



Resources and reading

Positively Women

Visit www.positivelywomen.org.uk
To find out more about the Primary Care Access Project, visit www.accessgp.org.uk

International HIV/AIDS Conference Vienna 2010

Visit <http://www.aids2010.org> for more information about this conference which coincides with a major push to expand access to HIV prevention, treatment, care and support, in line with the 2010 target for universal access.

Athena Network

Visit www.athenetwork.org for a series of documents exploring emerging trends at the intersection of HIV and sexual and reproductive rights, including: "Documenting human rights violations in health care settings: Experiences of HIV positive women in Namibia".

Homerton Hospital Centre for the Study of Sexual Health and HIV/AIDS

Visit <http://www.homerton.nhs.uk/our-services/sexual-health/csshh-centre-for-the-study-of-sexual-health-and-hiv/>

Mothers to Mothers

M2M works in South Africa, Lesotho, Swaziland, Malawi, Zambia, Rwanda and Kenya. Visit www.m2m.org

Salamander Trust

Listen to interviews on HIV and motherhood with Maura Mea and other women at <http://www.salamandertrust.net/index.php/page/Resources/>

PozFem UK

Women, HIV and Sexual Health in the UK (2008) at <http://www.poz-fem-uk.org/resources.html>

For more information on HIV positive health workers:

'Greater involvement of people living with HIV in health care', a 2009 article by Rolake Odetoynbo, David Stephens and Alice Welbourn, published in the Journal of the International AIDS Society at <http://www.jiasociety.org/content/12/1/4>

Heidi Nass, 'An Open Letter, Woman to Woman', at <http://www.thebody.com/content/living/art43373.html>

For more on HIV and pregnancy, including forced and coerced sterilisation and abortion:

ICW project addressing coerced sterilisation in the news: <http://www.icw.org/node/471>

Developing a human rights framework to address coerced sterilization and abortion: http://www.athenetwork.org/docs/HEAL_Policy_Brief.pdf

Jenifer Gatsi, Denying us the right to reproduce: <http://www.aln.org.za/article.asp?id=25>

Sophia



A UNAIDS initiative

In 2004, UNAIDS launched the Global Coalition on Women and AIDS (GCWA) www.womenandaids.unaids.org.

SOPHIA is the UK branch of the Global Coalition

The Coalition is a loose alliance of civil society groups, networks of women living with HIV, and United Nations agencies. It works at global and national levels to highlight the effects of AIDS on women and girls and to stimulate concrete and effective action to prevent the spread of HIV.

The SOPHIA Forum Network is an initiative founded to engage prominent players from a range of UK institutions to address issues related to women and AIDS.

Are you a health worker or a positive woman with a positive story to share? Contact us on

info@sophiaforum.net

www.sophiaforum.net/



In Sickness and in Health

Welcome to the third Sophia e-newsletter!
One of our key goals at Sophia is to promote HIV awareness. Our aim is to keep you informed about news and policy updates, to provide a resource which you can forward to friends and colleagues.
"Join the network; Spread the word; Call for action"

Editorial

The face of HIV is changing. Twenty-six years into the pandemic, more women are affected by HIV and the consequence of the health sector response than ever before.

Immense global efforts have been made to counteract the transmission of HIV from women to their children during childbirth. The PMTCT strategy as it is known (Prevention of Mother To Child Transmission) affects millions of women around the world annually. In the UK and globally, routine antenatal HIV testing is now the norm, raising challenging questions about informed consent, counselling, the ability to opt out of testing, the comparative rights of mothers and infants, and the rights and wrongs of involving male partners in antenatal couple counselling and testing, particularly in light of the association between partner violence, HIV and pregnancy.

Fortunately, there are some wonderful examples of women-focused models of care. Mothers to mothers (www.m2m.org) is one example. Across Southern and East Africa, HIV positive women who have used the M2M centre to deliver their babies are then trained and paid to work as Mother Mentors counselling pregnant women and new mothers about HIV.

Of course, women living with HIV do not need health care only when they are pregnant.

The presence of openly HIV positive staff in medical facilities is key to ensuring a supportive environment for positive patients. Heidi Nass, a lawyer turned treatment advocate and HIV educator, based in Wisconsin, writes,

'Not too long ago, in the course of discussing treatment with a newly diagnosed woman in the clinic where I work, I disclosed that I was HIV-positive. A short time later another woman on staff joined our discussion and, when she disclosed that she was living with AIDS, the patient looked at us and covered her mouth. Knowing that it can be hard to be surrounded by people with HIV if you are not ready to accept that you are one of them, I asked if it was too much. "No," she said in a teary voice, "It's just that I thought I was the only one."

However, in many settings the general lack of understanding and knowledge of HIV makes it difficult for health workers to be open about their status. It also acts as a barrier to HIV positive people accessing treatment, including in the UK,

This issue includes two articles from women who have experienced routine antenatal testing, and two articles describing work to improve the way HIV positive people experience primary care in the UK. We hope they are of interest.

The Sophia Team



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PNG, pregnancy, maternity and the health professionals

By Maura Mea

My name is Maura Mea, and I live in Papua New Guinea. I'm a nurse by training.

Pregnant with my first baby

I was diagnosed in 1997 because I was pregnant with my first baby. When I went to the antenatal clinic, without informing me and as part of their routine testing, they went ahead and tested me for HIV.

They didn't see me as a person

It was horrible. The nurses saw me as if I was some sort of infectious thing. They didn't see me as a person. I felt angry and confused. I asked myself, "We're all nurses here, and we made an oath that we would serve people no matter what their race, their culture or age. But here, that's not the case. No, they are treating me differently. They are breaching what they committed to do."

No support

There was no support in place. I just went home and waited for the day I'll die. They told me that there was a social worker who was coming to visit me to talk about HIV, my baby, and all these issues. I waited and I waited. No social worker ever came, and I didn't receive any counselling whatsoever.

They refused to treat her

My baby was OK until three months. Then I had to go back to work, so I left the baby with the grandmother, my husband's mother. When I came back, she wasn't looking after her well. She had breathing problems. I brought her to the emergency ward. When the doctors saw that on the front of her card it said the mother is HIV+ they totally refused to treat her. We just stayed there until the next morning. She died.



When my baby died I was angry

I was especially angry at the nurses. I was angry at my husband. I was angry at everyone. I shut myself away from the world. I was working in the pharmacy dispensing drugs, but I couldn't concentrate so I had to resign and stay at home. During my experiences, they made me feel very guilty, and that I had no right to become pregnant. They were very cruel to me. It made me depressed.

'There's nothing I can do right now'

My second baby got diarrhoea after I gave birth. So I brought him to the clinic. They gave him a shot of live oral polio vaccine. Within three weeks he developed polio. I was shocked. I went back to the doctor's and said, "What did you do to my baby. You have infected my baby with polio." The doctor just looked at me and said, "There's nothing I can do right now. You can stay at the ward." I said, "I'm not going to stay here. I've had enough problems. I'm taking my baby home to look after him." This baby, the pain he went through was so terrible. He would cry all night. I looked after him day and night until he died on 23rd December 1999.

When I saw that, I said, OK this is something I can advocate for with the health department so that other women don't have their children vaccinated with live vaccines. I told them, these are my experiences. You shouldn't be doing this to other women.

'You have to terminate the pregnancy'

I really wanted a child. The third time when I became pregnant, the doctor told me, "You have to terminate the pregnancy." They forced me to terminate, and they sterilised me.

We have the right to have children

I do not agree with the policy of routine antenatal testing, and have argued with the Health Ministries in PNG as well as with the World Health Organisation. I told them, "You know they are doing routine testing for women and group counselling. But the counselling is in groups, and is very judgemental. And there is not informed consent—all the women are put through for testing, and are not given the option to opt out.

When I tested positive I wanted to put an end to everything. When my first baby was born, I was so excited. But I didn't have the joy of being a mother, and know there are millions of women who are going through the same experience.

We need to talk about it so that health ministries around the world look into what is happening in antenatal and postnatal clinics, so that women of today have the right to motherhood and the joy of a family.

Listen to an interview with Maura at www.stratshope.org/d-audio.htm

The answers

1) HIV stands for "Human Immunodeficiency Virus". HIV attacks the body's immune system, making it weak so that the person infected is more susceptible to other infections.

2) AIDS stands for "Acquired Immunodeficiency Syndrome".

3) You can't "catch" AIDS and you don't have an "AIDS" test – HIV is the virus which people can catch, and the test is for HIV. HIV is the virus which – if you don't treat it with the right drugs – can cause damage to the body's defences resulting in serious complications, and at that stage someone is said to have AIDS.

It is good not to call it "HIV/AIDS", because nowadays, people who get the right treatment on time, as well as good care and support, don't need to develop AIDS at all. The drugs can have some bad side-effects for some people, but many people with HIV can live long, healthy and productive lives. People who do get sick do not die of "AIDS" – they die of an "AIDS-related illness", such as TB, pneumonia, a chest infection or a cancer (such as cervical cancer or Kaposi's Sarcoma). All these conditions can cause death in someone who already has a damaged and untreated immune system.

4) You can only tell if someone has HIV by having an HIV test. In the UK this can be done in less than 30 minutes using rapid tests.

5) You can't tell if you have HIV unless you have an HIV test. Many people with HIV can feel perfectly fit and well for years before the virus starts to affect their body's immune system.

6) A CD4 count or T-cell count measures a particular type of white blood cell, which controls the body's defences against infection. A normal range is about 600-1200. In people with HIV these cells are destroyed, and so the "count" falls. It is now thought best by many doctors to start taking HIV drugs when this count falls below 350.

7) You can get HIV through unprotected vaginal and anal sexual intercourse, sharing unclean needles, and receiving untested blood transfusions. A mother can also pass HIV to her baby during pregnancy, delivery or breastfeeding. These are the main routes. You cannot contract HIV through mosquitoes, sharing cutlery or plates or mugs, through hugging or kissing, or through other normal social contact. HIV is very short-lived outside the body. Urine and faeces do not contain HIV.

8) ARVs stands for "anti-retroviral drugs". These are the drugs that are taken by people with HIV when their CD4 count drops. If people are able to take their drugs in time and regularly, their CD4 count can rise again. Some people still have nasty side-effects from the drugs and they have to be taken for life, so it is still far better not to get HIV in the first place. But ARVs are a great advance.

9 a) Sexual transmission The answers to this question depend on what stage a woman has reached with her HIV and whether or not she is receiving effective treatment. Nowadays in the UK, if a woman is taking effective ARVs which reduce HIV activity, and she and her partner have no lesions caused by other sexually transmitted infections, the chances of her passing HIV to her partner are pretty low.

9 b) Transmission from a mother to her baby. Recent studies have also shown that the chances of a woman passing HIV to her child are also much reduced (less than 1 in 1,000, even with ordinary vaginal delivery) if she is on effective ARV treatment. However, for mothers who do not have access to antiretroviral therapy to prevent transmission to their baby (which is the case in many parts of the developing world), transmission rates can be up to 35%.

These recent results are signs of hope. Nonetheless, in the UK as elsewhere, many people with HIV don't know they have it, so the use of condoms is still recommended. Also, sometimes people who have HIV and are on treatment may not be aware that their treatment is starting to fail, so their chances of passing on the virus may be increasing without them realising it. This means that using condoms is still always recommended.

10) You can still get a different form of HIV from a partner, even if you already have HIV yourself. If you don't have HIV, you can get it. You can also get Chlamydia or other sexually transmitted infections, like gonorrhoea or syphilis – all on the increase in the UK. And of course, if you are not using another form of contraception, you can get pregnant.

Take the Sophia Mini Quiz on HIV and AIDS: the bare facts

The questions

- 1) What does HIV stand for?
- 2) What does AIDS stand for?
- 3) What is the difference between HIV and AIDS?
- 4) How can you tell if someone has HIV?
- 5) How can you tell if you have HIV?
- 6) What is a CD4 count or T-cell count?
- 7) List all the ways in which you can get HIV.
- 8) What are ARVs?
- 9) What are the chances of a woman passing HIV to
 - a) her partner and
 - b) her child in the UK?
- 10) What else can you get if you don't use a condom or female condom?

How did you get on?

Check your answers on the next page. If you scored:

15 - 22 Well done you! Keep up the good work. Spread the word to others around you. Most of them know far less than you!

10 - 15 Great try! But please learn more, to protect yourself and your friends and family...

0 - 9 Oh dear! Please learn more fast! And then spread the word!! If you don't know all this then who else around you doesn't?

For each question, award yourself

2 marks = fully correct

1 mark = partially correct

0 marks – anything wrong

A story of routine antenatal testing in the UK

By Fiona

In 2006 I and my partner had a baby girl. Something of a miracle, since aged 20 I had been told by doctors that I would not be able to have children.

My daughter's existence is testament to the difference medical advances can make to people's lives. But my pregnancy also highlighted to me some of the tricky issues that arise with new developments in health care when my antenatal care included a "routine", "opt-out" HIV test. Here's the story.

When I realised I might be pregnant, I went to see my GP. I didn't dare to let myself get too excited. My medical history made me hold back my emotions until I had more proof.

My GP was warm, friendly and helpful. She filled in an antenatal referral form, and sent me home to wait to get my clinic appointment. By 13 weeks I had heard nothing from the clinic, so I went back to my GP. The form had apparently got lost in the system, so she started the process again. Since I was now entering the second trimester, she decided to order my antenatal blood tests herself.

'You don't need to worry about that'

Having worked in the HIV policy field, I knew the tests would include HIV. "Yes, but you don't need to worry about that," the GP told me. This was not my first HIV test. Nevertheless I was worried. I had some feel for the shattering impact a positive result could have - especially in pregnancy. I also knew the value HIV positive colleagues and friends placed on pre-test counselling, and asked if it was available. My GP looked at me hard, and said the only people it really affected were African women. She implied that I, a white, educated woman in my 30s, should not give the HIV test a second thought. Well, I went for the tests, and waited to get my appointment and receive the results.

Where was the information on HIV?

Fast forward a week. Finally, my first appointment at the antenatal clinic. I was still keeping my pregnancy a secret, still worrying it was all in my head, and still refusing to let go of my emotions.

Surrounded by pregnant women, it seemed more

real. Perhaps I really was going to have a baby. I flicked through the leaflets in the waiting room. Nutrition, smoking, pregnancy, breast-feeding, child immunisation ... Where was the information on HIV?

'Just the usual tests - it's all in the booklet'

By the time the midwife called me in, I was tired, hungry, sick and overwhelmed. After a brief chat, the midwife reached for a bundle of forms and started filling them in. She handed them to me. "Here are your bloods forms. Take them to the end of the corridor and wait there." Again, I asked what the tests would be. "Just the usual things - it's all in the booklet I gave you." I couldn't find the strength to insist. I just wanted to get out of there. So much for informed consent.

Never told the result of the HIV test

So I had my routine antenatal test. Twice. I was never actually told the result, though the "negative" box was clearly marked in the antenatal notes I was required to carry round with me for the rest of my pregnancy. No-one involved in those tests knew anything about me or my personal history. They knew even less about my partner (who came to later appointments, and felt his presence and role as the father were barely acknowledged). At no point were any questions asked about the HIV status of my partner, and he was not offered HIV testing, routine or otherwise.

Informed consent?

I am only too aware that my life events, choices and actions are not different to those of many women who test HIV positive.

I wonder what would have happened if my test had been positive? How would I have felt? Would the very nice, and extremely busy, health staff have acted differently towards me? What would have happened with my pregnancy – and my relationship with my partner? Why had no-one asked about his HIV status?

For all the good intentions and professionalism of the health professionals I was seen by, my experience made me question just how UK policy is supposed to enhance equality, ensure "informed consent" and the right to "opt out" of routine antenatal HIV testing, or equip women to deal with an HIV positive diagnosis when they are already dealing with being pregnant and the emotions and vulnerabilities that entails.

Sophia's supporters are any individuals - especially women - who wish to take an active interest in HIV as it affects women and girls.

Many supporters contribute experience from business, law, health, education and other sectors, all of which have some connection with the many and complex issues at play in this global pandemic

www.sophiaforum.net

HIV stigma training for GPs and dentists

By Silvia Petretti



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 trainings had been designed following a small research project we did among people living with HIV in those boroughs. We distributed questionnaires and ran focus groups. The findings were quite shocking.

'60% would not tell GP their HIV status'

While 96% of people living with HIV 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.

'53% stayed away from dental care'

Looking at dental care, the picture is even gloomier: only 65% of the people living with HIV who participated in our research are registered with a dentist, and 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 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.

We contacted GP surgeries and dentists in Hammersmith and Fulham, offering them the training for free and on their premises. Only four surgeries replied. Delivering those trainings was one of the most difficult experiences in all the years that I have been an HIV and Sexual Health trainer.

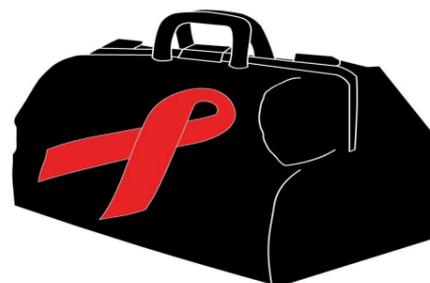
For the first time, I found myself addressing a definitely unsympathetic crowd. I constantly had the feeling that they were thinking that I couldn't possibly know more than they did with their medical training.

Some dentists felt HIV positive patients should always be booked last, because a special cleaning was needed. They even suggested there should be a 'special room' reserved for HIV positive people. I asked, 'What about the fact a third of those with HIV haven't been tested? What about 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 the Universal Precautions recommended by the World Health Organization for?' They seemed unmoved by these questions.

Another shock came with a group of GPs. My quiz included a question about preventing HIV transmission to the baby when an HIV positive woman has access to ARVs and all the recommended interventions. Most of them replied that transmission in those circumstances is 50%, while the reality is that in 99% of cases the baby will be healthy!

Afterwards, they did not let me play my DVD of positive people talking about stigma. 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 there is nothing imaginary about the stigma and discrimination many of us experience."

I left the GP training fuming, and 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?



One example of good practice is the Homerton Hospital's Centre for the Study of Sexual Health and HIV in London. The Centre was established to better understand and support the particular needs of people living with HIV. For more information, visit

<http://www.homerton.nhs.uk/our-services/sexual-health/>

Or contact jane.anderson@homerton.nhs.uk

Tell us about other good examples on info@sophiaforum.net

The Primary Care Access Project

By Angelina Namiba



'In the past 10 years, I have only been to my GP surgery twice - the first time to register and the second time to get my travel jabs'
[Woman living with HIV for 13 years]

What is the Primary Care Access Project?

The recent 'Healthcare for London' report recommends 'wrapping' healthcare around patient needs, and managing HIV and other long term conditions closer to the community. NHS Kensington & Chelsea and Westminster has commissioned Positively Women to develop a model of care to enable people living with HIV within these boroughs to feel safe, confident and secure in accessing primary care (GP) services.

Positively Women are well placed to lead on the project. We are a grassroots organisation with a good foundation and a solid relationship within the community and particularly with women and families living with HIV. Our expertise is in enabling marginalised people living with HIV, especially women, migrants and those in prison, to influence policy.

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

Positively Women's research identifies a number of key barriers preventing people living with HIV from accessing their GPs.

These include concerns about breaches of confidentiality and frustration at having to see a different GP every visit. There was also concern about the lack of GPs' knowledge, training and understanding of HIV drugs, treatment side effects, and interactions with other medications, as well as a lack of clarity over the distinction between a general medical condition and one which is HIV-related.

"The HIV medications I take can cause kidney problems. After 4 years on this drug, I started to experience cystitis and recurrent urinary tract infections. My HIV clinician promptly organised tests, which showed that

I needed to change medication. Would a GP, without the HIV clinician's specialist knowledge, have been able to make this connection?" [HIV positive woman]

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



What will the Project do?

A key aim will be to explore the feasibility of placing a GP within the HIV clinic, where patients will be able to get all their healthcare needs met and which will ensure patient choice when it comes to GP services. Overwhelming feedback from consultations with patients at the Wharfside clinic at St Mary's Hospital identified this as the model they would prefer.

The project will need to carefully consider accessibility for different groups of people living with HIV. Will a GP service within the HIV clinic be accessible for families? What happens to men and women who need assisted conception services which, although provided by the main hospitals, can only be offered upon referral by a GP?

The project will also take into consideration the barriers that GPs have in treating people living with HIV, including looking at their training and support needs.

We will be looking to work with a group of GP practices with expertise in dealing with patients with HIV, or who are ready to build on their sexual health skills in treating HIV.

The project runs to March 2010. A key aspect will be consultation with and meaningful involvement of people living with HIV, GPs, HIV clinicians and those who commission health care services, in order to ensure that any model developed can guarantee patient confidentiality and is robust.

Visit the Primary Care Access Project website for regular updates, input and dialogue on the development of the project at www.accessgp.org.uk

For further information, please contact Angelina on anamiba@positivelywomen.org.uk

For information on the HIV training work, contact Silvia on spetretti@positivelywomen.org.uk