

Winter 2010

POSITIVELY WOMEN



Access All Areas
Getting the best from your services

The only magazine for positive women written by positive women

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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 Silvia, if you would like to be our cover model please contact us by emailing Lucy at losman@positivelywomen.org.uk

Access All Areas

Guest Editor's Letter

Hello all

Access all Areas is a very special issue for me, not only because it marks my return to Positively Women – albeit for a year – but also because it focuses mainly on the different types of services we as people living with HIV need access to in order to enable us to lead healthy and fulfilling lives.

This issue's focus is on access to healthcare and the Primary Care Access Project, which I am currently managing here at PW, inspired the content. The project, which will run to March 2010, was commissioned by NHS Kensington & Chelsea and NHS Westminster. The project is looking at developing and proposing a model of care to enable people living with HIV to better access their GPs. It was initiated not only as a result of barriers that have been identified, both from the patients and healthcare providers perspectives that make it difficult for patients to access their GPs; but also as a result of recommendations from Lord Darzi's Healthcare for London report to 'wrap healthcare around patient needs' and the move towards managing long term conditions including HIV, closer to the community. Lord Darzi's report was about improving the quality of care [safety and effectiveness of services] and patient experience of the National Health Service. 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. For further information on the project please visit www.accessgp.org.uk



As per usual, we have strived to ensure that we have a mix of articles ranging from both the very good to the not so good patient experiences of accessing GPs, dentists, social, antenatal and immigration services; perspectives of healthcare clinicians. We have an article about what the healthcare of the future will look like; one on the implications of living longer with HIV and what this means in terms of how we 'mature' people living with HIV access our healthcare; we also have an article on what healthcare in other European countries is like – a real eye opener for those who like to moan about the NHS!

I hope that you will find the magazine both informative and enjoyable.

Please do not hesitate to contact us, via email, phone or freepost should you have any comments, suggestions or if you are interested in contributing an article for the magazine.

Best wishes

Angelina

Positively Women
347-349 City Road, London EC1V 1LR
Helpline 020 7713 0222
Admin 020 7713 0444
Fax 020 7713 1020

Email info@positivelywomen.org.uk
Website www.positivelywomen.org.uk
Positively Women is a national organisation providing support services to women living with HIV and their children
Charity reg: 1007685

Access All Areas

Some of us will look back at the era of Dr Finlay's casebook with nostalgia for those lost days of relaxed, fatherly, tweedy general practice. The world has moved on though and maybe in primary care for the better, especially in London. My personal opinion is that we are on the brink of a completely new way of receiving modern Primary Care.

Londoners were asked to pass comment on the Healthcare for London review in 2008. They agreed with the 'case for change' that stated, amongst other things, that they did not feel particularly well served by the NHS, wanted care closer to home and did not think that hospital was the only answer for health care delivery. There were many more points which if you have not read I would suggest you should read on the NHS London website, it's very exciting.

So following this consultation the NHS in London has been sanctioned to deliver a whole new range of services in the community, from testing facilities to therapists and GP and Consultant appointments, and to ensure that they are available at convenient times for children, parents, working adults and carers.

These 'poly-systems' or 'poly-clinics' are opening all over London.

What does it mean for you?

It **doesn't mean** that you will lose your normal GP. You will still be able to see them, but it's hoped, at more convenient hours for you.

The additional benefits will be, that your GP will be much closer to whole teams of nurses and therapists trained in the management of long term conditions (LTCs), like diabetes, asthma, COPD (chronic obstructive pulmonary disease) etc. So in the past when you were diagnosed with a new condition that your GP was not comfortable managing, the only place to send you, was to hospital, with all the hassle of making appointments and taking time off work that that entailed. Now these teams will be working with your GP in your surgery.

Supporting this care will be a completely new range of test facilities in or near to your

surgery, which will range from blood clinics to x-ray and ultrasound and others. Hopefully reducing the need to join hospital waiting lists for the tests your GP thinks you need.

As things develop over the next three to five years it's planned that more hospital out patients will move into these 'poly-systems' too. This will offer services and treatment much closer to our homes and families.

Clearly we are going to continue to need hospitals to look after us when we need an operation or have an accident or emergency. So work is now going on to work with hospitals so they can help support GPs and patients in these new 'poly-systems' as well reviewing how they can improve their new focused and specialised services in hospitals.

It's maybe that, for various reasons, many of you have never registered with a GP, I don't have time to visit all the reasons as to why that might be or apologise for where primary care may have seemed unattractive to you in the past. I can say though, that your concerns have been heard, and that is why so many improvements are being planned over the next few years. It has never been a better time to register or re-register with a local GP.

They should be offering you more convenient appointments, (more than 60% of GPs in Kensington and Chelsea offer appointments from 7am to 8pm and Saturdays too) and if they don't, then find one that does.

They should be more public friendly with requirements on them to respond to patient satisfaction surveys as well as requiring them to comply with rules on confidentiality and information sharing as well as infection control etc.

The range of services they offer will be increasing with quick access to specialists and investigations.

I hope you agree with me, that we have a unique resource in primary care in the UK, but you will see that in the next few years there is going to see a huge leap forward in the quality and range of care, as well as ease of access.

Dr Andrew Steeden is a GP in Kensington

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Managing Editor

Lucy Osman

Assistant Editor

Anca Nitulescu

Design/Layout

Intertype.co.uk

Print

Stephens & George

Editorial Team

Angelina Namiba, Bex, Carole Sturdy, Cate Jacobs, Janine, Julie, Maggie, Maureen, Mona Silvia Petretti, Susan and Tina.

Cover Photography

Nadia Bettega

Proof Readers

Anca Nitulescu, Angelina Namiba and Izabela Tolowinska.

Subscriptions

subscriptions@positivelywomen.org.uk

Send letters to the editor and unsolicited manuscripts to

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

Or email losman@positivelywomen.org.uk

Please submit articles of no longer than 1400 words, indicate what name you would like to use and supply photos (which can be returned to you). While we respect the individual's point of view, we will not print anything we deem to be discriminatory.

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Good Practice?

After nearly 20 years of living with HIV, I have seen many changes in treatment support and care, but, as far as I am concerned not all of them have been for the better. In the early 1990s we were literally fighting for our lives campaigning for treatments. However, in order for our lives to be improved a two-pronged approach was needed, so whilst we fought there was also a big push to raise awareness and fight stigma and discrimination.

HIV is and always has been more than just a medical issue, it raises fundamental questions of inequality between the genders and regions of the world, and it shone a beacon on the prejudice and discrimination that exists. No other condition has done this in the same way.

The mainstreaming of HIV and AIDS in the UK was meant to be about the process of analysing what the impact of HIV is and to decide how to respond. It was to be about best practice and approaches for expanding, scaling up and implementing responses to HIV and AIDS. If it worked there would not be a need for specialist services because HIV prejudice would be eradicated and everyone would be HIV aware. This would mean those of us living with HIV would be able to use mainstream services without fear of discrimination.

But is it working? Are HIV services no longer relevant and needed? What is the reality for those of us living with HIV? Have our lives improved? Do we get better treatment, support and care and has this approach reduced the stigma and discrimination we faced?

Whilst we are lucky that the medical advancements have brought us treatments, the price paid to off-set this has been lack of investment in social care and awareness and prevention programmes. We used to have a good HIV and sexual health education programmes in the UK. I was involved in some of these in the 1990s. Peer education programmes with young people in school and youth settings, awareness raising and training with everyone from the women's institute to nurses and social workers all with the aim of raising awareness and reducing stigma.

Rather than moving forward developing or even maintaining these programmes, it seems that they have lost momentum. As far as I can see, the UK has gone from being a glowing example of innovative and imaginative HIV and sexual health prevention programming and education, to being behind nearly everyone else in Europe and much of the developing world.

HIV infection presents great difficulties for those of us living with the virus and tough challenges for those providing our care. While many of us may have seen dramatic improvements in health and quality of life since the introduction of HIV treatments, there is improvement in the stigma and discrimination that we experience from the general population and worse still from those in medical and supposedly caring roles.

A couple of months ago I was on a training course about HIV and families run by a local authority. The majority of people on the course were health visitors and some of them were horrifyingly prejudiced and ill informed. One thought that a transmission route for HIV was a bite. I stated that this was not the case, that there had never been any known case of anyone becoming infected through a bite and this was as misinformed as thinking you could get it from a toilet seat. The health visitor said that she knew of a prison warden who had been bitten by someone in prison (as if this somehow increased the risk) and that in cases like this it was always advisable to get a HIV test. To my horror rather than supporting my position one of the trainers (who was a paediatric nurse) went on to say 'yes and people with HIV often have bad teeth and bleeding gums'.

Both the stereotyping shocked me and the unwillingness to correct what was at the very best someone who was misinformed at worst someone filled with prejudice. The same midwife went on to say she thought that anyone with HIV who had unprotected sex should be



prosecuted, adding that people with HIV often go around purposely infecting others. She also said that she did not think that everyone should have access to treatments, that it was unrealistic and too expensive to treat everyone and that there were more deserving causes. For the first time in almost 20 years, I did not feel safe to disclose my HIV status on a training course such was the venom of the health visitor and the lack of support from the trainer.

The psychological aspects of living with a condition that is so stigmatised can be as difficult to deal with as the condition itself. Moreover, this is a sample of the primary health care professionals whom I am supposed to trust to have my best interests at heart. Our needs are not only for medication, but for a range of health and social care services provided by people with compassion and understanding and without prejudice.

Whilst prejudiced attitudes persist HIV cannot be like any other chronic condition, no matter how much the powers that be insist it is. I wish that things were different, but they are not. Most other chronic conditions are not used as insults, you are not seen as deviant if you get them, nor do people insinuate that your rights to a family or sex should be curtailed or even prosecuted as a result. Generally, people are not judged because of the chronic condition as either an innocent victim or a dirty pariah who deserves everything they get.

We are moving into an era where we are being asked to let our GP's take care of most of our health needs, we are told that all unrelated health issues should be dealt with at our GP's. I am one of those people who does this. I always use the GP with health problems that I consider are unrelated to HIV. However, I have on several occasions been sent either to the HIV clinic or to accident and emergency, when the GP has not known what to do. Added to this is that it is not always easy to decipher if something is HIV related or not.

This year I had a large swelling on my leg misdiagnosed as phlebitis by my GP. Having ruled out a deep vein thrombosis, she was insistent that, despite the lack of other symptoms it was phlebitis. I made three visits to the GP she gave me anti-inflammatories and pain killers to be taken over a six week period. I took the anti-inflammatories for two weeks, but didn't take the pain killers as there was no pain.

On my routine visit to my consultant, he diagnosed a lipoma and sent me for a scan to make sure. Lipomas can be caused by the anti-retrovirals and are not serious; however, the GP's lack of knowledge of this is somewhat worrying especially when there is such a vast catalogue of side effects and unusual HIV related

conditions. Would she recognise other more serious symptoms? I live in London, outside the capital a GP's knowledge and experience of dealing with HIV will be even more limited. This is the backdrop against which I have to judge who is best placed to offer me the best treatment, support and care.

‘...the GP's lack of knowledge of this is somewhat worrying especially when there is such a vast catalogue of side effects and unusual HIV related conditions. Would she recognise other more serious symptoms?’

HIV is still relatively new, the long term effects of anti-retrovirals are still unknown, but the development of drug resistance and complications requires increasingly complex drug combinations and treatment monitoring. There is still no vaccine or cure, HIV disease remains potentially fatal and where treatments are available they can be complex and demanding and side-effects are common.

As a lifelong condition, HIV often has a major impact on many aspects of our lives; lifestyle, relationships, work, income, health, well-being and life expectancy. At different times, different issues will raise their snarling heads and take a snap at us. For many of us adjusting to living with HIV is a lifelong process not an event.

The continuing stigma and poor understanding of HIV can increase isolation and fear of disclosure, leading to failure to access appropriate medical and social support services. Over the last decade, there has not been enough government investment in appropriate awareness raising and education programmes, which has means that stigma and discrimination are rife across all sectors of society.

My recent experiences with some health care workers outside the HIV sector (and some within it) suggest that mainstreaming has not worked in terms of improving good practice and HIV awareness.

Julie

Care in the Community

The good news is that HIV therapy works. The bad news is we are all getting older. Ageing leads to an increased risk of disease in every organ of the body, but predominantly cardiovascular disease, bone disease, kidney disease and liver disease. Unfortunately many of the drugs used to treat HIV and potentially the HIV virus itself may lead to an increased risk of these conditions developing.

Whilst for many years, HIV clinics have been happy to deal with all of the problems that an HIV person may encounter, there is increasing pressure for care of non-HIV related conditions to be devolved into the community. One should remember that GPs are probably better trained than the average HIV clinician, in dealing with many of these issues with a wide experience of common complications such as cardiovascular disease,

hypertension and diabetes. It is therefore essential that there is a degree of shared care between general practice and specialist care for individuals living with HIV. This is the normality in other conditions e.g. if you see an orthopaedic surgeon with a bad hip, he will not treat your blood pressure and ear ache, but will refer you to a clinician who is much better trained.

It is also important to realise that although many clinics have prescribed non-HIV drugs to their patients, there is increasing pressure, in the present financial climate, for this to be moved back into primary care, allowing the monies, given for HIV care to be specifically spent on this issue.

However, there are some caveats. For shared care to work it is essential that communication is maintained between the clinic and your GP and vice versa. Patients can ensure that clinicians send a letter when there is any major change in their treatment, and that their GP is up to date with their results. It is not normal for GPs to write to clinicians with any changes that they have instigated, and it is essential that patients keep close records of their treatments when initiated by the GP, so that their HIV clinic is informed.

Secondly, there are many anti-retrovirals with drug interactions with commonly prescribed drugs in primary care. It is common for GPs, for example, to prescribe simvastatin for individuals with high cholesterol, but this drug is specifically contraindicated with many anti-retrovirals. Similarly, drugs such as atazanavir may be affected by acid lowering drugs, which may be given for hyperacidity or peptic ulceration by the GP. So it is essential that GPs dealing with those with HIV are aware of common drug interactions and common conditions which may effect HIV infected people.

There is therefore going to be increasing pressure, and indeed an increasing need, for HIV patients to receive some of their non-HIV care in the community. The biggest problem is going to be effective communication. One way round this is to ask for copies of all clinic letters to be sent to yourself, so you at least make up a file to make sure that all your doctors are informed of exactly what is going on. The idea of HIV clinicians dealing with all problems as someone ages is not going to be possible as this would increase the workload on these physicians, and mean that less of their time is able to be spent on what they do best i.e. the treatment and the augmentation of treatment for HIV..

Mark Nelson

Consultant Physician Chelsea and Westminster Hospital



Attitudes to HIV

As part of my work at Positively Women this year I have been running some HIV awareness trainings for dentists and GPs in the London Boroughs of Hammersmith and Fulham.

The training had been designed following small-scale research we did among people living with HIV in those boroughs. We distributed questionnaires, ran focus groups, and the findings were quite shocking.

Even if 96% of the respondents are registered with a GP, 60% would not tell their GP of their HIV status, and 33% perceive their HIV status prevents them accessing effective care from a GP.

Looking at People Living with HIV accessing dental care, the picture is even gloomier. Only 65% of people living with HIV, who participated in our research, are registered with a dentist. Moreover 55% would not tell their dentist about their HIV status. Overall 53% of our respondents told us that they felt that their HIV status was preventing them accessing dental care.

The HIV positive people involved in responding to the questionnaire and the focus groups suggested that to improve the situation GPs and dentists should receive more training around HIV and stigma.

So I designed a module that could be delivered in about an hour which would go through the basics of HIV awareness and address stigma. GPs and dentists have very busy schedules and I needed to have something that could be delivered during their lunch break.

We offered the free training to most GPs surgeries and dentists in Hammersmith and Fulham. Only four surgeries replied that they were interested in attending despite the fact that we were offering it for free and to be delivered at their premises.

I went on to deliver those few training sessions, and it was one of the most difficult experiences in all the years that I have been an HIV and Sexual Health trainer.

For the first time I found myself addressing a definitely unsympathetic crowd. In spite of my quizzes, a DVD with people talking about living with HIV, case studies, I constantly had the feeling that they were thinking that I couldn't possibly know more than them, as trained medical professionals.

Some dentists felt it was totally justifiable to always book HIV positive patients last, because special sterilising was needed, and they also suggested that it would be better to have a 'special room' to reserve to treat HIV positive people. They seemed unmoved by my questions: What about the fact that a third of those who live with HIV still haven't been tested? What about other blood born viruses such as Hepatitis C which are much more

endemic and contagious? Shouldn't everybody be treated as if they were potentially contagious? What are Universal Precautions recommended by the World Health Organisation for?

Another shock came with a group of GPs. I had a question in my quiz which asked what the probabilities were for HIV positive women who have access to anti-retrovirals and all the interventions to reduce transmission to have a healthy baby. Most of them ticked the box 50%, the reality is it is 99%!

Afterwards they didn't even let me play the DVD where people talked about stigma, and when I asked them if they understood the role that stigma played in stopping people accessing health services they corrected me saying: 'Imagined stigma...'. I felt like shouting: Well I have lived with HIV for 13 years and I can be pretty certain that there is nothing imaginary about the stigma and discrimination many of us experience!

I left the GP training fuming. I kept thinking, if these are the attitudes of well educated health professionals, how much worse can it be among the general population? How much more do we need to speak up, be visible and educate our communities, for ignorance and prejudice to be overcome?

Silvia

To read Silvia's blog visit: hivpolicyspeakup.wordpress.com



Fangs for Nothing

Since my diagnosis almost 20 years ago I have had mostly bad experiences with dentists.

I first disclosed my status to a dentist in the early 1990s. I took my friend to the first appointment and filled in the registration form. When I went in for my check up my friend told me that the receptionist shouted to her colleague: 'Look at this, she's got AIDS'.

Not to be put off by the prejudice I made another appointment, for two fillings – which was duly cancelled by the dentist. I was given another – the last on a Friday afternoon. Again it was cancelled. Ever thick-skinned I just continued to make appointments, only for them to be cancelled the day before. Eventually, I got annoyed and asked them if they were going to treat me or not and to stop messing me about.

Another appointment was made for late on a Friday. The surgery was eerily empty of people waiting to be seen. I sat alone before being shown into the dentist's surgery. Almost everything was covered in cling film. The dentist was in a green gown, hat, mask, visa, gloves and wellington boots; as was the dental nurse. I sang the tune to the twilight zone out loud as they gestured to the chair. I sat in the chair and grinned nervously and said to my faceless companions; 'It's very nice of you to dress up for me, but I don't think all this is completely necessary. I have come for a filling – not open heart surgery'

'It's policy' they told me as was the reason why I had to be the last on a Friday afternoon – so they could make sure there stuff

was sterilised properly. I said that I hoped that the equipment was always sterilised properly and that they didn't just do it on a Friday afternoon. It's policy the dentist said; 'now open wide'.

When they had finished I thanked them and said that a sterile practice was always a good thing. I also told them that I knew of two other people who were living with HIV using the practice. They had not disclosed and thought that it was unlikely that they would want to if it resulted in the same treatment as I had experienced.

When I first moved to London I had a great dentist whom I had been referred to by my consultant. For the first time since diagnosis, it felt like I was getting good treatment, by an understanding dentist who was neither fearful nor prejudiced. This was not to last.

I moved to Scotland and joined a new practice and they seemed happy to have me. Again the dentist said I needed a filling but my teeth were in reasonable order. However, at the second appointment the dentist sat next to me and pointed out that I had ticked that I had HIV, assuming I had done it by mistake. I asked the dentist if it was a problem and he said no, but went on to say that I had extensive gum disease that could not be treated at the practice and that I needed specialist dental treatment in order to save my teeth. I was horrified. Naively I believed him.

The dentist said he would refer me to the dental hospital. I spent three months waiting for the dental hospital



appointment to come through fearing that my teeth were going to fall out. Eventually when I saw the dentist at the hospital, he said that there was no gum disease. I pushed him as to why another dentist would say such a thing and asked directly if in his opinion I was being discriminated against. He would not say. It felt like ranks were being closed.

In recent years, I have had poor treatment and I am not sure if it is just bad luck and bad practice or prejudice and discrimination. In the last three years I have seen five different dentists.

My front crown disintegrated and I was given treatment at the dental hospital. It was a quiet part of the hospital and the dentist had microscopes for glasses. He looked like a mad professor and I did consider that maybe he was a patient from the Maudsley (mental health unit) who just thought he was a dentist. He spent a long time on his work and after an hour and a half, my teeth looked like a badly rendered wall.

I joined a local practice to get the problem solved. The solution to the disintegrated front crown was a bridge. In order to do this they had to file my other front tooth into a peg for the bridge to fit on. I wore numerous temporary crowns on my newly filed peg and an ill-fitting denture. The denture was so uncomfortable that I would have to take it out when I got home and sit toothless a big hole in the front where my tooth had once been.

The bridges that they constructed were far too big for my mouth. The teeth were massive. It was like they had been

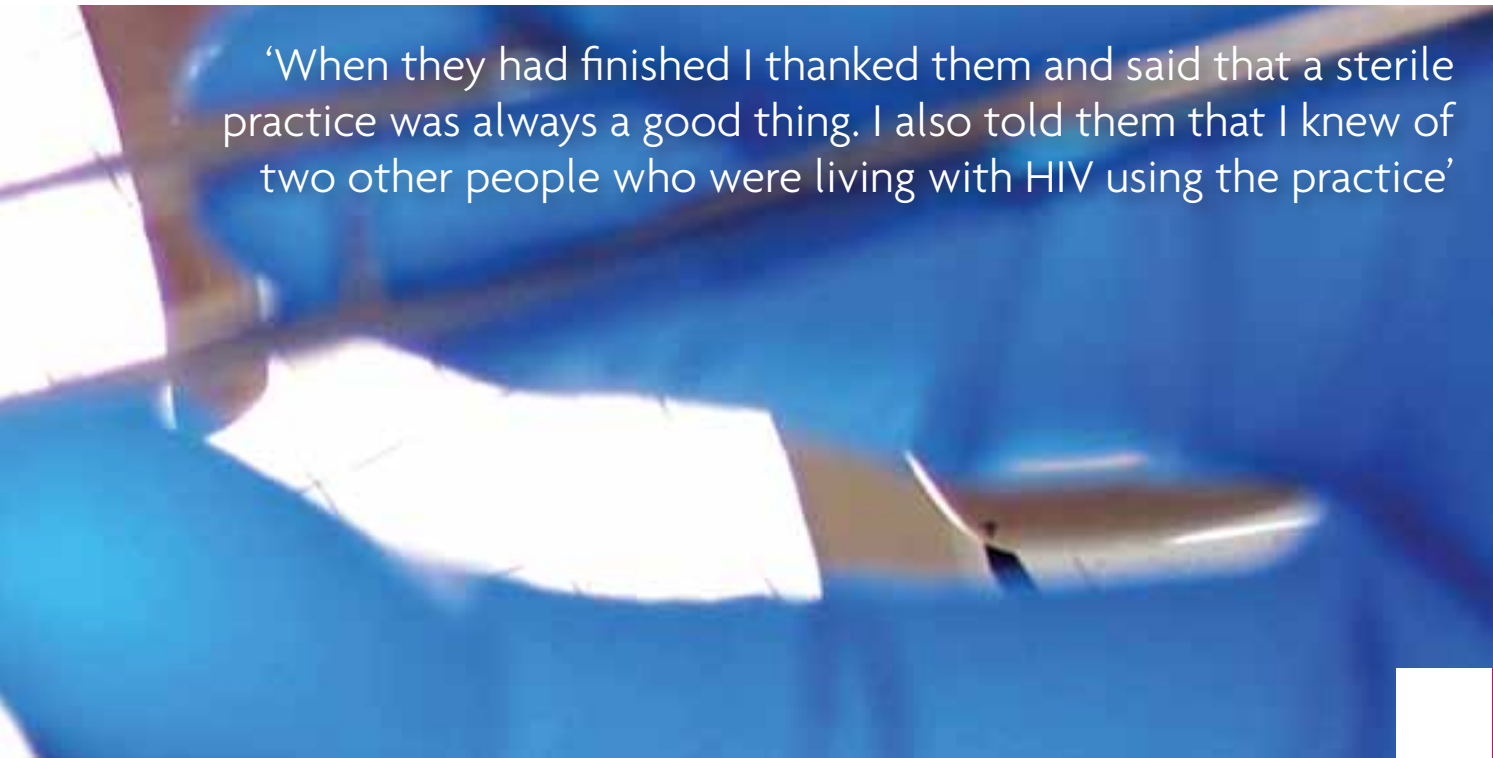
modelled on a mule. I could not close my mouth over them. The dentist filed my tooth down further to try to make the bridge fit. After three attempts with different bridges over a period of months the dentist told me that my mouth was too small and that they could do nothing more.

After all the filing my remaining tooth was a tiny peg and a nasty abscess appeared. The next dentist tried to drain the abscess and spent an almost a year doing root canal treatment on me and still I had a denture. Earlier this year she referred me back to the dental hospital, saying I was a good candidate for a dental implant. The consultant was friendly enough. He asked if I was on any treatment. I told him Atripla. He said he had never heard of it and referred to his Mims. Then said: 'Do you know how much you already cost the NHS? Do you really think more should be spent on you?'

I left feeling angry and somewhat humiliated. Would he have said this to someone having treatment for a heart condition or cancer? No, I don't think so.

I now have a lovely dentist, who resolved most of my problems very quickly. It has been a struggle to get good treatment and it would seem that for every good one, there are at least 10 who have bad practice.

Julie



'When they had finished I thanked them and said that a sterile practice was always a good thing. I also told them that I knew of two other people who were living with HIV using the practice'

Your Health or Your Purse: anti-retroviral therapy and prescription charges

When we are diagnosed with a serious medical condition, such as HIV, we do not necessarily have a script to follow and finding the skills to cope can be a wearily steep learning curve. I suspect I might have been less traumatised should I have been offered pre-test counselling and not been misinformed twice about the availability of my result. Perhaps oddly, to be told that my immune system was failing some months later was more devastating than the original diagnosis of HIV, though judging by the briefness of the telephone conversation with the nurse, whom spent most of the two-minutes discussing his impending trip to France, he clearly viewed the situation a tad differently. Perhaps that is the consequence of having highly effective anti-retroviral therapy these days. A diagnosis of HIV, followed by a falling CD4 percentage might no longer have the symbolism of death that it once did. While the drama of death and dying might have been significantly halted in the UK, HIV continues to claim lives and it reduces longevity. Thus, by default, it is incredibly premature to presume that informing a patient that their immune system is failing is not a hellishly distressing event.

After my diagnosis, I endeavoured to put life back into context. I reminded myself of our distant cousins with HIV in Africa, of the women coerced into the sex-trade in Asia and South America without the added protection of condoms, and of the women and girls routinely raped and infected with HIV by militia in war-torn areas of the world. These women and their children do not have comprehensive access to healthcare or

anti-retroviral therapy. Many will die and they will probably die young. In contrast, we in the UK have the marvellous infrastructure of the NHS – eroded and eaten away by the private sector, but when it works, it is a triumph of social justice. While HIV has slipped dramatically down the political agenda, there nevertheless remains a certain political pride in the belief that British citizens receive continuity in care and treatment once diagnosed with HIV. However, as I discovered first-hand, the reality does not always live up to policy or ideological rhetoric.

Nearly two years elapsed between my contracting HIV and having a CD4 percentage sufficiently compromised to require medication. Many folk would undoubtedly grab the drugs and run, but I questioned whether I would even start treatment; the side effects quite literally terrified me. Although I had the prescription to hand, I could not bring myself to visit the hospital dispensary so like a coward I raided my husband's pills. In a morbid fashion, I counted the days and the hours down to starting a life dependent upon and sustained by medication. Three hours after taking the first tablet, the side effects started in earnest and I was advised to discontinue the regime. My consultant delivered the next cocktail of drugs so once again I was not compelled to visit the dispensary. He reassured that the side effects, would be mild and I had nothing to fear. I popped the next two pills with great trepidation and like clockwork, I was violently ill.



The psychological barriers that I had to starting the third drug regime felt insurmountable. With great reluctance, I circled a weekend to start the new drugs with minimal disruption to work and social life. I quite literally psyched myself up like a rugby player about to receive a hammering. When I handed the assistant my prescription at Lancaster Royal Hospital Dispensary and she uttered with a smile, 'that'll be £7.20 please,' I looked at her askance and reassured her that HIV medication is dispensed free of charge. As I held up the queue, my HIV status was discussed openly in the presence of strangers and my judgement and sincerity were brought into question as though my very own hands were stealing from the Government's coffers. The assistant smiled victoriously as I walked away empty-handed. The humiliating exchange was repeated several days later at Westmorland General Hospital's Dispensary. As I turned to leave, I cast a severe glance over my shoulder to the pharmacists, and uttered 'I'd sooner die than pay for those drugs.'

'As I turned to leave, I cast a severe glance over my shoulder to the pharmacists, and uttered 'I'd sooner die than pay for those drugs'

The Department of Health's statement is definitive, though difficult to find; medication to treat HIV is supplied free of charge through a hospital or a PCT clinic. To double/triple check, I contacted the Terrence Higgins Trust and The George House Trust. Both advisors gave a resounding 'yes' to free prescriptions and suggested the mantle ought to be taken up by my HIV team – my consultant and nurse ought to be advocating on my behalf. Slowly, it dawned on me that NHS Cumbria was also charging others for anti-retroviral therapy. As I dug deeper, I realised that the postcode lottery in healthcare is now embraced as the norm by many clinicians and healthcare practitioners. Perhaps I ought to just shut up and pay. As my nurse stipulated, 'it's only £7.20 for God sake!' Well actually, mate, I need more than one item.

My reluctance to pay did not reflect my frugal side. My indignation was firmly rooted in a belief that the postcode lottery in healthcare is ethically and morally wrong. Why? Because evidence suggests that it causes fundamental inequalities in accessing primary and secondary healthcare, it impinges upon quality of life and it affects mortality rates. Paying £7.20 for a prescription may not sound like much to a comfortable middle-class person, but for someone living in 'relative poverty', i.e. earning the minimum wage, perhaps struggling to raise a family, and living in terrible housing with the concomitant problem of paying a disproportionate share of their earnings towards heating, £7.20 can be impossible to find. Historically, food and nutrition are sacrificed when a bill lands through the letterbox and a prescription charge is just that – it is a bill.

There is, of course, another dimension when the discussion is applied to HIV. There is a fundamental reason why medication used to treat STI are free at the point of supply through a hospital – to reduce transmission rates in the general population. People infected with HIV and adhering to anti-retroviral therapy are less infectious and can dramatically reduce the spread of HIV. Indeed, over the last few years the Swiss, the Germans and the French have all published research into HIV sero-discordant couples and their findings are unequivocal. Those with HIV are not sexually infectious when they adhere to their treatment regime and their viral load has been suppressed below 40 copies/ml for a minimum of six months, and where both partners do not have any other STI. So just what kind of message was Cumbria PCT advocating when they decided HIV patients ought to pay prescription charges for life-saving medication?

A few weeks after I uttered those dogmatic words 'I'd sooner die than pay for those drugs' my health started to decline and I conceded that there was only one thing for it; I kindly asked my husband to visit the dispensary – you honestly didn't think I'd swallow my pride wholeheartedly did you? In the interim, I penned a couple of emails. One to Lord Chris Smith and secondly to my local MP Tim Farron. The latter swiftly challenged Sue Page, Chief Executive at NHS Cumbria, about policy decisions surrounding HIV prescription charges. In the words of Tony Halsall, Chief Executive of NHS Cumbria on 21 August 2009,

'...The Trust reviewed its policy around prescription charges for HIV patients in August 2009 as the current guidance is not clear. The Trust has changed its policy and will now waive charges for HIV drugs...'

'The Trust has changed its policy and will now waive charges for HIV drugs'

I, however, do not accept the statement from Cumbria PCT. It was terse and blatantly unapologetic. Nor do I believe their stated reason 'current guidance is not clear' constitutes a credible argument. Deliberate rationing of resources is a more plausible explanation. The systemic rationing of resources might be unavoidable in a system with competing needs. But the ideology of rationing is premised upon winners and losers and in this instance HIV patients lost out. I feel that Cumbria PCT saw a socially isolated and vulnerable group of patients – a group of patients who would not kick up a fuss because kicking up a fuss means being named; it means being singled out and above all else it means being identified as a person who is infected with a sexually transmitted infection, which is shrouded in fear and stigma.

C.Mc
clairemcqclaire@yahoo.co.uk

Know the Drill:

A dentist's view

Many people living with HIV are quite health conscious with a very positive attitude to their overall health. Hopefully this also extends to their oral health as research is indicating that poor oral health may be associated with important medical conditions such as diabetes and heart disease. Some recent studies have also shown that pregnant women with advanced gum disease are more likely to give birth prematurely.

HIV infection can have an impact on the mouth and although HAART (highly active anti-retroviral therapy) tends to reduce the severity of these, but problems may still arise and good mouth care is therefore important.

Common problems associated with HIV include dry mouth, gum disease (bleeding gums) thrush and sometimes mouth ulcers.

Regular effective tooth brushing, twice a day, and the use of dental floss to clean between the teeth once a day will do much to improve oral health by preventing gum disease and generally making the mouth feel and smell nicer.

Another factor which has a tremendous impact on oral health is tobacco. Smoking tobacco can cause and also aggravate any existing gum disease – encouraging it to progress more quickly than in a non-smoker. More importantly tobacco is one of the two most important risk factors for mouth cancer – the other being alcohol. All forms of tobacco – including chewing tobacco are linked to mouth cancer, as is chewing betel leaves or areca nuts.

Stopping smoking is thus one of the most beneficial steps you can take towards improving oral health and reducing your risk

factors for mouth cancer – as well as lung cancer, lung disease and heart disease.

Visiting the dentist regularly allows the dentist to monitor your mouth for signs of decay, gum disease and other oral problems and keep the amount of treatment needed to the minimum.

Most people with HIV are relatively fit and well and should be able to receive their regular routine dental care from their local general dental practitioner. The General Dental Council (the dentists governing body in the UK) recommends that most people with HIV should be treated in general dental practices.

Although in the past there were sometimes problems finding a dentist prepared to accept someone with HIV, most dentists today are pretty well informed about the condition and are happy to provide ongoing routine dental care for people with HIV.

If there is a complicated underlying medical condition then the dentist may refer someone to a dental hospital or specialist for a second opinion or as part of their treatment. For some people with associated bleeding disorders their HIV consultant may refer them directly to hospital for specialist dental care.

Confidentiality concerns can also be a problem when registering with a dentist, for example when asked to fill-out a medical history questionnaire in the waiting room and then hand it to the 'receptionist' at the desk.

If concerned, you can always fill out most of the questionnaire and wait until you actually go into the dental surgery before discussing your HIV status and medications with the dentist directly. Most dentists will understand this approach, as we are well aware of the delicate nature of such personal information and appreciate the fact that you trust us enough to share it.

Knowing your HIV status and medications is important for two reasons.

Firstly, it allows the dentist to monitor your mouth more closely for any HIV associated conditions.

Secondly, it helps to avoid any interactions between your medications and the local anaesthetics or other drugs the dentist may use or prescribe.

Finally, choosing a dentist is a very personal thing. The relationship between patient and dentist should be one based on good professional care and mutual trust and respect.

Tony Burcombe



“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...”

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10 Things About GPs:

Information for people with HIV

- 1** Effective treatment can mean that people with HIV can live a long, healthy life. Even though you receive your HIV care from a specialist HIV clinic, it is still important to have a general practitioner (GP) or family doctor for health needs that aren't related to HIV.

Your HIV clinic and your GP can work together to ensure you get the best possible care. Your GP will leave HIV treatment decisions to your HIV doctor, and your HIV clinic can discuss (with your permission) other aspects of your health with your GP.

- 2** Don't wait until you're ill to look for a GP. You will need to register with a GP to have access to their services. Most HIV clinics keep a list of GPs, and may be able to recommend a GP with experience of caring for people with HIV.

Or you can go to the **NHS services directory** website (at www.nhs.uk) or contact NHS Direct on 0845 4647 for details of GP practices in your area.

If you have problems finding a GP who is able to register you, then contact your local **Patient Advice and Liaison Service** (PALS; you can find out more at www.pals.nhs.uk).

GPs cannot refuse to register you because you have HIV or any other medical condition, or because of your race, colour or sexuality.

- 3** If you have children or you're looking after other family members, it's important they are registered with a GP as well (children under 16 must be registered by their parent or guardian). You will probably want to register them with the same GP or in the same practice. If you're registering a new baby, you'll need to fill in the registration card you receive from the registrar when you register your baby's birth, and take it to your doctor's surgery.

Some mothers may not have had an HIV diagnosis when they are pregnant and give birth to a child without realising there is a risk that HIV may have been passed on. It is therefore very important to have children tested for HIV if you then discover you are HIV positive. Do not be afraid of telling your HIV service that you would like your children to be tested. HIV services will offer the same confidential service to children being tested for HIV as they do to adults and will offer you support regardless of the test result.

Some doctors will give advice over the phone – you can ask the receptionist for a good time to call. And some GPs





will see small babies at the beginning of surgery hours or without an appointment, but you will need to be prepared to wait.

Most GPs provide developmental reviews and immunisation for children. Some GP practices specialise in child health. You can find out where these are at www.nhs.uk.

4 GP care is free.

If you are not a UK citizen, you may still be able to get free treatment from a GP. You are entitled to care if you are seeking asylum (find out more at www.ukba.homeoffice.gov.uk) or if your country has a reciprocal healthcare arrangement with the UK. You can see a full list of countries where an agreement like this exists on NAM's website for people living with HIV, at www.namlife.org – go to the section on travel in 'The facts'.

Also, some GPs may be willing to treat people with immigration problems. You can get help with registering with a GP from your HIV clinic or from the **Refugee Council**. You can contact one of the Refugee Council's advice lines (find out more at www.refugeecouncil.org.uk).

The **Department of Health** has produced a leaflet about the NHS and the care GPs offer for people new to the UK; you can find copies in English and in other languages at www.dh.gov.uk.

5 Telling your GP that you are HIV positive will help them have a full picture of your health to ensure you get the best possible care. For example, they will be able to take HIV into account in assessing any symptoms you have. And, if you are taking HIV drugs, they will consider potential interactions with any other medications.

6 Regular health monitoring is important in helping you stay well when you are HIV positive. GPs have lots of experience of helping people manage long term conditions. Leading a healthy lifestyle is an important way of staying well with HIV. Your GP can help you with things such as: eating well and losing weight, doing exercise, stopping smoking and cutting down on alcohol and drugs. More information on all these aspects of looking after your health can be found on www.namlife.org.

7 Your GP can help with all sorts of services you may need that may not be available at your HIV clinic. They can treat

conditions and prescribe drugs that your clinic might not, such as high blood pressure or cholesterol medication or anti-depressants, and provide other medical care such as flu vaccines – including the new swine flu vaccine. (You can find more information on HIV and swine flu at www.aidsmap.com/swineflu.)

8 Your GP surgery may be more convenient than your clinic – closer to home, or open longer hours. GP surgeries have emergency services if you need to see a doctor during the night or at a weekend, and they can arrange for you to go to hospital if that is what you need. GPs can do home visits if you are too ill to come to a clinic or surgery.

9 Your GP medical records are confidential, and nobody can see them without your consent (including insurance companies – you will need to sign a consent form for your doctor to provide information on your health to an insurer. You can find more information on this in the Preventing HIV section of aidsmap.com).

If you are concerned about disclosing your status to a GP, you can discuss the pros and cons with staff at your HIV treatment centre, or an organisation that provides advice, support and advocacy to people with HIV. The section on 'Finding information and support' on www.namlife.org is a good place to start in getting this help.

10 If you are not happy with the way your GP has treated you, it is a good idea to follow this up. You can do this directly with them, but if you don't feel comfortable doing this, you can ask for help from the **NHS** (see www.nhs.uk) or from an organisation that provides advice, support and advocacy to people with HIV.

You can also change GPs. You do not need to tell your current GP that you are leaving or the reason for it if you don't want to. And you don't have to tell your new GP why you are changing. There is information on how to go about changing your GP on the **NHS Choices** website at www.nhs.uk.

There are plenty of places where you can get more information, advice and support on health care and HIV. You can ask at your HIV clinic, at organisations like Positively Women and other information and support agencies, contact THT Direct on **0845 12 21 200** or go to www.namlife.org.

Are You Getting the Right Kind of Service?

Key to managing a HIV diagnosis and status is accessing health services, where you feel supported and have confidence in their ability to meet your health needs and concerns. For me that place is the Ian Charleston Centre at the Royal Free Hospital. I know the staff and my consultant well and he has a detailed knowledge of the major issues in my life. This goes beyond purely medical concerns, like what operations I've been through. Importantly to me, they ask after my children, pregnancies they helped nurture. They ask how I am feeling about my life, what the stresses are and there is an awareness that the answer will impact on my HIV profile. My consultant will regularly go through the significance of my blood results, feedback on my liver, cholesterol. Together

we'd discuss and decide on any medical action plan I might need to take. I mostly appreciate that there is always time – to discuss – to provide that sense of personal care. This has a knock on affect on waiting times; I allocate four or five hours when I go (inclusive of travelling). Any inconvenience to me is more than offset by the confidence I have that my health is well monitored by a comprehensive service. However my appointments are now set at once every six months, invariably there are other common medical issues that crop up in between times such as sprains, eye infections that require medical attention from a local service, my GP.

My relationship with my GP feels much more superficial in comparison. I will only attend there if I'm sure the issue is minor, fairly straight forward in how it processes and not related to my fundamental health. There is a lack of confidence on my part that they have the knowledge or expertise to look after my health relative to HIV. This was illustrated for me when, recently I needed to get a morning after pill, it actually proved quicker to access my HIV clinic than to get an appointment with my GP. At the clinic they supplied me with double dosage because my combination therapy affects its efficacy. I was immediately struck by the fact I had no confidence that the GP would have been aware of the necessity of this measure.

There has always been a communication problem between myself and my GP, concerning my HIV status. When I originally disclosed to him, he remarked: 'How does someone like you, get something like that?' My reply, whilst quite taken aback was: 'How do you think?' Subsequently we almost never talk about that aspect of my health. It is something I'm sure he's uncomfortable with; recently I requested paperwork from him to support an application for concessionary access to a gym, there was that astonishment again that I was prepared to put my status in writing to fulfill the concessionary criterion. The inference I get from him is that it is something I should keep quiet, hide. I haven't really confronted this situation head on. I view it as his shortcoming as a professional, however such displays of ignorance do have worrying implications for newly diagnosed and more vulnerable patients and suggest GPs in general may need a lot more information and training around the support needs of HIV positive people.

In accessing dental care, I have experienced similar issues of confidence in local healthcare services as opposed to the specialist dental health service I used to attend at the Royal



London Hospital. There, quality of care and a professional attitude towards your status was automatic. Approximately eight years ago they disbanded the service on the basis that there was no reason why we could not be treated in our local communities. My local dentist was happy to treat me but I was soon made to realise that my appointments for treatment would always be at the end of the day, at which time the equipment can be thoroughly sterilised after use. I accepted this in part – not really acknowledging the resentment of being treated as a second class patient. Not to mention the illogicality of the thinking around the extra hygiene precautions I generated.

The upshot of this lack of confidence in my right to equal treatment was that I didn't return for two years. A new dentist had taken over the practice in the interim. Yet again I was offered an end of the day appointment, initially I accepted, then decided to confront this low expectation and ask for an early appointment that better suits my timetable. To my surprise, they agreed. I kept waiting for the phone call to re-schedule, when they'd realise their supposed predicament; 'knowingly treating someone with HIV in the flow of other patients'. However my appointment passed on cue, with friendly concern and the whirl of a drill.

'The upshot of this lack of confidence in my right to equal treatment was that I didn't return for two years. A new dentist had taken over the practice in the interim. Yet again I was offered an end of the day appointment...'

I guess the point is over time, there is probably at least possibly a greater understanding and practice of qualitative care of HIV patients amongst local community health professionals. A decade ago there were more HIV specific clinics and services available to support affected people. The undoubted benefit of which is the patients confidence that that the clinician was happy and able to treat you.

Some of the services that have been lost have been of great value and irreplaceable in their acuteness of purpose and response to need. The Mildmay Hospital which still survives as a fraction of its former self, used to provide a family service, where positive mothers and their children could access early years childcare from staff specifically trained to deal with this issue.

To be able to openly talk about the health and, development of your child and the realities of your family life and routine did so much to alleviate often acute problems and stress in the lives of those concerned. The trust that your child would be loved and supported, without discrimination, was implicit in the open sharing of information.

If mothers were ill or had recently delivered, often by caesarean, they could receive assistance and respite with a stay on the family ward. On my last visit there about eight years ago, that had changed to an adult, mixed gender ward, which was fairly traumatising, to have men with all manner of illness in the immediate company of new born babies and young children. I knew I would never go back. It no longer felt like respite.

I cannot imagine how I would have got through the demands of my children's early years without the support of the Mildmay nursery. It now serves as a local community nursery, many of the same staff still work there, which seems to me something of a waste of a highly specialist resource. In Hackney, social service provision, in regard to HIV has been dismantled to the point of non-existence. If I had respite needs now my only hope would be to access the advice of the Clinical Nurse Specialist.

Accessing services, gaining support for your needs is very much about navigating your way through an, at times an ad hoc system, one in the process of transition from specialisation towards general care, which HIV now viewed as a manageable, chronic condition, is supposed to fit into. The advice from peer support groups like Positively Women can be invaluable, certainly time saving in understanding your entitlement and accessing the services applicable to your needs.

Changes in how healthcare provision is delivered, over time seems inevitable. However it would be remiss to not carry forward into the local health services the lessons and best standards of practice as exemplified in HIV clinics such as the Ian Charleston Centre and the Mildmay nursery.

These services are characterised by space and time being made available for discussion between client and practitioner. Moreover there is an openness to the communication in addressing the manifold expression of HIV in people's lives. An excellent delivery of service majorly relies on creating an aura of confidence that the condition and its associated problems are manageable and treatable and that service providers are able and willing to achieve this.

A greater change I would like to see is: For it to be possible and considered normal to consult health professionals not only when there is a problem but address them in preventative terms, how to maximise one's health, prevent any worsening of condition, enhance one's health – this implies a broad understanding of related health concerns in HIV sector like mental and emotional well-being, dietary and nutritional needs. Then we would have made a quantum leap in our services; I believe gearing us more towards the potential of our health rather than the illness in our life.

Janine

Smear Campaign

You may all be wondering what it is I am talking about but let's be honest, am I the only woman who raises this question when you get a reminder from the GP or your consultant for that routine smear test? And I am sure I am not the only one who puts it off again and again and again... It is not only an invasive procedure but can also sometimes be uncomfortable, so I am with the rest of the ladies on this one.

What with all this talk about patients now being encouraged to access GP services more often, I thought perhaps I could talk about my latest experience around my recent cervical smear test prompting me to think about where the best place to get them done would be. I know some of us may feel a little more comfortable about having them done at the same time and in the same space where we have our clinic appointments – I know I did for a long time. I can see why it is more convenient having everything attended to at the same time and by the same person – a person who is aware of my HIV positive status but until more recently I hadn't thought quite so seriously about having the smear test done at my GP's.

My GP is aware of my status and in lots of ways, it makes it a whole lot easier with everything else. However, the one thing that I did get away with was getting my smear test done at the hospital in conjunction with my clinic appointment. Whenever the GP asked whether I would like to have my smear test done, my response would be something along the lines of, 'Already had it done at the hospital'. The next question would inadvertently be to ask me to get the results sent to them so that they have a record of result. I have lost count of the number of times I have made this request but it had never been fulfilled. Much as I adore my clinic I have to say the admin side of things moves at a snail's pace – but hey can you blame them with so much else to do?

So as I mentioned before I started thinking more seriously about having my smear test at the GP rather than the clinic and as if the GP read my mind the last time I went to see him asked if I would like to have it done there and then. Now you ladies know that one has to go 'prepared', you know? Wear the appropriate underwear and ensure 'down there' has recently had its monthly grooming (and I mean that literally!) Of course, I said NO! with a somewhat horrified look on my face, but my GP was quick to suggest that perhaps I could come back the next day which after having gone through with it I was glad I agreed. I turned up the following day having made an appointment with the nurse, fully-groomed of course, without my Bridget Jones underwear and it literally took five minutes, and was the most painless smear test I had ever had. I was in and out of there quicker than you could say 'put your knickers back on'. That experience changed my mind about going to my GP practice for my smear test. For one thing it is nearer and I know I will always have someone to remind me and it was quick and a lot more comfortable than any of the other smear tests I have had. The results were sent to me promptly and to top it all off the nurse was very nice.

Bex



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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.**



Antenatal Care

Good antenatal care is important for any woman expecting a baby. For women with HIV, it is essential, in order to maximise the chances of preventing mother-to-child transmission. Especially for women who have been diagnosed during pregnancy, there may be a 'complex mix of emotional, psychosocial, relationship, economic and even legal issues that arise directly out of the HIV diagnosis'.

Recently diagnosed women may only have a short time to build a relationship of trust with the healthcare team, and to gather information to make informed choices. The The British HIV Association (BHIVA)/Children's HIV Association (CHIVA) guidelines emphasise that prevention of MTCT can only be achieved if the woman 'embraces the medical interventions appropriately', and recognise that social and other factors can prevent her from doing so. They recommend a very early assessment of every woman's circumstances, and identification and careful follow-up with patients who refuse medical advice or care, or who fail to attend further outpatient appointments.

The multidisciplinary antenatal team may include counsellors, psychologists, social workers, community midwives, patient advocates and others, as well as an HIV clinician, obstetrician, specialist midwife and paediatrician.

In addition to the HIV positive women's medical care, support and advice should be offered in antenatal clinics on issues such as:

- Welfare – for example, housing, finances, drug use.
- Immigration – including eligibility for NHS treatment.
- Sero-discordance – advice for newly diagnosed women whose partners are HIV negative on avoiding onward transmission.
- Advice on feeding their baby.
- Adherence to treatment during pregnancy and after the birth.



Women usually receive significant individualised support during their pregnancy, but this tends to concentrate on HIV-related issues and there may be an expectation that some of the more basic antenatal preparation will be delivered by generic antenatal services. This may not always be appropriate or welcome – for example, these services will not cover disclosure of HIV status, and the discussion of mode of delivery will not take the HIV positive woman's situation into account. Generic classes usually include strong promotion of breastfeeding and discourage the taking of medication during pregnancy; this can directly contradict the advice a woman with HIV is receiving and potentially cause feelings of awkwardness or confusion.

Sexual health screening

The presence of a genital infection can – because it can result in the increase of HIV replication and therefore a higher viral load in genital secretions, and/or cause ulceration or inflammation – significantly increase the risk of mother-to-child transmission of HIV. BHIVA/CHIVA guidelines suggest it is prudent to screen all pregnant HIV positive women, as early in the pregnancy as possible, for genital infections, and to repeat the screening at 28 weeks of pregnancy.

The successful treatment of any genital infection is particularly important if the woman is planning to have a vaginal delivery.

Amniocentesis

Amniocentesis should not be carried out before the woman's HIV status has been established.

The BHIVA/CHIVA guidelines recommend that healthcare staff discuss testing for Down's syndrome with all women during the first three months of pregnancy. Ideally, this should be done using the most specific and non-invasive tests: nuchal translucency (looking at the fluid space at the back of a baby's neck) with serum screening (a test on the mother's blood), with appropriate counselling. This should reduce the need for more invasive procedures.

The guidelines suggest that women considering invasive genetic screening should be given counselling at a specialist foetal medicine unit.

Earlier studies suggested that there was a higher incidence of HIV mother-to-child transmission if an amniocentesis (where a fine needle is inserted through the mother's abdomen and into the fluid surrounding the foetus) was carried out, and that efforts should be made to avoid this procedure if possible.

Pregnant and Living with HIV?

Please don't worry!

Turn on the TV at the moment and you'll face a barrage of lurid tales about the state of the NHS. Well, I'd like to buck that trend and state that my experience of care at an NHS hospital was fantastic. Chelsea and Westminster Hospital offer outstanding antenatal care for women living with HIV.

Thankfully we've moved on a great deal from the dark days when some women living with HIV were encouraged to terminate their pregnancies. It's now recognised that the risk of transmitting HIV from mother to baby is less than 1% if the mother has an undetectable viral load. I was aware of this when I discovered I was pregnant with my second child post HIV, but still had some concerns. During my previous pregnancy I had developed resistance to some of my medication and was worried that this could happen again. My HIV care was transferred to a doctor who specialised in pregnancy and HIV, who listened to and acted upon my concerns. We decided to alter my combination and I was offered tests to assess the level of medication in my blood.

I was assigned someone who co-ordinated all of my appointments, met me when I arrived and always made time to discuss any of my worries. I felt extremely well taken care of and was treated with respect at all times. Most of my antenatal appointments were routine as I stayed in good health through most of my pregnancy. All of the scans showed my baby's development was fine and I was delighted to discover I was having a girl after four boys!

I started to have a few problems towards the end of my pregnancy, but I think this was less to do with the fact I was HIV positive and more to do with being close to forty. I frequently became quite

faint and had to deal with the indignity of collapsing in public places, including the waiting room of the antenatal clinic. Again this was fully investigated. Issues with my heart were ruled out and I was found simply to be very anaemic, easily rectified with iron tablets. As with my earlier pregnancy I had some problems with my pelvis and was quickly referred to see a physiotherapist.

I was given the choice of how I wanted the baby to be delivered. I was aware that as I had an undetectable viral load, there was still very little risk of transmitting HIV through a vaginal delivery. However as I'd had a c-section in my previous pregnancy I felt that this would be the safest option. I was given a date for a caesarean and assumed all would go to plan. My baby however had other ideas.

A week before I was scheduled to have a caesarean I went into labour. My husband managed to drive from Croydon to Chelsea, despite the rush hour traffic, in record speed. I was met at the hospital by members of the HIV team who ensured everything went according to plan. Despite experiencing very little pain I was discovered to be in established labour and was quickly taken in to theatre accompanied by my angst-ridden squeamish husband. Half an hour later my beautiful perfect daughter was born. Eighteen months later she's a healthy, albeit exhausting active toddler.

If you're pregnant and living with HIV please don't worry. The antenatal care I was given was outstanding. Thank you Chelsea and Westminster Hospital.

Jennifer



The Real Treatment

I had had a persistent cough and complained about it to my long term HIV specialist. She was always too busy or preoccupied with something else to look after her patients and in spite of my complaints, she did nothing; I don't know whether she ever felt any kind of responsibility for how my health deteriorated in the following months. I had major health problems: there was something wrong with my lungs (eventually I began to cough up blood) and I was really starting to lose hope of ever being healthy again. In Romania, all the doctors I went to were very unprofessional or turned away from me after I revealed my HIV status.

Closed doors for HIV patients

When I first arrived at the Chest Hospital in Bucharest, I was very hopeful and confident, as I was going to be evaluated by one of the best lung specialists in the whole country. Unfortunately, my enthusiasm quickly waned: after a very short evaluation, I was diagnosed with chronic pneumonia and prescribed antibiotics. I was doubtful that this was the right diagnosis and I was proved right.

I was surprised that they hadn't suggested I come back for a follow-up. Since I did not agree with this doctor's diagnosis, I booked myself a second appointment. This time, the appointment was even shorter than the first one and it made me extremely upset. I was invited to enter his office, and he seemed to be in the middle of a very important matter: he was exchanging text messages with someone and was paying very limited attention to what I was saying. His typing on his mobile distracted me even more than it seemed to bother him. Then he wrote a prescription, while in the middle of a phone call. As I sat in his office, I noticed his impressive collection of diplomas and certificates and was even more disgusted with his treatment of me. I had questions that I was going to ask, but was so upset at his unprofessional behaviour that I couldn't remember any of them, except the big one: Why did I continue to cough up blood, even after completing the treatment he

prescribed? His answer was that I had some complications (as if it wasn't obvious) and if the new medications weren't working I might need to go into surgery. But there was 'one little problem': my HIV status. As he put it, there were very few surgeons interested in a case like me, an HIV positive patient.

Ignorance and unprofessionalism

I wasn't ready to give up; I was in desperate need of help! There was only one thoracic surgeon whom I heard was treating HIV positive patients like me, so I went to see him.

He started his action plan by admitting me to hospital and doing a series of tests. But before any results came back from the laboratory, he jumped into a 'blind treatment' strategy: administering and switching intravenous antibiotics every week or two, without having a clue about what sort of infection I had. (I only later realised that this was his plan.) Whenever I saw him he was always very busy. As a result, I asked questions but received very little information in response. The medical investigations included a lung function test, which was supposed to be performed at another clinic, but because of my HIV status, the clinic refused to do it. Ironically, the hospital nurses did not even wear gloves to protect themselves while taking my blood.

It's not just HIV patients that are of little concern to hospital personnel. I was sharing a room with a disabled old woman and she too was virtually ignored by hospital staff. Hygiene was also in limited supply: when it was bedpan time, the room would literally smell like a public toilet. I don't remember the room being cleaned regularly, but I do remember the caretakers coming around at midnight to mop the floors, and the smell of chlorine kept me up all night. Summers in Bucharest are extremely hot. Most of the time the room was a real sauna as the air conditioning system did not work. On top of all that, everyone was having a hard time taking a shower, since there was only one shower room out in the hallway and usually it





A possibility of change

At my request, I was finally out of the hospital and a week later I took a risk by leaving the country for a long expected trip with my ex-boyfriend. My health was slowly improving, although my cough never went away. It's ironic that I would get better once I was no longer getting treated but I think getting away from the treatment in Romania was the beginning of getting the help that I needed.

On my visit to England, I experienced another haemoptysis episode. Luckily, I was staying near an East London hospital that had an HIV clinic that was willing to treat me. In no time, I was sent to a hospital specialising in lung diseases, where I was admitted at the end of summer 2008. This was my first time as an in-patient in a British hospital and the whole system was new to me. I remember how nervous I was initially because I didn't know what to expect. The first thing that got my attention though was how clean everything was. I was thinking with some sadness about the hospitals back home and everything that I'd been through there.

On my first day in the London hospital, I talked to and was visited by so many people it was hard to remember their names. Doctors, nurses, medical students, they all had one thing in common, that positive optimistic attitude that gives you confidence, and this I wasn't used to. I spent the first couple of hours thinking about this and it was quite a shock to me. I was wondering if that was the way they were actually treating everyone else, or if I was somehow special. That was very silly of me to think that, I realised later. I also looked silly when I didn't realise that I could choose my daily menu and that I could have whatever food I wanted. I must have had a very surprised look on my face when the janitors offered me basic toiletries and clean sheets every morning. When I mentioned that I was HIV positive, the medical staff still acted and treated me just as they had before, rather than as a freak.

In addition to my medical care, I was getting professional counselling, emotional support and advice from a community nurse. Being in a supportive environment, I was able to ask my questions and receive the right explanations. The medical tests done in London showed no sign of TB or Chronic Pneumonia, and the right treatment for me was not antibiotics. Once it was confirmed that I had a fungal infection, I started the new treatment and began to feel better.

Spending weeks in hospital can be quite frustrating, especially after my previous experience. Even though at some points I was bored to death, that is the only thing I can complain about; I don't regret spending a moment there because it was all worth it. Now I am able to receive medical care in London, and it looks like I'm finally getting my health back.

Anca

was locked. When I finally was able to shower one evening, a cleaner yelled at me wanting to know the reason I did that.

Nursing care was also dreadful. The nurses did not give medication at the correct time, so the patients would have to remind them about it. When my mum had an argument with them because they missed my dose, one of the team doctors threatened me and said I would 'have problems'. I had never thought about what he meant by that, maybe it meant they would kick me out of the hospital or refuse to operate on me.

I spent three weeks in that hospital, I was on the verge of a major depression. My only salvation and distractions from the nightmare I was living in were my mother's visits and my friends' phone calls.

Hospitals are for healing. Unfortunately, by the end of my stay there, I felt even sicker. I was exhausted both physically and mentally. The doctor decided I would have to be transferred to the infectious diseases hospital, which was supposed to have a new medication. I asked why they haven't sent me there in the first place but that was another question without an answer.

At the HIV clinic in that hospital (the same one where I've been going for years), I spent two weeks with a bad rash on my body, high fever, and other symptoms that led to different interpretations. They did a number of new tests, including ones for Tuberculosis and Rubella. As the test results all came back negative, there was more even confusion. My CD4 cell counts were dramatically low and I was terrified that my immune system would not be able to fight off any other infection. It turned out that I was having an allergic reaction to the treatment I had been given.

Sadly, my treatment as an HIV positive person was not unique: I had seen an HIV positive person dying and how she was being treated was horrendous.

28 Poverty Street
Do You Care?
I Still Need Help
PC775522J
UK

To
Social Services
Somewhere in Glasgow
(I think)

Dear Sirs,

RE: WHAT EXACTLY IS YOUR REMIT?

A few years ago I found myself in the unfortunate position of needing your help. It has been a continuous battle from start to finish. When I first applied for income support I was just coming out of hospital. I had spent most of that summer in and out of hospital and in my bed at home. I had lost half of my body weight and was unable to walk without assistance. The staff at my local Jobcentre Plus were very understanding and helped me to fill in my forms. (Whatever you are paying them it's not enough!) We also spoke to someone at your head office and checked to see that we had all the right documents. It took over a month to receive an answer from you and guess what? I was given income support for one week and told that I did not have the right to appeal or to have it backdated to the time that I started needing it because according to your rules I should have applied as soon as I became ill (from my sickbed).

We called you again and were told to re-apply. We did. I also sent a letter to your head office and I was advised to appeal. I went to a Tribunal. I won, but your head office sent me a letter and said they would not pay. Eventually I received the money.

Now I feel I must point out to you that I suffer from a long term health condition and I need help. From what I had been told I was legally entitled to help from social services. But during the three or four months I was in and out of hospital I had one visit from a Social Services somebody (it may have been a social worker) which lasted all of ten minutes. She gave me a list of telephone numbers which I was supposed to call. I was in a hospital bed, unable to walk, and receiving all my medication and nutrition through various drips. I had no money. In addition to all of this I was for the most part incoherent and unconscious yet, somehow, I was expected to find a telephone and make my own arrangements. I even had to fill in my own housing forms when I left hospital and felt well enough to walk to the housing office. Until then I had to make do with various friends' couches although I soon overstayed my welcome. No one wants to take responsibility for a dying person. Not even your 'best' friend.

I have rarely received any good news from you; 96% of your letters are bad news. Now when I receive any mail from you I feel ill. It takes me weeks to open any mail that I receive from you. It is always highly invasive, threatening or demanding the most intimate details of my life; information which I am usually reluctant to share with you. You ask for everything but the colour of my underwear. Then once you have all the information you require you proceed to tell me all the things I cannot have. Just once I would like you to give me some good news. Am I asking for the impossible?

Yours sincerely

Reluctant Service User

Reluctant Service User

P.S. One of my friends turned out to be a real friend and found me a job. I hope I never need your help again but given my circumstances I am pretty sure I will probably be back. I hope it never happens or I die first.

Then and Now:

HIV social care services

In the early years of HIV, the 80s and up to late 90s people testing positive for HIV were told to expect an early death, roughly within five years. There were no medications and true, people did die, but before they did they were guaranteed support services to make their last days as comfortable as possible. Employed people left their jobs to await their fate, some sold their possessions, and others ran up debts getting things they had always wanted, but couldn't afford; now they could because they wouldn't be around to pay for it.

Activists, health authorities, and social services soon realised that support was urgently needed. The good old days of support services was born. HIV positive people became entitled to extra welfare benefits such as Disability Living Allowance and other Income support benefits that came with being disabled. Specialist agencies were funded to provide emotional support, information, counselling and advocacy.

Long term diagnosed will sometimes talk about the 'good old days' of HIV services because their social care needs were being met in one way or another. Home care, specialist housing, respite care, in London women who had caesarean sections could have a two week stay in the Mildmay Family Centre, while older children were cared for in the nursery. Children had priority for nursery places if one of the parents were positive. Social services were proactive in helping families to plan for future care of children and respite for children so parents could have a rest.

Some local authorities social services department had HIV awareness training programme for its employees some had specialist social workers, some had specialist units (such as iCARE in Islington), or voluntary sector HIV organisations were commissioned to provide support.

So, what has changed? Treatment. Hugely expensive, anti-retroviral combination treatments. More funds going into providing treatment less on social care. HIV is now under the generic umbrella of manageable long term chronic conditions and has to compete for its place in the social care arena. One thing that has been ignored is that unlike other long term chronic conditions HIV has and still carries huge amount of stigma, isolation, short and long term mental health difficulties, and even prosecution for transmission. The medicines although effective carry its own side effects that can be life limiting (socially), psychologically impacting.

If you are HIV positive you may argue that your social care needs have been forgotten, are being ignored or not being understood by health and social services. Voluntary sector support services are rapidly disappearing as accessible funds dry up and organisations close.

What is needed now is a reassessment of social care needs, not the ones that you hear or read about but didn't get the opportunity to participate in, but one that you can have your say about your individual needs.

Families with children needs some support that they can rely on when needed without fearing that social services will take their children because of an HIV diagnosis. People still sometimes need a bit of advocacy support in difficulties such as day care and schools for their children, benefits, housing, managing bills etc. Social service could play a helpful role in supporting HIV positive people through ill health, managing tenancies, transport needs and helping people to maximise finances. Creating a partnership with the specialist voluntary sector organisation can only benefit and support people living with HIV. Parents very often say 'if I had cancer I would get more understanding, sympathy and more of my needs met'.

Things can change, the same way that HIV positive people campaigned for better medical treatment and the AIDS Support Grant, you have a voice and you can use it to bring about changes in the social care structure for people living with HIV.

Beulah

Beulah Gordon
Case Work Manager
Positively Women



Accessing Immigration Advice

Some tips from an immigration solicitor's point of view

Positively Women magazine has asked for a piece about accessing immigration advice and so in this short article we have tried to set out some tips when getting advice about your immigration status.

I am an immigration solicitor doing legal aid work at Fisher Meredith LLP and Alison Hunter is a partner at Wesley Gryk LLP. Between us we have represented a large number of women and we have experience of asylum and non-asylum work.

1. Getting advice

It is important to access good immigration advice as soon as possible. This means if you are in the United Kingdom on a valid visa but are considering an application for further leave to remain or would like advice about whether it might be possible to switch to a different visa you need to make sure that you get advice before your visa expires. If you have overstayed your visa you need to try to get advice about the possibility of regularising your status as soon as you can.

If you do not have the money to pay for a solicitor then you should be eligible for legal aid, which means the Government will pay your solicitor and you do not have to.

2. Good advice

It is important that you feel comfortable speaking to your solicitor about your immigration case and your current situation. If you are unhappy with your solicitor or cannot speak to them easily then you can change solicitors.

Also your immigration solicitor should listen carefully to your story before they give you advice. They should help you to prepare for the application that you are making, for example, if you are going to the UK Border Agency for an interview they should explain to you what will happen during the interview and what will happen after the interview or if you are going to have an appeal hearing at the Asylum and Immigration Tribunal you should be told what to expect.

You should also be aware that it is possible to ask for a female solicitor, a female interpreter, a female caseworker at the UK Border Agency and also an all female court if you have an appeal before the Asylum and Immigration Tribunal. If you feel that this will make you more comfortable, do not be afraid to ask for this.

It is also useful to know that you can ask for appeal hearings to be heard in private if you do not want any members of the public in the courtroom when you are giving evidence.

3. What you can do

There are also a lot of steps that you can take to progress your immigration case and you should ask your solicitor what you can do to assist them.

Some examples of things that you can do (which will of course depend on the type of application you are making) include: providing your solicitor with all the background documentation to your immigration case, such as any previous applications that you have submitted to the UK Border Agency; preparing a chronology of important dates in your case; and providing your solicitor with information regarding your country of origin, this is especially important if you are making an asylum or human rights application as you might be able to get information from national newspapers/local sources that your solicitor does not have access to.

We hope that these tips are of assistance to you. If you need more information, please contact us.

Catherine Robinson

Fisher Meredith LLP
catherine.robinson@fishermeredith.co.uk
Alison Hunter, Wesley Gryk Solicitors LLP
020 7401 6887





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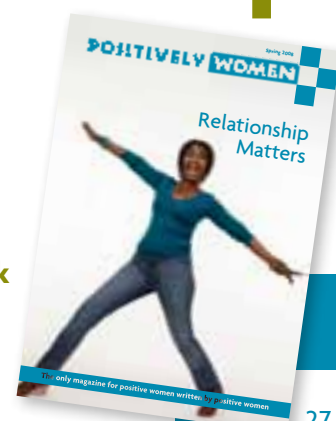
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Positive Self Management

Since my HIV diagnosis in 2005 dreams have been shattered and a new life has been started. I have stumbled upon uneven surfaces and walked on some smooth ones as well and I would like to think that at the end of the journey I will end up and remain un-bruised and unscathed.

Soon after my diagnosis Living Well NHS was one of my main groups that I joined as a participant on their Positive Self Management Programme (PSMP). It allowed me to understand, in a way that I was not on my own in the battle. I remember the group had a mixture of people, from those even younger than I was to adults. I was able to comfortably place myself and find a balancing route to follow. The following year in 2006 they invited me to train as a PSMP facilitator and I have to say that of all the things that I thought I would ever do in my life, standing in front of a group of people delivering courses in a facilitating mode was never on my to do list. But the staff were very supportive and complementing so much so that they gave me enough confidence and guidance to prosper. In the same year I became accredited.

The accreditation gave me a new perspective as doors of opportunities started opening for me. From that training I was able to work with Macmillan Cancer Support and Chronic Diseases delivering the same course. The course in itself is a Stanford University Copyright and is delivered by peer leaders who actually don't teach or advise but offer techniques in managing HIV on a daily basis. The Self Management Programme was originally designed for arthritis patients and then later included all the chronic conditions. In those groups

the peer educators found out that people living with HIV were not opening up as much as they should to address most of the issues that they were facing. After a successful pilot in 1997, in 2002 Living Well was funded to deliver the programme in the UK. It is a seven-week programme delivered one day a week for two and half hours per session. It all sounds very regimented and structured but the beauty of the programme is that it allows addressing the many issues that people living with HIV come across throughout their journey; managing depression, managing medications, dealing with difficult emotions, healthy eating and making action plans. There is only a slight difference with the Expert Patients Programme, which deals with more generic chronic conditions and does not necessarily address the specific issues around HIV.


'... it was one of the programmes that gave me a mighty position to stand on because it gave me the self-confidence, the self-esteem and has re-enforced the courage within me to want to achieve a little bit more with each day that comes'

Personally, it was one of the programmes that gave me a mighty position to stand on because it gave me the self-confidence, the self-esteem and has re-enforced the courage within me to want to achieve a little bit more with each day that comes. From a facilitator's, point of view, every group is always different, but the outcome is always the same, the enthusiasm and gratitude that the participants feel to be able to commend that we have managed to help them take that one step away from their comfort zone. Not everyone we come across goes on to positively manage their lives, but in every group there is always at least one person who goes on to do more than manage the basic things and it is always a privilege and honour to be part of their process and I am forever grateful for that.

The list, in my little white diary, of groups and individuals I have to be grateful for is ever growing but I will not forget where it all started and it is always a constant battle with myself to make sure that I stay motivated. That's why we need such groups to be kept because not only do I help others, but when I deliver the programmes I will be helping myself.

Pamela





IS IT
TWO RED AND
ONE GREEN, OR
THE OTHER
WAY ROUND?

**If you don't take it,
talk about it.**

Anti-HIV medication can be complicated, but that shouldn't stop you taking it properly. Your doctor or nurse can help you deal with problems or make changes to your prescription.

Find out more at www.yourstoryyourscript.co.uk

Interview with Vuyiseka Dubula

by Mem

Vuyiseka is the general secretary of the Treatment Action Campaign (TAC), a leading social movement campaigning for the rights of people living with HIV and AIDS in South Africa. She is the dynamic young leader of TAC, who has lived openly with HIV for nine years and has been at the centre of most of TAC campaigns over the last 10 years.

I met with her at HIV i-Base in London where she has been visiting for three weeks in October/November on a British Council Chevening leadership programme, aimed at establishing contacts and networks that will strengthen TAC's HIV response in South Africa. She has also been visiting organisations that have similar work on development and community response to HIV and youth, with specific interest on leadership skills and development for TAC members and leaders.



Mem: Could you please tell us a little about yourself?

Vuyiseka: I am 31 years old, born in the Eastern Cape province of South Africa and now live in Cape Town. I am married and mother to a three-year-old girl. I have been on HIV treatment for five years now; I am still on first-line therapy: my pride and joy because adherence is important!

M: Why were you diagnosed, what motivated you to test?

V: I went to test for HIV out of curiosity; I was not sick. I had no reason to test as many people back home test when they are very sick. I have proven the saying that goes 'what you don't know won't kill you', if I had not tested I would be dead by now. My CD4 was 215 meaning my immune system was severely compromised and I was probably highly infectious due to my viral load. That HIV test changed my life for better: because I took steps to remain alive and healthy or for worse: because treatment was not available in the clinics when I tested. At least now there is treatment available in the public sector after a long struggle and fight with drug companies and government. I became involved in the struggle for access to treatment for people living with HIV because everyone has the right to health including access to life saving drugs not just in South Africa but across Africa and internationally.

M: Tell us what TAC is, and what they do...

V: TAC was founded 11 years ago in Cape Town, South Africa and advocates for increased access to treatment, care and support services for people living with HIV and campaigns to reduce new HIV infection. It was founded after the death of Gugu Dlamini, a woman who was stoned to death in KwaZulu Natal province when she disclosed her status to the community. TAC has more than 16,000 members and has become the leading civil society force behind comprehensive health care services for people living with HIV and AIDS in South Africa. TAC's mission is to ensure that every person living with HIV has access to quality comprehensive prevention and treatment services to live a healthy life.

Since 1998, TAC has held the government accountable for health care service delivery; campaigned against official AIDS denialism; challenged the world's leading pharmaceutical companies to make treatment more affordable and cultivated community leadership on HIV and AIDS. TAC's efforts have



resulted in many life-saving interventions, including the implementation of countrywide mother-to-child transmission prevention and anti-retroviral treatment programmes. For its efforts, TAC has received worldwide acclaim and numerous international accolades, including a nomination for a Nobel Peace Prize in 2004. On 30 August 2006 the New York Times named TAC, 'the world's most effective AIDS group'.

(More information on TAC's website: www.tac.org.za)

M: How did you get involved with TAC?

V: I was referred from the clinic after testing, having never heard of TAC on TV or radio, you know how messages about HIV do not get to people who assume they not are infected or affected? From that day onwards I started hearing about TAC everyday. I went to TAC to get help, when I got there I learnt about HIV treatment, my rights and how to get involved. I joined and opened a branch in my township.

M: What do you believe are TAC greatest achievements?

V: The broadest achievement was asserting that access to treatment was a human right and not a privilege. This has made many people aware that not accessing treatment is violation of their human rights; they are denied a right to live; and this argument can be applied to all governments and pharmaceutical companies.

We have used the South Africa's constitution to force the government and that our governments have legal obligations as the state to provide health for all.

We have succeeded to demonstrate the power of social mobilization to promote active citizenship and that on its own demonstrated the power from the grassroots and communities.

We demonstrated that monopoly by big pharmaceutical companies led to many people not able to access cheaper and

affordable treatment. This resulted in much more competition and allowed generic cheaper drugs to enter the market and that resulted in the reduction of drug prices as there is much more competition. This way we were ensuring that profit and greed doesn't lead to less access to treatment and healthcare for the poor.

South Africa now has a national strategic plan for HIV/TB/STIs that aims to treat 80% of people who need treatment and also aims to reduce new infections by half. Currently there about 800,000 people on treatment in the public health sector, compared to 11 years ago when there was none.

M: At the moment there is a huge debate globally about whether funds directed to HIV/AIDS would be more effective in improving health if they were invested in strengthening health systems. What are your thoughts on this issue?

V: That is a global debate started in the US and UK claiming that AIDS is receiving a lot of funding and aid. I don't think that AIDS funding should be shifted to health system strengthening I think we need money for both, where I come from we need both. Our health systems in Africa or developing countries are under severe pressure because of TB, Malaria and HIV. Therefore you can't speak of the health system in isolation to HIV/TB/Malaria because of the burden of disease, which mostly kills young women and children.

For Africa if you do not close the leaking tap which is HIV/TB/Malaria, you'll lose more water. You need to FIX the leak first as a priority while you are trying solve the challenges in the health system. So if you do not stop HIV/TB and malaria our health system will always be on its knees.

M: What would you be your words of advice to a woman living with HIV who is taking her first steps in becoming a treatment advocate and an activist?

V: Every activist must read, and read! Education is very important and is the key in all our struggles.

We must empower ourselves, because activists have to be informed and we cannot be un-empowered activists! Each of us must do it for ourselves first! Activism starts with you!

I would like to encourage everyone living with HIV to move away from just wanting to receive only but also realise that there are bigger things out there as we cannot make HIV our career.

We must go back to school to claim our space in life and become fully active global citizens AND human beings!

Cate's Column

Hot potatoes and cold soup

'Unprotected sex' is the elephant in the room that is rarely addressed in depth by the HIV community, although the issues surrounding it are written and even legislated against by medics, researchers, drug companies and journalists.

We hear a lot about the 'gifting' scene; where negative men are deliberately having unprotected sex with positive men in order to contract HIV, which seems to make it a designer disease. Personally I think it's sick and insulting to the memory of those we have all loved and lost. Why anyone would **choose** to contract HIV is beyond me. But there is an ironic twist in the tale here – how many of us have had unprotected sex since being diagnosed with HIV? And when and where is there a forum in which we can honestly and openly discuss these issues as HIV positive people, without fear of reprisal, judgement or prosecution? And what are the **real** reasons why we do it?

It would make a long and complex study.

I imagine as women our reasons would range through social, cultural and economic. That they would take us on a journey through the issues of fertility and parenthood, moments of passion and desire, fear, coercion and rape. We would have to question the nature of **choice** and what it means and then take a painfully **real** look at how often women are truly empowered in their lives to make such choices.

I can only speak from my own experience of this and it isn't easy or comfortable to do so but here goes.

Over the years of my diagnosis I have had a number of lovers, who knowing my HIV status, haven't wanted to use condoms. Top of the list of reasons has been a dislike of condoms on their behalf, accompanied by those all too familiar words: *It feels better without!* One lover had the arrogance to say: *I just want you to feel normal.*

Others have believed that their willingness to not use a condom somehow proves how much they love me!!!!!!

You may be forgiven for thinking that I applied my boot to their rear and kicked them swiftly out of bed and my life altogether... But the truth is I didn't. I let them. The question is why?

In the early days it had a lot to do with acceptance and fear. The relief that someone wanted to touch me, have sex with me and the fear that if I said no they would leave and I would

be left high and dry! So letting them had a lot to do with my own lack of self-worth.

I have been in situations where a partner hasn't asked, they've just done it without my consent. When you're naked and beneath someone who is considerably larger and stronger than you, what chance do you have? Throw into the mix the confusion that can come with being lost in the moment, or the lack of clarity and assertion that comes with drug and alcohol use, and it's easy to see how it happens.

When it has happened in the context of a more established relationship there has been little negotiation and a lot of gentle persuasion/ emotional coercion. I have succumbed to it but **not ever** because I truly wanted to. I have never been able to relax and enjoy it; not whilst every cell in my body is trying to hold the HIV back, not whilst every prayer on my breath implores God not to let them catch it or me become pregnant. It has **never** been worth it for the fear I have felt afterwards. All it does is erode me.

I recently began a relationship with a man, where from the very beginning I was both clear and assertive about the use of condoms – I turned the line around and said *if you have any love or regard or respect for me you will never ask me to have sex without a condom.* But what do you know – it happened. My distress each time was immeasurable – not in the moment perhaps but every moment afterwards. Wave after wave of fear crashed against my love for him. I was angry at him for doing it and equally angry at myself for letting him.

Just before Christmas he developed an NSU (non-specific urethritis). He was advised to have a sexual screen and so was I. Amongst the tests was the inevitable HIV test and because he didn't tell them that he'd had unprotected sex with me, we had to wait nearly three weeks for the results. It was an agonising time for me; I went to every hell and back. He, on the other hand, took it all in his stride and remained stoical and unphased by it.

He was lucky, the result was negative.

As for me I never intend to go through any of that again. No man is worth it. I, on the other hand, am worth a lot more respect than I have been getting or giving myself and I'm working on that one.

Meanwhile, back between the sheets, I'm wearing kick-ass boots and any man daring to cross the condom line, will feel it swiftly applied to his rear!

HIV in the News

compiled by Anca

The US lifts ban on HIV positive visitors

America has lifted the travel and immigration ban for those with HIV and AIDS, which was imposed by Ronald Reagan in 1987, and strengthened by the Congress in 1993. The law required visitors to declare their HIV status, which, listed by the US authorities as a 'communicable disease of public health significance,' would bar them from entering the country.

Twenty-three years later, president Obama has scrapped the ban, decision welcomed by public health organisations and human rights groups. Other countries that deny access to HIV positive travellers include Armenia, Brunei, Iraq, Libya, Moldova, Oman, Qatar, Russia, Saudi Arabia, South Korea and Sudan.

The US plans to host the 2012 World AIDS Conference, for the first time in over ten years.

www.bbc.co.uk

Visiting the US

From January 4, 2010, people living with HIV can enter the U.S. like anybody else.

Customs regulations require people entering with prescription medication like antiretroviral drugs to carry a doctor's certificate in English, stating that the drugs are required to treat a personal condition. This requirement applies to all prescription drugs.

Medication should always be carried in hand luggage, as checked luggage may be delayed or get lost. If you are carrying-on liquid medication exceeding 3 ounces / 100 ml, you must declare it at the checkpoint for inspection.

Residency seekers

New instructions are being provided to panel physicians and civil surgeons who administer medical exams as for immigration purposes, but it may take time until they are all aware of the change, so residency seekers should be prepared. The revised instructions can be found at: www.cdc.gov/ncidod/dq/technica.htm

The Departments of Homeland Security and State still need to determine the process for those HIV positive residency seekers who have/had current applications pending that were filed under the old restrictions.

Stem cells could be engineered to fight HIV

A research study has demonstrated how human stem cells could kill HIV infected cells. The process involved taking CD8 cells, also known as 'killer' T cells that help fight infection, from an HIV

www.positivelywomen.org.uk

positive person. The molecule present in the T cells was firstly identified, and then cloned and placed in genetically-engineered stem cells. The cells developed into mature HIV specific CD8 cells, which allow them to target and fight the HIV infected cells.

Further research is needed, and the next step is to find out whether the same process would work in human patients. The experiment was tested on mice. Scientists suggested that the treatment could be used for a 'variety of viruses that cause chronic disease, or even different types of tumours', according to Scott G Kitchen, lead investigator and assistant professor of medicine at the University of California, where the study has taken place.

www.pinknews.co.uk

ARVs could be extended to a million extra lives

Routine laboratory blood tests for HIV related side effects have been long regarded as vital for HIV treatment, but they are also expensive and require sophisticated medical equipment.

Researchers have come to the conclusion that by removing the need for lab testing, the money saved could be used on extra anti-retroviral treatment. In addition, this would mean that treatment can be delivered in rural areas of Africa, where at present HIV positive people are unable to attend the nearest hospitals where HIV testing is available.

The trial was carried out in Zimbabwe and Uganda and involved over 3,000 patients who were given a combination pill, twice a day. 'The drugs are very safe and don't need regular monitoring for side effects... This is not just about money – it is about getting the treatment to where it is needed', explained Professor Diana Gibbs, joint leader of the study.

www.independent.co.uk

HIV vaccine cuts risk of infection

A combination vaccine has, for the first time reduced the risk of HIV infection, according to researchers. The experimental HIV vaccine is a combination of two earlier trials, that on their own had failed in decreasing infection rates.

The new study was carried out by the US Army and the Thai government, and involved 16,000 HIV negative people, aged between 18 and 30, over a period of seven years. Nearly 8,000 participants were given the vaccine, and the other half was given a placebo.

The results showed that the chances of contracting the virus were 31.2% less for those who had been given the vaccine, compared with those on placebo.

The vaccine is considered to be a scientific breakthrough, but additional research is necessary, as the vaccine did not provide total prevention from HIV infection.

www.cnn.com

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:

- HIV positive women's group every first Thursday of the month, 4-8pm
- Lesbian, bi-sexual and transgender HIV positive women's group every second Thursday of the month, 5-8pm
- 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

YOU WANT
TO BE YOURSELF FOR YOUR FAMILY

LET'S TALK

MENTAL WELL-BEING

The person depicted in this advert is a model.

Talk to your doctor if you are concerned about how HIV and HIV-related therapy may affect your physical and mental well-being.



THT DIRECT > 0845 12 21 200

POSITIVELY WOMEN