

For HIV positive gay men
Issue three



Myths and facts

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side effects

the HEALTH issue

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of your health



Welcome to the third edition of U+ magazine.



You've probably picked up this magazine because you are living with HIV. You may also have heard somewhere that HIV is now a 'chronic' condition. But what does that mean? What I think our HIV doctors mean is that it's manageable: in a similar way to asthma or diabetes.

So there you go, HIV is now 'manageable': just like long hair after using a good conditioner. What's the problem? Well no-one teaches you how to manage a long-term, chronic and potentially life threatening condition until you've actually got one.

At times, HIV can be a real challenge both physically and emotionally. It can leave us with feelings of fear, anger and frustration. It's possible to deal with those challenges but sometimes we need some help. That's where this magazine comes in.

We've brought together some great thoughts and advice on how you can manage HIV: how to take control of our lives with it, and some suggestions on how to take care of our bodies and our minds, as well as taking care of our HIV.

Take a look, try some of the ideas out and share your experiences with your mates.

Please tell us what you think. The address is u+@ttht.org.uk

Gordon Mundie
Positive Men's Outreach Worker
at Terrence Higgins Trust



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Contact us: u+@ttht.org.uk

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Special thanks to Carmelo di Maria.

Useful organisations

THT Direct: 0845 12 21 200
www.ttht.org.uk
Details of local services,
information, advice and support.

www.ttht.org.uk/drugfucked
Comprehensive drug information
for gay men.

GMFA: 020 7738 6872.
www.gmfa.org.uk/positive
Website for gay men on all
aspects of living with HIV.

Living Well: 020 8746 2274
www.livingwelluk.com
Weekly courses to help you live
with HIV.

NAM: 020 7840 0050.
www.aidsmap.com
HIV treatment information.

HIV i-Base: 0808 800 6013
www.i-base.info
HIV treatment information.

NHS Direct: 0845 4647.
www.nhsdirect.nhs.uk
Advice on all health topics.

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MYTHS and FACTS HIV treatment

MYTH: Once I start taking my anti-HIV drugs, I will start having diarrhoea, nausea, vivid dreams, skin rash... the lot.

FACT: Side effects vary from drug to drug, and from person to person. They are normally short-term and tend to disappear after a few weeks of treatment. Some people may not have any of them at all.

MYTH: I'm on treatment so I can't pass on HIV.

FACT: Anti-HIV drugs reduce the amount of HIV in your body, but the virus is still there. If you have unprotected sex, transmission can still take place. If your viral load is high, the chance of infecting someone is higher. Viral load can rise if you're not taking your pills regularly, if you have a sexually transmitted infection or when you're not on treatment.

MYTH: Anti-HIV drugs will cure me of the virus.

FACT: There is still no cure for HIV. The drugs used for treatment (antiretrovirals, otherwise known as combination therapy) can only reduce the amount of virus in your blood. This makes it a long-term or 'chronic' condition for which you'll need to take drugs for the rest of your life.

MYTH: I can take a break from my meds if I want to.

FACT: One of the biggest research trials ever tested this idea out, and the results weren't encouraging. People who went off treatment occasionally were more likely to get sick, have problems with their heart and have poorer quality of life.

MYTH: After some time anti-HIV drugs will give me fat loss.

FACT: Only the long-term use of some antiretrovirals, not all of them, has been associated with fat loss in the face, or elsewhere in the body. These drugs are AZT and d4T (AZT is also found in the combined tablets Combivir and Trizivir). If you are currently taking one of them, you might want to discuss your options with your clinic doctor.

MYTH: One day or another, I'm bound to get resistance to my anti-HIV drugs.

FACT: As long as you keep taking the drugs everyday, at the right time and in the prescribed way, this doesn't need to happen. Many people are able to take drugs which continue to work for them for years on end without developing resistance.

MYTH: Once-a-day pills are best.

FACT: They can be very convenient, but a once a-day drug regimen has its own drawbacks. If you forget to take a dose, your body will be without any HIV drugs in your system for longer than if you were on a twice-a-day regimen. Even if you forget to take your pills just once a month, there's a risk of getting resistance that could jeopardize your treatment choices in the future.

MYTH: It's up to the doctor to decide whether I have a resistance test or not.

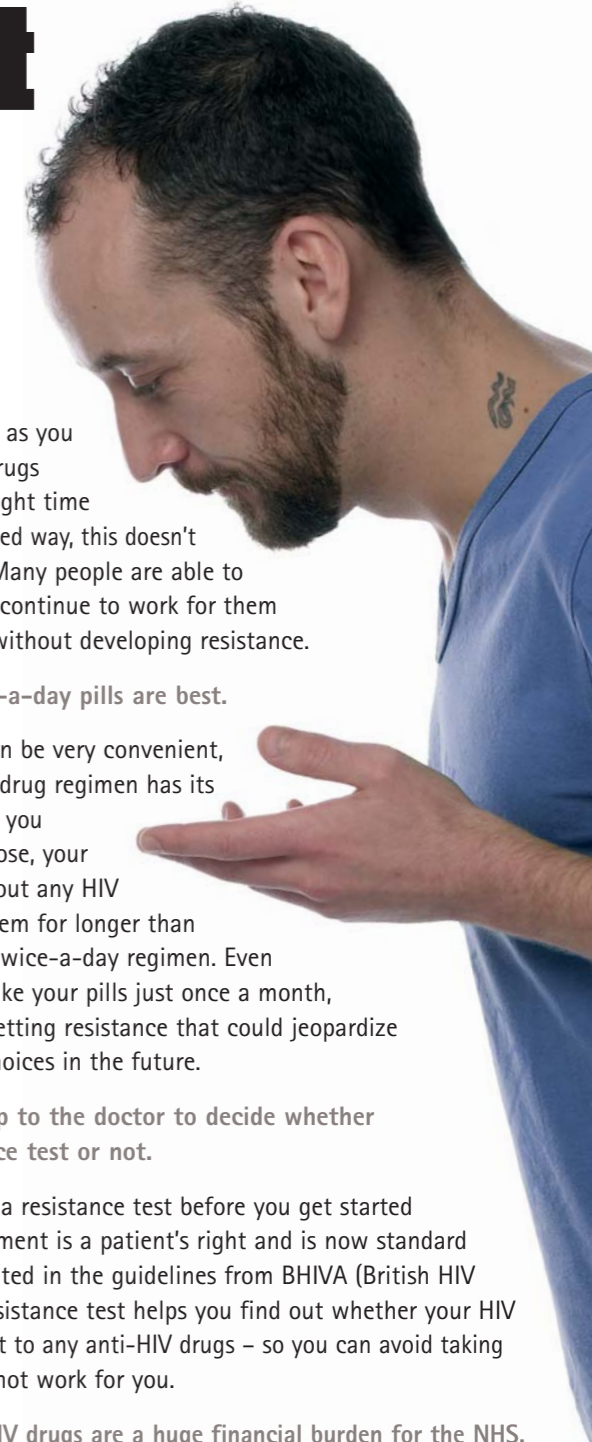
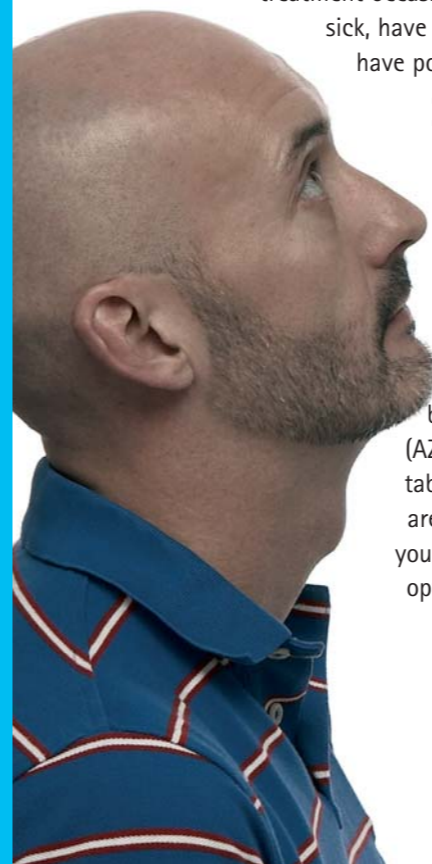
FACT: Having a resistance test before you get started on your HIV treatment is a patient's right and is now standard practice, as indicated in the guidelines from BHIVA (British HIV Association). A resistance test helps you find out whether your HIV is already resistant to any anti-HIV drugs – so you can avoid taking drugs that might not work for you.

MYTH: My HIV drugs are a huge financial burden for the NHS.

FACT: Although anti-HIV drugs are expensive, they still save the NHS money. If we didn't take them, we'd get sick much more often and would constantly be spending time in hospital. Thanks to combination therapy, most of us are able to carry on working and pay the taxes that keep the NHS going.

MYTH: I only need worry about starting treatment when my CD4 hovers around the 200 mark.

FACT: In this country it used to be the case that people were generally put on meds when they had a CD4 of about 200. Not any more. The new guidelines from BHIVA will probably recommend that as long as you feel ready, you should normally start treatment when the CD4 goes below 350.



Sort out those side effects

You don't have to suffer in silence

Lipoatrophy This can involve losing some fat from the face, resulting in sunken eyes, cheeks and temples. Or it might involve losing fat from the arms, legs or bum.

It can be difficult to live with, as it can affect the way we see ourselves. You might be worried that other people will notice the problem and realise that you have HIV.

The drugs which cause it, like d4T (Zerit) and AZT (Retrovir, also found in Combivir) aren't prescribed as often as they used to be.

Ask your doctor about New Fill and Bio-Alcamid, two different types of injections which fill out the face. These cosmetic surgeries have helped lots of people, but they're not always available on the NHS.

Feeling sick Lots of different drugs can cause this problem, especially during the first few weeks of treatment.

Anti-nausea drugs (also called anti-emetics) are often very effective. If one drug doesn't work, try another. Some people find that ginger helps – either in tablets, as ginger tea, or in food.

Nausea may be worse at mealtimes. Bland and cold food is usually better than hot, spicy, greasy or smelly food. Having several snacks and small meals in the day will be easier than a few large meals.

Taking your drugs with food, more frequently or at lower doses might help – but speak to your doctor before making any changes. If the problem doesn't go away, ask about changing treatment.

Diarrhoea As well as anti-HIV drugs, infections and intolerance to specific foods can also give us the shits. Diarrhoea is really unpleasant, but can also lead to nutritional problems, so it's important that your doctor knows what's going on.

Drugs like Immodium and Lomotil help slow down the gut's movements. That means you won't need to go to the toilet so often.

A dietitian can give you good advice on foods to avoid (the ones which make the diarrhoea worse), and foods to eat more of (to replace your lost nutrients).

The body loses a lot of water through diarrhoea, so it's important to drink more. Even better than water are unsweetened teas, vegetable and fruit juices, and light vegetable or chicken soups. They all contain minerals that are lost with the water.

Efavirenz side effects Some people taking the drug Efavirenz (Sustiva) get side effects like insomnia, drowsiness, vivid dreams, nightmares, dizziness, confusion, problems concentrating, abnormal thinking and mood swings. They often go away after a few weeks, but if they don't it may be possible to change treatment.

Don't take Efavirenz with a high fat meal. This unnecessarily increases the amount of the drug in the blood, and makes the side effects worse.

Taking the drug about two hours before you go to bed may help. That way the feelings of dizziness and anxiety will be most intense when you are asleep.

If your sleep is disturbed, try to relax before going to bed and make sure that your bedroom is as comfortable as possible. Avoid anything else like alcohol or a late meal that can also disturb your sleep.

Peripheral neuropathy This means damage to the nerves, and it usually affects the hands or feet. They may feel sensitive, numb or tingly. Neuropathy can range from being a bit annoying to being really painful.

Drugs that begin with a 'd' are often to blame: ddC (Hivid), d4T (Zerit), ddI (Videx), but also 3TC (Epivir). And there can be other causes.

If drugs are the cause, it's best to switch treatment without delay. If you continue to take the drugs, the nerve damage may become permanent.

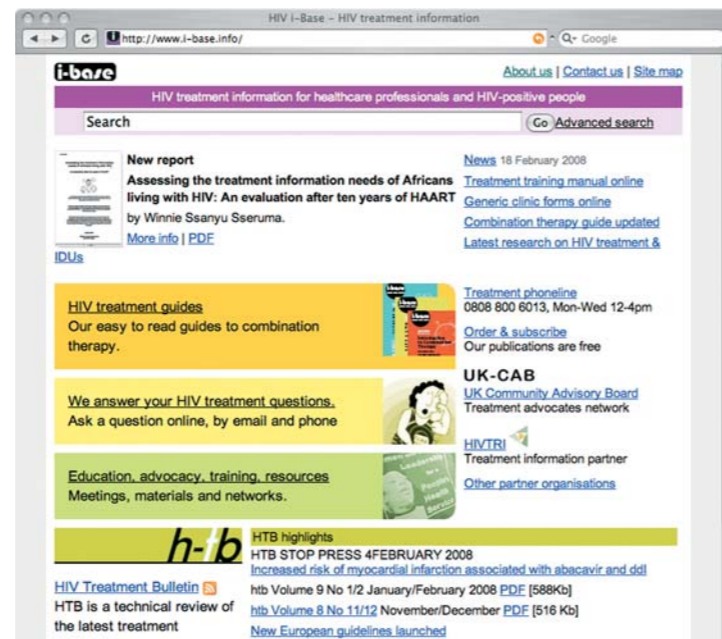
Acupuncture, and other complementary therapies, can reduce the pain. Also, try wearing looser shoes, not walking too far, not standing for long, and soaking your feet in cool water.

For more information about managing side effects, see HIV i-Base's guide, *Avoiding and Managing Side Effects*. You can get a free copy through their website: www.i-base.org.uk

Web review:

www.i-base.info

In each issue of U+, a reader will review a website. In this issue, William from West London takes a look at a site for treatment information.



The internet is the obvious place to look to get a basic understanding of HIV, information on local services and getting the hang of working your way through such a large and cumbersome system as the health service. There are also a number of websites which offer a mixture of empathy, sympathy and information. But where do you go once you have a grasp of the basic issues and want the latest, most pertinent medical information?

Many of us know www.aidsmap.com, but how about www.i-base.info? It presents itself as 'HIV treatment information for healthcare professionals and HIV-positive people.' This is the place to come for more detailed information. A dedicated resource, it has a friendly approach. But, look deeper and their information is quite cutting edge and in depth. So, if you know what you are looking for, you can come here to get to grips with the more detailed facts.

On the home page there are links to a series of easy to read treatment guides, covering things like Starting Treatment, Side Effects and Hepatitis C. There's also a Q & A function where you can ask your own treatment questions, and read the advice that other people have already received. Visitors will find these great places to start.

Scrolling down the home page you delve into the more technical stuff, the site's speciality, for example their *HIV Treatment Bulletin*. For healthcare professionals the site must be a great help as the language used is both scientific and clinical, citing references where necessary. The site makes

no apologies for this and excels in getting straight into the heart of the research.

Elsewhere there's a focus on intravenous drug use and HIV. Not everyone who gets HIV gets it through sex, and this is a very open minded approach.

The site is also technologically advanced with Really Simple Syndication (RSS). This allows news to be fed directly to your desktop, which is great for up-to-the minute developments.

Reading the 'About us' section, the authors talk about themselves as an 'activist' group. Having spent sometime looking through the *HIV Treatment Bulletin*, I'd say this is not a rowdy, protesting activism; it's research based commentary on the latest in medicine. A finely balanced argument to keep the sponsors and research community happy is fine, but for me this is not 'activism' despite its intimate knowledge of the research and facts.

For me what's lacking are arguments that put the research in a real world context – without this, research is just research and can have no impact. The site could also benefit from informed opinion from peers about social issues and service delivery.

The site is a great news service, a place for detail and is ideal as a researcher's secondary source. But you need to know what you are looking for and have an appreciation of the underlying issues and detail to make sense of the information.

QUIZ: Taking control of your health

We all have our ups and downs with HIV. How much do you do to prevent any problems getting out of hand?

1: Your doctor asks how you're feeling. Today you're feeling fine, but a month ago were feeling lousy. Do you:

- A Say: 'I'm fine.'
- B Say: 'I'm feeling a bit better now, thanks.'
- C Pull out the notes you make each week about how symptoms and side effects have been affecting you.

2: You're getting some unpleasant and severe symptoms that you've never had before. Do you:

- A Ignore them and hope they'll go away.
- B Wait till your next doctor's appointment to mention them.
- C Phone the clinic (or NHS Direct) and describe them to a nurse.

3: You think that it would be a good idea to get more exercise. Do you:

- A Think about it for a bit and then forget the idea.
- B Go to the gym everyday for a month, and then give up.
- C Start off with a goal of walking 15 minutes a day and going swimming once a week, and see how you get on.

4: When you've got a problem, do you:

- A Phone up social services and tell them how dreadful your life is.
- B Ask a friend what he or she would do.
- C Think of some possible solutions, try a few of them out, and don't give up if the first doesn't work.

5: When you've got a doctor's appointment, do you:

- A Try to remember to go, as long as you're not too busy.
- B Go and see what the doctor has to say.
- C Come prepared with a list of your questions and concerns.

6: There aren't many people you can turn to when times are hard. Do you:

- A Do nothing and feel sorry for yourself.
- B Try to meet new people by joining a support group, a class or a club.
- C Try to give a bit more support to the people you know – perhaps they'll help you out too.

7: Your doctor wants you to start some new drugs and he mentioned in passing that the side effects could be difficult. Do you:

- A Wait to see what happens.
- B Get a bit of information about the side effects.
- C Find out enough about the side effects and how to deal with them so you can decide whether these drugs are right for you..

8: You don't think your partner is really there for you when you need some support. What do you say?

- A 'You're so selfish. You never listen.'
- B 'I don't think you understand what I'm going through. I need you to help me.'
- C 'I'm finding things difficult right now. I need some help.'

How did you score?

Mostly A's It sounds like you're having some difficulty dealing with problems that come up. Life might be easier if you learn some simple techniques and skills (see below).

Mostly B's You're well on your way to taking control of your own health. You usually try to tackle difficult situations and you're ready to ask for help.

Mostly C's Well done, you are what's known as an 'expert patient'! That's someone who can face up to problems and find a way through them. You get information to help you make decisions and you ask for support when you need it.

Improve your score 'Expert patient' and 'self-management' courses take place across the country, run by the NHS or HIV organisations. They usually consist of seven or eight weekly sessions, and cover skills like problem solving, goal setting and making the best use of support. To find out more, call **THT Direct on 0845 12 21 200.**



Who's who at the clinic

HIV clinics can be busy, daunting places, especially when it's all new. Not all are the same, but to help you get the most from your appointments, we've spoken to seven members of staff you might meet during your HIV care.

MICHAEL, the doctor



From my point of view, the patients I have the best relationships with are the ones who are open and honest. An ideal patient is somebody who feels comfortable being able to tell you everything that's going on or that they're feeling. Knowing what's happening in their lives gives me a better picture of them as an individual, and can sometimes help with their treatment. Giving the best HIV care involves dealing with psychological and social issues as well as the medical problems.

I enjoy the fact that we have a long-term relationship with patients. It's sometimes quite humbling because you're often involved in difficult or intimate parts of people's lives, but it's very rewarding.

"The doctor may not be the best person to deal with an issue."

Dr Michael Brady

Patients can get the most of their appointments by thinking and preparing beforehand. Write things down and prioritise them. If there's something that you think is going to take more time, perhaps try to book a double appointment if that's possible.

Patients understandably find it difficult knowing when to go to their HIV clinic and when to go to their GP. What we try to encourage is some education around what's the appropriate use of services. We encourage people to register with and use their GPs because often the GP is the best person to see. GPs are much more experienced at managing things like depression, or blood pressure.

Clinics are increasingly busy so patients may get less time with a doctor, but there are other members of the team who can help with what they need. It may be that your HIV doctor, in the 15 to 20 minutes you have with them, is not the best person to deal with a particular issue so it's worth knowing who else in the team might be able to help.

Dr Michael Brady is Consultant Physician in HIV/GUM at the Caldecot Centre, King's College Hospital NHS Foundation Trust, London.

VIV, the pharmacist

As a specialist pharmacist my main role is to promote the safe use of medication, so we are really involved in the education of patients about how to get the best out of their anti-retroviral treatment.

We also use our pharmaceutical expertise to help consultants with their prescribing. Our involvement starts from the choice of medication as we tailor patients' regimens to meet their individual needs. So if the patient has another condition, as well as HIV, like heart disease, diabetes, liver or renal impairment, that can affect the way that we manage their treatment.

We also look out for interactions with other medication, be that things prescribed by their GP, over-the-counter medication, herbal remedies or recreational drugs. We want to know about all these things so we can monitor and assess for interactions. We would rather know about recreational drugs and that way we can help avoid complications.

We do have more knowledge nowadays about how to manage side-effects. There are things we can do to help patients to tolerate their medication. People don't just have to grin and bear it or stop taking it.

You get some people who only really want to know the bare basics like when to take their medicine and how much to take. Whereas other people want as much information as possible, like how treatment works and how the body is going to accept the medication. I think it is so important that people are adherent to their medication – they do need to understand the basics. But sometimes too much information can frighten people. We leave it up to the individual to decide how much they want to know.

People don't need an appointment to see us; they can literally just drop in.



Viv Man is Senior Pharmacist, HIV and Infection, Mortimer Market Centre, London.

PAUL, the patients' rep



What I aim to do as a patients' representative is elicit a broad range of patients' views and experiences, and get a body of opinion about what seems to be working well, what doesn't, and get ideas for what might be improved. I then put those to clinic management.

"You need to be a patient to have credibility as a patients' representative."

Paul Clift

Not all clinics have patients' representatives. There are two reasons why a clinic might. One is because they're told to by the NHS! Some clinics, however, like King's, do so because they want to. They see patients and staff as partners in the same process, bringing different bodies of experience together towards the same shared goals, namely better healthcare outcomes.

I think you need to be a patient to have credibility as a patients' representative. If somebody's not a patient they have no experience of using a clinic or of the specific illness concerned.

I really would encourage people around the country to get involved in this constructive way with their clinic. It does break down barriers. It does help to improve the care that they receive. If it's managed skilfully, it can keep the general standard of the clinic up.

I used to be patients' representative in Brighton. My greatest achievement there was keeping the ward open. The hospital trust suddenly announced they were going to close the ward specifically for people with AIDS without telling anyone. I was angry about it and quickly found out what people thought about it. Doctors thought it was a bad idea, nurses thought it was a bad idea – together, we kept it open!

Paul Clift is the Patients' Representative at the Caldecot Centre, King's College Hospital.

HELEN, the psychologist

There's a wide-range of issues that people come to see us for. People may benefit from talking to a psychologist about coping with a recent diagnosis and starting treatment. We also work with issues around disclosure, sex, relationships, stigma, discrimination, depression and anxiety.

It can often be the case that a new diagnosis can act as a catalyst for other issues that were already present. Many people have told me that their diagnosis has helped them to work through other issues that they had previously avoided such as low self-confidence or childhood issues.

Our services are built around helping people to live well with HIV, which means looking after your health while at the same time getting on with other things in your life that are important to you, like work and relationships, and how everything fits together.

Someone may be struggling with particular parts of their life and this may affect their ability to get on with things. For example, they might not be sleeping well, they are feeling depressed or they're not motivated to do things like they were before – and this has been going on for longer than a month.

In situations like this, it might be a good idea to ask for a referral through your HIV doctor or nurse to speak to someone about how you are feeling. A psychologist can help you to think about what the issues are and what you'd like to change. If someone is very depressed it sometimes helpful to think about taking anti-depressants for a while, so they would need to go and see a psychiatrist or their GP.

A psychologist will help you to make sense of unhelpful patterns of thinking, feeling and behaving and to find alternative ways of coping with those difficulties. Sometimes it's not always easy to talk to friends and family and talking to a professional who is neutral and objective can often be more helpful. Some people worry about what it means to come and see a psychologist or psychiatrist and that it means they are 'weak'. I believe it takes strength and courage to deal with your problems and that we can't always do this on our own.



Helen Rowden is Chartered Counselling Psychologist, with CASCAID HIV Mental Health Team, part of South London and Maudsley NHS Foundation Trust.

ENRIQUE, the specialist nurse

My role is very innovative and was introduced three years ago to respond to the demands of patients who were well and wanted more flexibility. I have my own group of patients who are stable and well, who may or may not be on therapy, and who perhaps don't need to see a doctor every visit to the clinic.

We review patients every four to six months. During our consultations we make sure their health is as good as it can be: medically, psychologically and socially. We review their results, issue prescriptions, and carry out sexual health screenings.

We've got very specific criteria about the patients that can have joint care with a doctor and the specialist nurse. In some cases, we alternate visits between a doctor and a nurse, so the patient gets to see a consultant every 8 to 12 months and in between they'll see us.

Our service aims to respond to the current needs of people living with HIV. Once a week we have a dedicated telephone consultation clinic. For a selected group of patients this is the most suitable option. They're well and busy, so don't need to come to see us and we can keep in contact in that way.

We also do treatment support and advice so patients feel encouraged when they first start or switch treatment. Part of the job is to ensure that all patients are well-informed, as we know that this helps them to have more input into their care and make informed choices. For patients that don't have the time or the opportunity to find things out for themselves, we make sure we present information in a way that they can understand.



Enrique Castro-Sanchez is a Nurse Specialist at the Mortimer Market Centre.

VIVIAN, the dietitian



When they are newly diagnosed, some people are concerned about nutrition and want to know that they're eating well and getting all the right nutrients. That can help with taking control of the illness.

Sometimes I see people about healthy eating advice and do nutritional assessments; I ask people what they eat and give them advice based on that as well as other healthy lifestyle interventions, like encouraging exercise, not smoking and things like decreasing stress.

Another important thing is food safety and hygiene information. That's things like being careful with high-risk foods, making sure that food is cooked properly and avoiding cross-contamination.

Before the introduction of treatment we were dealing largely with weight loss and wasting. Then lipodystrophy and the side-effects of medication became a major concern.

We're involved in measuring body composition, assessing those changes and also the metabolic problems people can get with high blood fats and high cholesterol, and preventing and treating those when they happen.

These days, people's long term prospects are very good. But people are becoming more aware of the other conditions associated with HIV. As well as metabolic problems, there's concern about certain cancers, liver disease and renal disease. Good nutrition and good lifestyle practices are very important for people's long term health.

Sometimes the doctors send people to me but the patients don't have a clear idea about what they're coming to see me for. It's a good idea to ask your doctor why first, so you know what to expect. We are largely talking about lifestyle changes, so you need to be in a situation to make those changes.

Vivian Pribram is Specialist HIV Dietician at the Caldecot Centre, King's College Hospital.

DARREN, the health adviser

We're here for the milestones on people's journey around being diagnosed with HIV. For many we're the first people they come in to contact with and a health adviser will probably have done their pre-test discussion and given the positive result.

We do orientation on the first clinic visit, check out how someone's doing, and discuss what's going to happen next and how the clinic works. We try to put things into context and help people explore their feelings about being HIV positive.

We see people at significant times and crisis or when things have changed in their lives. The doctors might refer someone to us after they've noticed a change – they may seem down. We can explore what's going on and how to move forward. We're also here to discuss practical issues when patients are diagnosed with STIs.

People should see us as a resource – please don't see us as something scary! People don't have to wait until they're in crisis before seeing us, we're available to help prevent bad situations. Health advisers can meet with patients and help them plan a healthy life living with HIV, rather than waiting until they're depressed when it's all more of a struggle.

Encouraging people to tell their partners about having HIV also comes into our role. We sit down and talk about the pros and cons, the different strategies and can do role play, which often helps. When people have told their partners, they're often very relieved because it's a big burden to carry.

Working in a clinic you never know what's going to happen from one day to the next. HIV and sexual health bring up a range of emotional responses. When people are in a form of crisis they can sometimes respond to you in a very open way. You meet people you'd never normally meet, people from completely different cultures all with very different experiences of HIV.



Darren Tippetts is Sexual Health Adviser at the Mortimer Market Centre.

"People should see us as a resource – not as something scary!"

Darren Tippetts

"Good nutrition and good lifestyle practices are very important for people's long term health."

Vivian Pribram

Ask an expert

Q I've read that HIV can take several years before you develop any symptoms, but I seem to have developed 'AIDS' very rapidly. Why did the virus progress so fast in me?

A I tested HIV negative in August 2000, but then in October 2001 I started to feel unwell. I had had flu-like symptoms, it was really painful to swallow, and I was told I had heartburn, so I started using medication for that. Then I developed a pain in my leg and was told I'd probably torn a ligament. The problems got worse, and I lost a lot of weight because it was so painful to eat. My leg suddenly swelled up and I was rushed into hospital. After various tests, I found that I was HIV positive with a CD4 count of 7 and a high viral load (177,000). I had oesophageal candidiasis and a muscular leg infection.

After three months in hospital and starting anti-HIV treatment, my situation became much more stable and I was pretty much back to normal within six months. But I still don't understand why HIV made me so ill so soon after I was infected.

A by Dr Sarah Fidler, consultant at St Mary's Hospital, London

HIV is the virus that causes 'AIDS'. It can take on average 10 years from becoming newly infected with the HIV virus to develop the clinical disease of AIDS which is where the immune system can no longer fight infections. AIDS develops when the immune system has been so damaged by the virus that it can no longer control certain cancers or unusual infections that ordinarily would not cause disease.

On the other hand, you developed severe immune damage very rapidly after you were infected with HIV (within 14 months). This is unusual – only around 5% of all people infected with HIV become ill very quickly.

The reason why the HIV virus can cause immune damage more rapidly in some people than others is usually a result of the natural strength or function of their immune system. The strength of the immune responses to HIV infection are affected by genes inherited from our parents as well as our general state of health and nutrition. It has also been suggested that some strains of HIV virus can damage the immune cells more rapidly than others. This would be a 'superbug', but there is very little evidence to suggest that this is a common or significant factor.

The most important thing to know is that combination therapy works just as effectively in 'rapid progressors' as in those people where immune damage takes longer to develop.

If you've had rapid and quite severe immune damage, you should probably remain on life-long treatment. But you can expect to live a long and healthy life, because control of the HIV allows the immune system to rebuild.

"I don't understand why HIV made me so ill so soon after I was infected."



Q I'm confused about vitamin supplements. People have said that having HIV means my body needs more nutrients than otherwise, but which ones? Which are the vitamins and minerals that I need to make sure I get enough of? Some HIV positive friends I know swear by multi-vitamin supplements, but they all seem to take different ones with different things in them.

A Will I be getting enough nutrients from food? I do try to eat fairly well, but this can be tricky when I'm busy at work. Breakfast is a bowl of cereal, lunch is usually a sandwich and an apple, and for dinner I'll have a ready meal or a soup from the supermarket. I try to get low fat versions when I can.



A by Clare Stradling, specialist HIV dietitian at Birmingham Heartlands Hospital

Vitamins and minerals are essential to support the chemical processes within our cells. Those processes include the functioning of the immune system, so are obviously important for someone with HIV infection.

It is possible to get all the nutrients you need from food, but you do need to be eating the right things! The meals you describe probably contain sufficient protein and energy foods, but the evening meal needs a bit of tweaking to ensure that you are getting enough vitamins and minerals. For this you need vegetables and fruit – at least five portions every day, in all the colours of the rainbow (as different colours indicate different vitamins). It would be helpful to have a consultation with the dietitian at your HIV clinic to get detailed advice on different meal options that will meet your nutritional requirements, while staying within your budget and your need for convenience.

There is no conclusive evidence that people with HIV need more of any particular nutrient than anyone else. However, if you feel that your diet may be lacking, then there is no harm in taking a general multivitamin and mineral supplement. You only need one tablet per day of a product that says it supplies 100% RNI or RDA on the label. Don't be drawn in by all the advertising hype from named brands – own label versions are just as good.

But be careful that you do not use products containing added herbal extras, as they have the potential to interact with your antiretrovirals with serious implications. If in doubt, take your vitamin bottle to the clinic and show your dietitian or pharmacist.

Change Reaction

With healthcare changes never far from the headlines, we look at three that may affect our HIV care and examine what they could mean for us. We asked HIV positive gay men for their reactions.

1 Is it OK for clinics to do CD4 counts only every six months?

My clinic tests my viral load every four months, but my CD4 only every eight months. My CD4 count is OK. If it was a bit lower, I would press to have it done more often. **Mark, London**

I just want to know what the science is for this. They've told me it's what they do, but they've never given me a leaflet or explained the reasons behind it. They haven't asked if I have any concerns, or given me different options. I haven't felt involved in these decisions. **Frank, London**

I look at it in a very positive way by saying that if the doctor doesn't want to see me for a long time, it's because the drugs are working and I'm doing well. **Philip, London**

They're trying to save money everywhere – it's not that they're giving you less tests to pay for something else; they're cutting things in every single department. **David, London**

I think it's wrong. Both are as important as each other. Leaving one for six months, a lot could change in that time. **Paul, West Yorkshire**

My CD4 has been going up and down, so my consultant said they wouldn't do it less often for me. They know that they have to monitor me more carefully. **Thomas, London**

Explainer

Most HIV clinics used to take CD4 counts and viral load tests every 3 or 4 months. Some doctors think this is expensive and unnecessary, so are now doing blood tests less often. For example, for people not taking treatment, viral load tests may be every 6 months, but CD4 counts would still be done every 3 months, as it is the CD4 count which shows whether treatment needs to be started. On the other hand, for people taking treatment, viral load tests are more important, so these will be done every 3 months, while CD4 counts will be less often. For people whose health is not stable, tests will be done more frequently.

2 Should people with HIV have to register with a GP?

I'm concerned about starting from scratch with a non-specialist and explaining my whole clinical history each time I see someone new. I doubt I would ever get to see the same doctor at each visit. **Stephen, London**

I went to my GP because I was depressed and wanted to know about support services. He asked why I was down and I ended up talking about HIV. His first reaction was to ask whether I got it from a prostitute! **David, Coventry**

The GP says I should go to the HIV clinic, but the clinic says I should go to my GP. So I feel like a ping-pong ball. **Emiliano, London**

I've got a very good GP. I go to him for flu jabs and a problem I have with my knee. He's gay (well, I assume he is) and very easy to deal with. I like the security of knowing that he's down the road and I can see him quickly. **Frank, London**

My clinic recommended a GP who has lots of experience with HIV positive clients. I always see the same doctor, but if he left the surgery, I would want to change. It's just that one doctor who knows about HIV, and my only experience with another doctor there was very negative. **Michael, London**

Explainer

HIV clinics no longer have the budgets to take care of all our health needs. Many clinics have had to stop issuing prescriptions for anti-depressants, blood pressure drugs, flu vaccines, and so on. This means that for treatment of non-HIV health problems, clinics are asking patients to register with GP services (general practitioners or family doctors).

3 Electronic patient records: are they a good idea?

I like to be able to manage who knows I have HIV, and who doesn't. I wouldn't want everybody in A&E to find out. On the other hand, the medical notes we have now are hand written and look pretty chaotic. If I ask the staff when I last had a specific test, they often can't find the information. **David, Coventry**

I've worked in IT for 25 years, and I know the dangers. Once you make data available over a network, then it's at risk. The security rules won't be followed and access rights will be given to too many people. **Paul, London**

I think most patients are ignorant about how easy it is for staff to get hold of paper records, and about how notes are transferred around the hospital. People worry about computer systems, but we should have the same fears about paper records. **Graym, London**

I don't feel confident or safe about this. I certainly don't know enough about it, and to be honest I don't think the people in charge know enough either! **Mike, Bristol**

I instinctively feel anxious about the sheer amount of data that will be available about me electronically. But if it means staff aren't chasing illegible notes around the hospital then it will be a good thing. Properly handled it should improve care and decision making. **Stephen, London**

Explainer

At the moment, every hospital and GP's practice has its own system to keep patients' medical records. These systems may be paper based, or computer based. The government wants to introduce a national system of electronic patient records, called 'the spine'. NHS staff that are caring for you will be able to read your record. It will contain limited information about who you are and any allergies you have. HIV status won't be included, but the names of medicines you take will be. You'll be able to see your own record. You'll also be able to ask not to be put on the system.

1: Love yourself

You may have to deal with discrimination linked to being gay or having HIV. And if you don't think you're worth it, you may not take care of yourself. So boosting your self-esteem makes sense – talk things over with a counsellor, sign up for a GMFA assertiveness course, read up on the subject, use positive thinking.

3: Eat well

Give your immune system a little help by feeding it the right stuff. That means plenty of fruit and vegetables, and not many fatty foods – especially as your HIV drugs may already be raising your cholesterol levels. Equally important is drinking enough liquid to keep your body hydrated (two litres a day is recommended). But remember that alcohol and caffeine have the opposite effect and will de-hydrate you.

5: Deal with addictions

Too much drugs, alcohol or sex can take a toll on your body and jeopardise your social life. When these get out of hand, it can be a sign of an underlying problem like lack of confidence or not feeling good about yourself. Help is available from HIV and gay organisations – you could talk to someone one-to-one, or join a group of other people dealing with similar problems.

7: Give up smoking

HIV positive people who smoke are more likely than negative smokers to get diseases like emphysema and lung cancer, even before the age of 40. With a new law guaranteeing smoke-free public places, quitting has never been easier. To help you ditch the habit, try an NHS smoking cessation course – some are specifically for gay men.

9: Develop a support network

Build up friendships where you help each other out and talk things over. If you want advice on all thing HIV related or professional emotional support, you may want to call THT Direct (0845 12 21 200) – they will be able to tell you about support services in your area.

2: Take your drugs on time

Taking your HIV drugs every day at the right times and in the prescribed way will mean there's a good chance that your HIV will be kept at undetectable levels. Remember that alcohol and drugs can get in the way of adherence. If you have problems, pill cases, alarm reminders, a chat with a specialist nurse or attending a workshop on the subject can all help.

4: Have a good night's sleep

Sleep refreshes your body and mind. Being deprived of sleep makes you feel sluggish, irritable and unable to concentrate. If you have difficulty sleeping, try regular exercise, avoid napping during the day, avoid caffeine late in the evening, and try to keep a regular bed time routine. Some drugs including Efavirenz (Sustiva) can disturb sleep – you may want to talk to your doctor about this.

6: Exercise regularly

Exercise gives you strength, combats fatigue and may make you feel better about yourself. It even releases feel-good chemicals in the brain! Conditions like high blood pressure, high cholesterol, heart disease and diabetes (which can all be long-term side effects of HIV medication) may be counteracted by keeping fit.

8: Look after your sexual health

Remember that HIV positive people have a greater risk of getting hepatitis C, and that sexually transmitted infections are a stress for your body. Take regular sexual MOTs.

10: Enrich your life

Expand your horizon beyond the club and sex scene. Make your life as varied as possible by enjoying nights out at the cinema or theatre, signing up for a course, joining a sports club or volunteering for an organisation close to your heart. Volunteering can help you make new friends, provide renewed motivation and give a sense of direction in life.

10

TIPS on looking after your body and your mind.

It makes sense to look after ourselves in a holistic way. Whatever we do to boost our physical health will help our mental well being, and vice versa.

Not as bad as I expected



Catching hepatitis C not once, but twice in the space of two years has taught me a few things.

Lots of them were part of a journey of self-discovery, but I won't bore you with that here. Hopefully you'll find some of the practical things I learned from the experience useful if you are starting treatment for hep C.

There's a lot of talk about Hep C and its treatment and it's often hard to get a clear picture. Many people say that the side effects of Hep C treatment are the worst experience they ever had. I know people who had a really dreadful time, taking months off work, feeling weak with flu-like symptoms, having stomach problems and getting very depressed. Others, myself included, found that it wasn't nearly as bad as I expected. Still it certainly wasn't a stroll in the park, and I reckon the chances of anyone breezing through it completely unscathed are pretty low.

A key thing to remember is that, unlike HIV, hep C treatment isn't life-long and you will come out the other end. But you will have to make adjustments to your life in order to cope with the treatment. How many and how great they are will depend on how you react to the treatment, and that you'll only know that once you've begun.

Let's start at the beginning. If you've been infected with hep C quite recently, in the last six months, this is the 'acute phase' and treatment is more likely to be successful at this stage. Also, the treatment may be for a shorter period of time. There's even a small chance that the virus will clear itself without treatment, so your doc might advise you to wait and see what happens.

Regardless of when you start Hep C treatment, there are two components to it. First come the ribavirin tablets, in two doses a day. Next is a weekly injection of pegylated interferon. The clinic appointments are monthly, so you'll have to factor in the time for those.

Hep C treatment generally causes depression so you might want to think about antidepressants. If you do, sort out getting them prescribed as soon as possible as they take about three weeks to become fully effective.

Prepare for the worst, hope for the best, and take it as it comes.

So, the first part: taking the ribavirin (the daily tablets). Best with food as this decreases the chances of any stomach nasties. If you're on twice a day HIV meds, combine the doses for simplicity's sake. But if you've been once a day, the new schedule might take a bit of getting used to.

Ribavirin also causes insomnia and your clinic will probably offer you sleeping tablets for this. If you don't want to use them, take the evening dose of Ribavirin early (say 6pm?) to let the effect wear off a little before going to bed. I opted for the sleepers as I preferred a metallic taste in my mouth to being wired and irritable through lack of sleep.

Second part: doing the weekly interferon injection. It's not scary and the clinic will give you a lesson in

technique. You do it at home and it's injected into the fat around your abdomen so you just have to pinch an inch, stick it in and push that plunger.

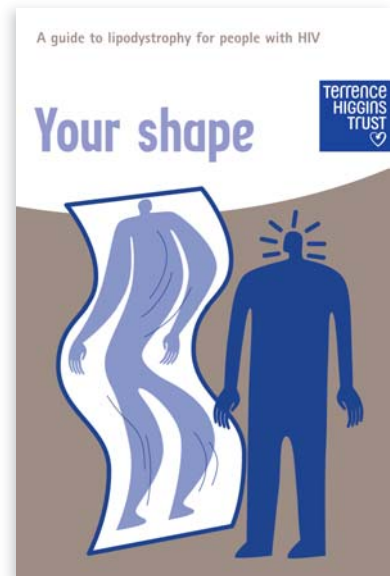
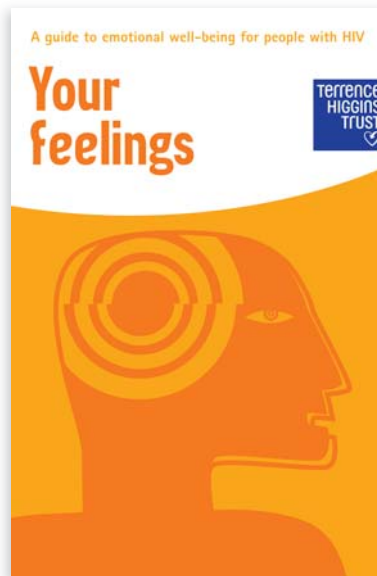
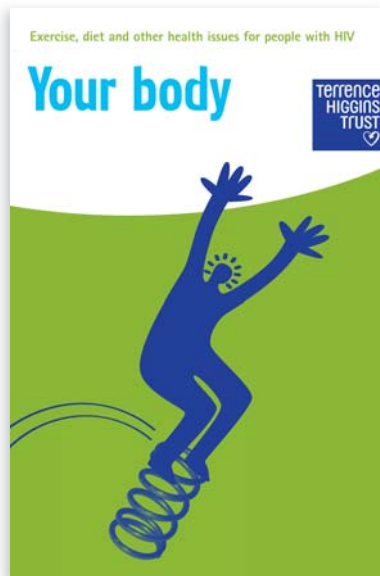
It's the injection which often causes the flu-like symptoms, so plan to do it when you have the time to handle the side effects. I found the best time was on a Friday evening at about 9 or 10pm. That way I could go to bed if I started feeling unwell and sleep through the initial burst. And I knew I could spend all day Saturday on the couch in front of the telly if I felt crappy when I woke up.

Another thing to think about is alcohol. Most likely your doc will advise you to abstain, but mine told me that a couple of units a week wouldn't be a problem. However, if your idea of a great weekend is to see how many tequila shots you can get down your neck before passing out, then you're in for a shock. In fact, cutting right back isn't as hard as it sounds – if you do drink too much you'll certainly know about it as it can make you feel dreadful. Not surprising given the strain your liver is under.

Unfortunately it seems that hep C is as stigmatised among poz gay men as HIV is among neggies, so who you tell in terms of getting support is very much up to you. If you're out about your HIV status to supportive friends, relatives or employers then think about letting them know, as offers of shopping or flexible working can come in handy. If you can't get support from personal sources, then there are websites and helplines you can access.

However you choose to deal with hep C, I'd say get informed, consider all the options and do what you feel is right for you. You might decide not to start treatment, but if you do, my advice is: prepare for the worst, hope for the best, and take it as it comes.

Living with HIV



These easy to understand booklets
are available in most HIV clinics.

THT DIRECT  0845 12 21 200

www.tht.org.uk