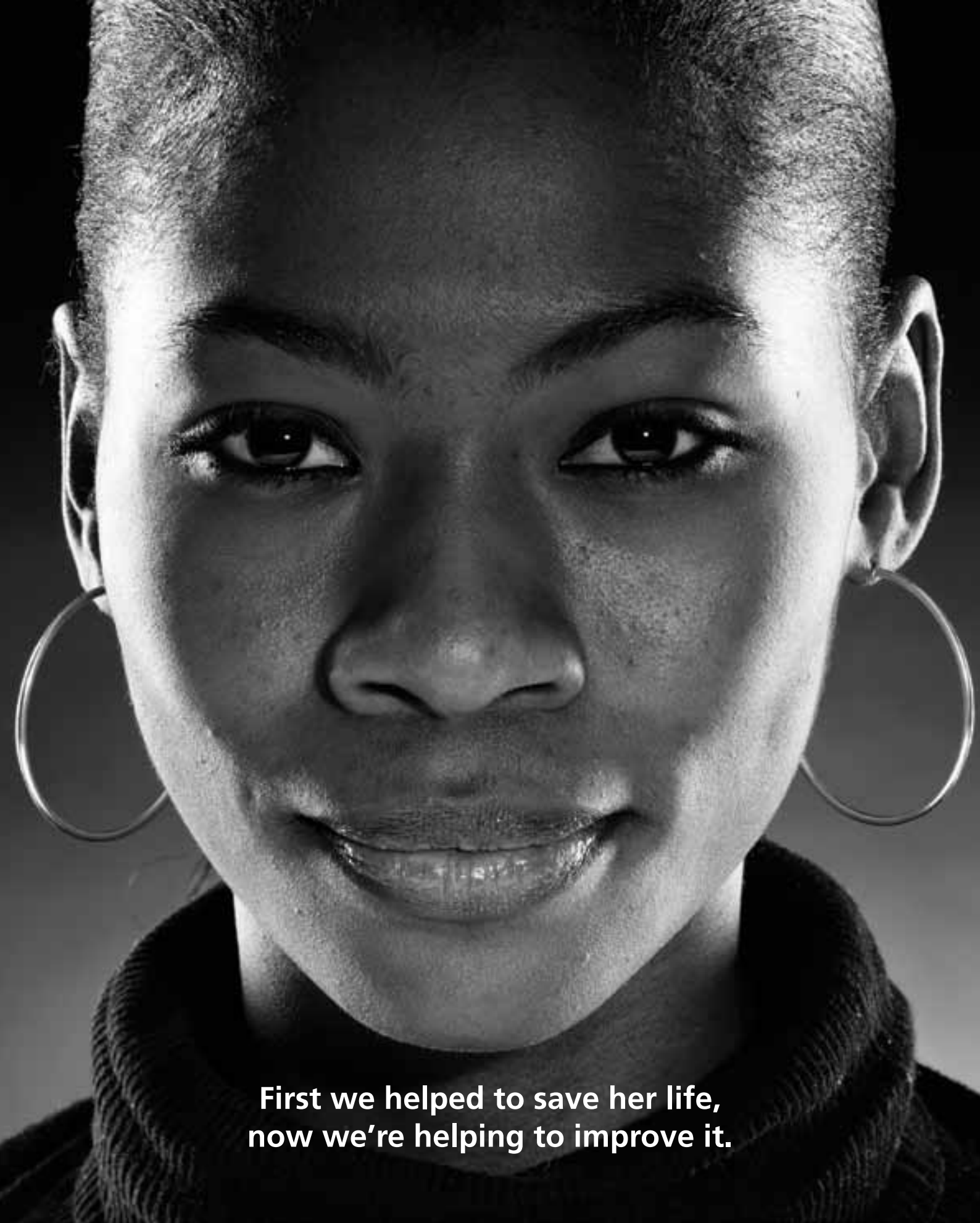
- £80 for an initial consultation
- £50 for additional sessions with a hygienist
- £150 for a complete checkup and comprehensive clean
- £60-£130 for fillings, and £90 for an extraction
- At least £460 for a crown
- For more complex procedures such as root canal work we are talking fees in excess of £1200.

One reason for going private might be dental phobia. Steve is a specialist in sedating phobic patients and sees a lot of people who have put off treatment for years because of their fear of dentistry. Some NHS practices do have sedation contracts with the NHS which means they are licensed to offer sedation as well as local anaesthesia.

Even if you don't have an extreme fear of people putting sharp metal objects in your mouth, Steve says, 'It's very important to establish a rapport. It's a very intimate procedure. You might simply not like the dentist. Well, if you don't, move on.'

If you're looking for an NHS dentist, you can find one at the NHS webpage at www.nhs.uk/Pages/HomePage.aspx or via NHS Direct on 0845 4647.





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now we're helping to improve it.**



Bristol-Myers Squibb

A future for people living with HIV

Use it or lose it:

One of the certainties in life is that time moves in one direction and day by day, if we are lucky, we will get older. Around 25% of HIV positive people in the UK are now aged over 45 and 10% are over 55.

If you are HIV positive, every day is an achievement, and as these days turn into years, many of us are seeing life that was difficult to dream of a few years ago. Now, it is possible to make long-term plans – almost as if HIV is not an issue. But this planning needs to include how to look after your long-term health.

With the wisdom, understanding and experience that should allow us to enjoy every period in our lives, comes additional health worries. Some of these are undoubtedly more complicated because of HIV.

Ageing itself reduces your immune system, but HIV positive people also have higher rates of age-related illnesses including reduced bone density, higher rates of heart, liver or kidney disease and some cancers, and higher rates of dementia and other neurological problems.

Fact box: Important monitoring

Heart disease (use online Framingham calculators)

Lipids and sugars: cholesterol, triglyceride and blood sugar levels

Liver and kidney function tests

BMI – an indication of whether you are over- or under-weight for your height

Bone mineral density – using a DEXA scan – many doctors think this should become a routine test, especially in people with other risks

Neurological function – there is currently no agreed consensus on which test will pick up early symptoms of problems relating to brain disease, but this is an area that should change in the near future.

Cervical and breast cancer – smear tests and breast scans are important if you are HIV positive – be sure that you access national screening programmes either at your clinic or through your GP.

Some of this will need more careful monitoring and advice to the general population about reducing the risk factors that you can change, becomes even more important if you are HIV positive.

These include:

- keeping physically active
- eating well
- stopping smoking
- only using alcohol or recreational drugs in moderation
- sleeping well – letting your body rest when it needs to
- developing a good network of supportive friends – and finding time for fun
- setting achievable short-term and long-term goals
- managing your treatment (see below).

Exercise

'Use it or lose it' certainly applies to fitness. The best way to delay creaky joints and brittle bones is to lead a more active life. The best way to keep your heart strong is to make sure it beats faster every day. This can include obvious types of exercise – fitness classes, swimming, using a gym and other sports – or just being more active generally by walking more and sitting less!

Walking is one of the best forms of exercise. Mile for mile it burns about the same amount of calories as running. Walking is a cardiovascular exercise, which means it is good for your heart and blood circulation.

Aim to reach 10,000 steps a day (5 kilometres). Even if you build up to this slowly, this is the recommended guide. Or take more active exercise for 30-40 minutes at least three times a week.

Weight-bearing exercise will strengthen your bones.

Diet

In general, moving to a more healthy diet will help you in the long run. For example:

- eat vegetables and fruit every day
- eat more fish and/or chicken rather than red meat
- limit the amount of solid fats like butter and cheese. Olive oil and vegetable oils are better
- cut back on fried food – grill, steam, boil, bake – all are better for your heart
- foods that are less refined like whole wheat bread, pasta and brown rice are better for you than refined white bread, pasta or rice, because they release energy more slowly, and affect blood sugar levels more gently

HIV and ageing

- high sugar foods, especially refined sugars, increase the risk of insulin resistance and diabetes
- aiming for a BMI (Body Mass Index) that is between 18-25 is a good goal.

Smoking

There is no easy way round this. You may not manage to stop smoking this year, or even next year, but cigarettes probably have the biggest impact on your life expectancy and long-term health and these effects are worse if you are HIV positive. Your risk of lung complications including cancers and cardiovascular problems including heart attack and stroke are much higher if you smoke. They increase with age and increase from being HIV positive.

There are numerous ways to stop smoking, and you may need to try several until you find one that works. However, when the time is right for you, doing this with other people in one of the free NHS programmes is a good place to start.

After quitting, your body is good at repairing the damage that smoking has caused, and you quickly get the benefits in terms of reduced health risks.

Mental health

This is a tough one because it covers all sorts of difficult areas including medical, social and psychological issues, which are all related.

Medical issues include potentially higher risk of brain-related illnesses including Alzheimer's disease and dementia. This may mean we are at higher risk, or that they occur at an earlier age. Currently there are lots of questions about how HIV affects the brain and not so many answers – so this is a major research area. Several studies are suggesting that the time spent with a detectable viral load, may impact on long-term health because your immune system is permanently over-active, even at high CD4 counts.

Social issues include dealing with prejudice and stigma – whether real, or self-imposed through fear of being open about this aspect of our lives. This can reduce your self-confidence and bring special problems to relationships and social life in general.

Without a good support network of friends, life can be more difficult. Isolation can also contribute to depression. If you feel unhappy or self-conscious about your body and appearance – perhaps because of changes caused by the meds in terms of fat loss or accumulation, this can limit your social interactions with people.

Your mental health is also related to how you feel about yourself and your life, and HIV positive people, for many complicated reasons, have higher rates of depression. As you get older, there is a risk that your social network gets smaller, yet you need this interaction to keep in touch with the world.

Dealing with HIV can be difficult: dealing with it on your own is usually more so. This is one of the reasons it is so important to have support networks, which can help break this isolation.

HIV treatment and care

With everything else going on, it can be easy to forget some of the most important basics for long-term health.

HIV drugs can only work if you continue to take them, and continue taking them on time. Adherence is just as important after five or ten years as it is when you first start. This commitment to treatment can be difficult to maintain, especially if you still get side-effects. Ask your doctor about alternatives – new HIV drugs are developed each year and the latest ones may be better than the ones you started a few years ago.

Make sure you keep your routine blood tests and that you get the results promptly.

Diet and exercise can help with one of the commonest problems related to treatment including increased cholesterol and triglycerides. They can also reduce the risk of diabetes and heart disease.

Conclusion

This summary of issues associated with ageing and how to manage them is easy to write but may be harder to put in to practice. Start with small goals though and you could be surprised at how this can make you feel more in control of your life and how this in itself can help you feel happier.

So far we have been lucky to benefit from treatment. As treatment now becomes more refined, we need it to carry us through into old age, and for that we are going to have to play a more active role in our own health.

Thanks to Winnie Sseruma and Memory Sachikonye for help with this article.

The *i-Base* website has detailed information on these and other aspects of HIV and treatment. You can also ask a question confidentially and receive a personal answer (www.i-Base.info).

Simon Collins
i-Base

Here and Now

Cate's Column

I'm angry and pissed off! Since the day I was diagnosed, it seems that either subtly or at times blatantly, others in my life have hijacked centre stage around my status. That somehow I have come second to the needs of others.

Initially peoples concerns were about how Martin (my partner) was coping with the 'guilt' of having infected me. Then the focus seemed to shift to his illness and dying, to family, how my children were coping, the needs and concerns of subsequent partners etc, etc. The list is endless and tumbles through the 14 years of my diagnosis right up to last week, when on a visit to see my GP, he put across an argument for me starting anti-retroviral treatment that has got nothing to do with my health and wellbeing but everything to do with that of my new lover!

I sat and listened to his logical and reasoned arguments about reducing the risk of transmission should a condom burst – although he never once discussed the possibility of me becoming pregnant from a burst condom, which is probably more likely than my partner becoming infected.

He went on to remind me that in the event of a condom bursting, my partner could of course take PEP – never mentioning the fact that I may want to consider taking the morning after pill. In fact

we never discussed the more relevant issue of my fertility at all, which is ironic, because as my blood picture stands right now, being pregnant would be the only thing that would make me consider ARV and a baby's life and health – the only life that I would consider more important than my own! Not that I want a baby at 46!

He also gave me the 'in Africa people are crying out for treatments' routine which is about as helpful as telling me to finish up my dinner because there are people in the world who are starving.

I left the surgery some 40 minutes later feeling meek and selfish for not wanting to take treatments just to reduce the risks to my partner. I also left feeling dirty, infectious and totally responsible for his sexual health, but perhaps more pertinently, I left feeling invisible. Somehow, Cate Jacobs, sexy warrior woman and twentieth century goddess, had completely disappeared.

I landed on my lover's doorstep in a flood of tears, convinced that the best idea would be to end the relationship and take a vow of chastity to annihilate the risk of my passing on HIV to anyone at all.

He held me while I sobbed and wailed and babbled incomprehensibly with my head hung in shame. He stroked my hair and encouraged me to look at him, which was a struggle. When I managed it, his eyes were brimming with tears. He reminded me that we were in this together and nothing in our relationship was solely my responsibility.

A great sweep of cynicism swept over me and I muttered something like 'you're not the first person to say that,' which is true, he's not. Promises were made in the past which were broken, taking my heart and all my princess dreams with them in the process. I don't believe in 'happy ever after' any more, but I do believe in the here and now.

Here and now this man says we're in it together. Here and now he says he loves me. Here and now he says he chooses to be with me. All that may change tomorrow but here and now his arms embrace all that I am... including the HIV.



Primary Care Access Project



'In the past 10 years, I have only been to my GP's surgery twice. The first time to register and the second time to get my travel jabs.' [Woman living with HIV]

So why are many people living with HIV so reluctant to access their GPs?

There are a number of key barriers preventing people living with HIV from accessing their GPs. These include concerns about disclosing their HIV status for fear their confidentiality would be compromised; a number of patients even reported breaches of confidentiality. There was also frustration at having to see a different GP every time they visited the surgery and this caused a lack of continuity in care. Other patients raised concerns about being sent back and forth between their GPs and HIV clinic due to a general lack of knowledge, training and understanding by GPs around HIV drugs and treatment side-effects as well as their interactions with other medications.

GPs are meant to treat patients for non-HIV related conditions such as diabetes, high blood pressure and high cholesterol to name but a few. Incidentally, some of the anti-HIV medications cause these conditions and sometimes the only way to deal with them is to change medication. Unless a GP is aware of this, and given that many people living with HIV are now expected to only see their HIV clinician every three to four months, is the move towards treating patients with HIV within primary care wise?

A lack of clear communication between the GP and the HIV clinic in terms of information sharing, even in cases where patients had given permission for the information to be shared between the healthcare professionals was another issue for concern. Or patients being sent back and forth between their GPs and HIV

clinic due to unclear clinical governance and decision making about what is a general medical condition and what is HIV related.

As a result of the above issues as well as recommendations from the Healthcare for London report to 'wrap' healthcare around patient needs and the move towards managing long term conditions including HIV, closer to the community, NHS Kensington and Chelsea and Westminster commissioned Positively Women to develop a model of care to enable people living with HIV within these boroughs, to better access primary care [GP] services. The project will look at the identified barriers and how these can be addressed in order to enable patients to feel safe, confident and comfortable in accessing their GPs.

The project will also explore the feasibility of working with a group of GP practices who have expertise in dealing with patients with HIV or who are ready to build on their sexual health skills in treating HIV.

Key to the development of the project will be consultations and the meaningful involvement of people living with HIV, General Practitioners, HIV clinicians and those who commission health care services in order to ensure that any model developed is robust and can guarantee patient confidentiality.

The project will run to March 2010 and a project website will give regular updates and providing a forum for input and dialogue to inform the development of the project. Visit www.accessgp.org.uk or for further information please contact me by email anamiba@positivelywomen.org.uk.

Angelina
Project Manager

Angelina with Fergie from the Black Eyed Peas at the launch of the African Policy Network's new Stigma Campaign.



WHAT'S HAPPENING AROUND THE UK?

BIRMINGHAM

Universal Women's Group and is on the last Friday of every month.

Contact Alex on 0121 622 6471 or email alexbergman@abplus.org.uk

Terrence Higgins Trust Birmingham provides support or advocacy services for women living with HIV.

For more information contact Michaela on 0121 694 6440

BRIGHTON

The Sussex Beacon run a Women's Group and provide one-to-one support in Brighton. The group is run once a month from 10:30am - 3:30pm.

Contact Paula Evenden on 01273 645698 or e-mail paula.evenden@sussexbeacon.org.uk

BRISTOL

Terrence Higgins Trust multicultural women's group. Monthly on Saturdays.

Contact Bonnie on 0117 955 1000, 11.30am-3pm

CARDIFF

Terrence Higgins Trust. African women last Thursday of every month 1-4pm, women and carers group – 2nd Monday 11am-1pm, parents group.

Contact on 02920 666 465

CORNWALL

Kernow Positive Support (KPS) has a new peer support group meeting monthly. Tuesday 10am-1pm drop-in for HIV positive women.

Contact KPS on 01208 264866 or visit www.kpsdirect.com

COVENTRY

Terrence Higgins Trust. Peer support service is available for HIV positive women. Women's social events are also organised.

Contact Kate and the Community Support Team on 02476 229 292

DUNDEE

Body Positive Tayside – Care and support group offering a range of services for people with a blood borne virus. Women's group meets regularly.

Contact Kim on 01382 461424 www.sol.co.uk/b/bptayside

EAST ANGLIA

PLP – Support group for HIV positive women.

Contact 01502 537 985 or email info@plpea.org.uk

Women Living Positively runs a monthly support group for infected and affected women.

Contact Joe on 01473 692 616 for more details

EAST SUSSEX

Terrence Higgins Trust. African positive women's groups meet monthly in Eastbourne and Hastings.

Contact Caroline 01323 649927

EDINBURGH

ISIS – a group for women living with or affected by HIV – continues to meet every Tuesday from 1.00 – 3.30pm at Waverley Care, 1 – 3 Mansfield Place, Edinburgh EH3 6NB

Contact Maro on 0131 558 1425 or email fphealth@waverleycare.org

Waverley Care – Offers a number of services providing practical and emotional support to people living with HIV in Scotland and to their partners and families.

Contact on 0131 661 0982 or visit www.waverleycare.org

Positive Help – Practical support for people affected by HIV and AIDS.

Contact on 0131 558 1122

ESSEX – SOUTHEND-ON-SEA AND THURROCK

Terrence Higgins Trust Safe Haven African Women's group monthly.

Contact Winnie on 01702 340 791 or 07766 428 355

GLASGOW

Phace Scotland – Provides a range of services for people who are HIV positive.

Contact on 0141 332 3838 or visit www.phacescotland.org

Body Positive Strathclyde women's support group. Weekly, Friday 5-8pm.

Contact on 0141 332 5010

HAMPSHIRE

Monthly Support group for women infected or affected by HIV/AIDS

For details contact 01252 345 019 or email info@positiveaction.org.uk

INVERNESS

Terrence Higgins Trust Scotland Highland Services. Free and confidential HIV, HepB, HepC testing, HepB vaccination. Welfare rights support, one to one support and monthly support group for HIV positive people.

Contact Agnes on 07816 064 752

LEEDS

One-to-one emotional support. Every 2nd Monday 6-8pm, children welcome.

Contact Becki on 0113 236 4720

WHAT'S HAPPENING AROUND THE UK?

LIVERPOOL

Sahir House hold a monthly mentor-led women's peer support group.

Contact Serena on 0151 708 9080 or email info@sahir.uk.com

LONDON

Str8Talk – Islington. A multi-cultural self-help group for heterosexual HIV positive men and women.

Contact Str8Talk on 020 7812 1777

Riverhouse – Hammersmith, Weekly groups for HIV positive women 11am-4pm.

Call 020 8753 5190 for details

LUTON/BEDFORDSHIRE

Bbpositive HIV positive women's support group. Wednesdays 4-6pm. Food and refreshments available.

Contact Kirsten or Chrissie on 01582 484 499 or 01582 485 448 or visit www.bbpositive.com

MANCHESTER

George House Trust HIV positive women's support group and African Service. Alternate Tuesdays.

Contact Lynda on 0161 274 4499

Body Positive North West women's support group. Weekly, Friday mornings.

Contact on 0161 873 8100

SOUTHAMPTON

Ribbons Centre HIV positive women's group. Monthly, Wednesdays.

Contact Ginny on 0238 022 5511

STOKE ON TRENT

Espirit Women's Group for HIV positive women. Fortnightly on Wednesdays from 11.30am-4pm.

Contact Rosie on 01782 201279

WOLVERHAMPTON

Terrence Higgins Trust – Support for African women who've been diagnosed HIV positive, monthly on Thursday afternoon.

Contact Jane on 01902 711 818

SURREY

Monthly Support group for women infected or affected by HIV/AIDS

For details contact 01252 345019 or email info@positiveaction.org.uk

SWANSEA

AIDS Trust Cymru. Monthly women's group 11am-3.30pm. Usually the first Wednesday of the month.

Contact Silvia on 01792 461 848 or visit www.AIDStrustcymru.org.uk

Please get in touch if you know of a group or service that can be included.
Call 020 7713 0444 or email losman@positivelywomen.org.uk

LONDON – POSITIVELY WOMEN'S SERVICES

Support Groups:

Cara – Ladbroke Grove

Weekly groups for HIV positive women. Every Thursday 11am-3pm

Call 020 7745 7257 for details

Positively Women – Islington

Monthly support groups:

- Lesbian, bi-sexual and transgender HIV positive women's group every second Thursday of the month, 5-8pm
- HIV positive women's group every first Thursday of the month, 4-8pm
- Parenting groups for HIV positive parents every last Wednesday of the month 11.30am-2pm

- Caribbean Group last Saturday of every month 2-5pm

Call 020 7713 0444 for details or crèche booking. Or see www.positivelywomen.org.uk/supportgroups.html

Riverhouse – Hammersmith

Weekly one-to-one sessions and groups for HIV positive women. Mondays 3-8pm.

Call 020 8753 5190 for details

One-to-one sessions:

- General support
- Newly diagnosed support
- Immigration support
- Evening and daytime sessions

PW – call 020 7713 0444

Outreach one-to-one sessions:

Homerton – call 020 8510 7996

Royal Free Hospital – call 020 7794 0500

Complementary therapies:

Weekly appointments for Shiatsu, Cranio-Sacral Therapy and Hypnotherapy.

New Yoga class is drop-in term time, (outside school holidays) 11-12.30 on a Friday.

PW – call 020 7713 0444



Committed to you
and your family