

Sophia 



A UNAIDS Initiative
The Global Coalition
on Women and AIDS

**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 by former
GCWA Leadership
Council members Alice
Welbourn and Lesley
Bulman-Lever, and by
Sara Tye, to engage
prominent players from
a range of UK
institutions to address
issues related to women
and AIDS.

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Issue 2: HIV and ATTITUDES

Welcome to the second 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

A huge on-going challenge for people with HIV, especially women, around the world, are the discrimination and judgmental attitudes which they face.

A recent survey in the UK, carried out by Ipsos MORI on behalf of the British Red Cross (www.redcross.org.uk/uploads/documents/ipsosMORI_HIVsurvey.pdf), interviewed young people aged between 14-25 in Great Britain in an effort to understand young peoples attitudes and behaviours towards HIV ("If your friend had HIV, what would you do?"). The survey confirmed this as a continuing challenge in the UK also, despite access by most people with HIV in the UK now to life-saving drugs, which can mean that many can stay well and lead fully productive lives both at work and amongst their families and friends.

The Red Cross survey found that one in seven young British people would not be willing to stay friends with someone diagnosed with HIV. The findings have exposed a worryingly high level of stigma and complacency around HIV in the UK. One in five young Britons would not care for a member of their family suffering from the disease, whilst only 29% of those surveyed agreed that a teacher diagnosed with HIV should be allowed to continue working in a school.

Despite the fear and prejudice which seems to exist, and despite a recent UN report showing a marked increase in incidence of HIV in the UK, only 32% of young people in this country are worried about contracting the virus.

What makes these findings especially disturbing is that it means that people with HIV continue to fear public knowledge about their status.

Women especially also want to protect their children and other family members from stigma by association. Ironically because they fear talking openly about their condition, the media, many professionals and the public at large still have limited knowledge of how HIV is not passed on through normal social contact; and how it can now be a long-term chronic condition, like breast cancer, leukaemia or diabetes. So the myths and fears remain intact.

This newsletter brings you three views from three of our supporters. Please read, share and discuss them with your friends, colleagues, family members.

The Sophia Team

Prejudice or prudence?

By Hannah Wallace-Bowman

Sophia Newsletter: HIV & Attitudes (Issue 2) Apr 09
www.sophiaforum.net - info@sophiaforum.net



If you found out that you were living with someone with a contagious and potentially fatal virus, you'd take precautions.

Disinfect the dishes after said contaminated housemate had used them perhaps? Use separate bathrooms, separate cutlery, separate mugs, even avoid returning home when possible?

But would this be enough; what happened if said housemate experienced a mishap which resulted in them cutting their finger say, what then - move out altogether? According to a highly intelligent, sensitive and educated friend of mine, in her early twenties like me, upon discovering that a person you existed in close proximity to was HIV positive, such evasive action would not only be sensible but necessary. And, whilst initially shocked to hear this opinion coming from my friend, I would suggest that this type of attitude is in fact highly prevalent, and rather closer to home than we'd like to admit.

I started working with Sophia back in the summer. Wielding phrases such as 'promoting awareness' and 'tackling discrimination', I went forth, disseminating leaflets on the work of the organisation; Sophia, a badge of how open-minded and forward-thinking a citizen I was. Yet, when it came time for me to set up the Sophia Facebook group, I hesitated. Although fleeting, a thought crossed my mind that people may think that that I myself carried the virus. I think it unlikely that had I been taking steps to set up a group on Alzheimers or Heart Disease, such a niggling anxiety would have registered.

Just the mention of HIV or AIDS - the boundaries between which are continually blurred - conjures up apocalyptic images: rows of emaciated and sickly individuals quietly struggling towards death in faraway lands, haggard crack fiends sharing a rusty needle huddled in a forgotten doorway, 80's ad campaigns threatening early graves for society's sexual deviants; all scenes of distinct otherness.

According to common conception, people infected with this virus operate on the peripheries, they exist and die in worlds that bear no relation to our own. I would argue that the stigma which distinguishes HIV and AIDS from other illnesses is that there is nothing more scary than the unknown, and AIDS is the embodiment of that abstract. Indeed, even the origins of the virus are mysterious, and until the later stages, it is symptomless.

This epidemic is one characterised by taboo and, although an underlying fear of HIV and AIDS continues to pervade, it exists below the surface and is rarely broached in everyday conversation. It is easier to ignore this uncomfortable subject and leave it where it belongs, in the elsewhere, than to get to grips with its reality; it is easier to be afraid than to understand the risks and disrupt your own sense of safety and normalcy. This would explain why some of my intelligent peers genuinely see not sharing a bathroom with someone who is HIV positive as a viable precaution whilst at the same time, in their personal life, their behaviour suggests that they do not see themselves as vulnerable to contracting the disease.

Prejudice is born out of fear and ignorance, prudence would be to practise safe sex.

What you have said on Sophia:

On our lecture on HIV and Legal issues which can be heard at: http://www.sophiaforum.net/index.php/Events/Legal_rights_and_social_wrongs

"I found Helena Kennedy's talk rousing and delivered in such a way as to be appealing and accessible to a wide range of people, whether or not they had direct personal experience of living with HIV or AIDS.

I also came away quite profoundly affected by meeting some of the women from PozFem and Positively Women, and reading the literature included in the packs (which I read from cover to cover!) that were handed out. I would like to know more about the work of SOPHIA and these other organisations, and to be able to offer assistance in any way I can".

Angela Randall (Lawyer)

Here's one feedback of our Conversations for Change dinners (for more information www.sophiaforum.net/index.php/page/Events or email info@sophiaforum.net):

"My daughter lives with HIV. Since her diagnosis I've tried to keep myself informed. I will always support her. There is still ignorance and lack of understanding of the true facts about HIV. It is still a subject that is not discussed. People feel embarrassed and shocked at their own limited awareness. I surprised some of my neighbours when I disclosed my family's very personal journey [...] I surprised myself with how confident I now am in talking about HIV issues. My guests built new bonds [...] - new friendships were made as well as awareness raised about [...] the issues facing women living with HIV in Britain as well as worldwide."



Attitudes towards Women Living with HIV

By Winnie Ssanyu Sseruma

As I write this, another Women's Day approaches. It is important to take the opportunity to highlight how far women have come in fighting for gender equality. But it is just as important to use this day and every day to continue to raise awareness of the issues that remain a challenge in obtaining that goal. HIV is one of those issues.

When HIV was first identified, HIV was a disease that mainly affected men. For the few women who were infected in the very beginning, they were classified as unworthy of society and or prostitutes. The labelling and the stigma had started in earnest. As women increasingly got infected, it took time for the world to acknowledge the vulnerable nature of women and the necessity to address their needs. The struggle for recognition, as with gender equality, continues to be tough and quite challenging.

Over a quarter of a century into the HIV epidemic, half of the people living with HIV in the world are women, with the majority living in Sub-Saharan Africa. Young women between the ages of 15 - 25 in many Sub-Saharan African countries are six times more likely to be infected with HIV than boys in the same age group. In the US, the leading cause of death for African Women between the ages of 25 - 44 is HIV and AIDS. The other running theme through these statistics is the other dimension to this disease, its impact on Black women. The face of HIV in many countries where the epidemic has taken hold, is increasingly that of a Black woman.

Women living with HIV also continue to experience stigma at a different level than that of men. At the source of the stigma are gender inequalities not helped by the fact that many women are usually the first members of the family to get tested, through antenatal care. They then end up being blamed for bringing the infection in the family and shaming the family. In some cases, that blame has resulted in violence, rejection, loss of property and at the very worst - death.

In the UK, there are fewer and fewer women living with HIV willing to stand up and speak on the issues that impact on their lives. For all sorts of reasons, even those that were outspoken before are now retreating. HIV related stigma persists whether it is societal or self stigma. Stigma rears its head sometimes in very subtle ways like the assumptions healthcare workers make when you walk into a clinic, the way some tabloid newspapers report on HIV especially if there is a Black African woman involved or it is the judgemental questions people ask, borne out of ignorance.

In light of the numerous barriers faced by women living with HIV, it is important to remain vigilant, pro-active and solution orientated. Women living with HIV have been very effective at mobilizing at the grassroots but there are still too many hurdles that keep them from accessing care and support.

We have to start thinking out of the box just that little bit more. It is time to gather our strength, fight harder for what we are clearly are as entitled to as any other population. It is important that we get effective representation at all levels - grassroots, policy, research and at all levels of government.

It is crucial that we are part of any decision making processes, planning and implementation. It is only then that we can start to compete on equal footing with the opposite gender. Giving up, retreating and moaning sessions are not options we should continue to consider. Our children's lives are at stake and that ought to energize us.

Sophia suggests

Link to two 5 minute films you might like to watch online:

"Lullaby" (two Dutch young people talking about their HIV positive mother)
"The Dream" (a Dutch family affected by HIV)
: www.lifeboatfilms.org/films.php

For more information on HIV and attitudes, please see our website: <http://www.sophiaforum.net/index.php/News/>

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 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

Relationships and HIV

by Susanna

I keep telling myself: I am lucky. In spite of having been diagnosed with HIV over 12 years ago I have never experienced physical ill health. By living in the UK I have had access to some of the best medical and psychosocial support available in the world.

However I can not help thinking that HIV has deeply affected and made impossibly difficult an essential part of my life: relationships.

I have had 3 long term relationships since my diagnosis. The first boyfriend I went out with was initially apparently OK with my diagnosis. However he didn't want to use condoms. No matter how much I insisted. It was very stressful for me. I never felt he was doing it because of 'Love', but more for a complex/confused death wish mixed to a macho mentality: he didn't want to show he was scared of HIV. After about a year of a difficult relationship I decided to finish it. He called me after a few weeks to tell me he was HIV+ and that it was my fault. Somehow, I don't believe he was, he just wanted to get back at me by making me feeling guilty.

My second long term relationship lasted four years. It took me 6 months to disclose my HIV status. I used condoms all the time, and he was OK with it. When I disclosed to him, initially, everything was fine. He was shocked, but was in love with me so he decided to continue. However I can not say he was very supportive. HIV was something we couldn't speak about. He would never ask me how hospital appointments went, or anything. He was not interested in my work for an HIV organization. The relationship was deteriorating and we were growing apart as I became more involved as an activist. Once, while we were on holiday in a Latin American country we had a terrible argument on some menial thing which just escalated. We were staying with some friends who didn't speak any English who watched horrified while we screamed at each other. It was one of the most horrible days of my life. He started screaming at me that I deserved to have AIDS that I was a whore, and that if any of our hosts would know they would throw me in the street. He kept threatening me to tell everybody. I was crying like a fountain, and all the Spanish speaking people kept asking what he was saying to make me cry like that. He didn't speak any Spanish and I refused to translate. The relationship continued. I was unable to leave, maybe in the subconscious I feared that I wouldn't be able to find another boyfriend. Luckily for me after a few months he left me for another woman!

My last relationship lasted about a year and half. My boyfriend initially seemed OK with my HIV status. However as time went by he started feeling more and more uncomfortable about it. What worried him most was the fact that I had made the choice of being an activist and being open about my status. I believe this is extremely important for me in order to challenge stigma and discrimination. However he was really worried about his family's reactions, especially the mother of his children, and his children. Moreover he was also concerned that if it was known his partner was HIV+ everybody would assume he was positive too and it could affect his business, which had a lot to do with the public. My romantic mind whispers: 'If it was True Love he would have stayed'. But my practical mind replies: 'In the world we live in with the prevailing negative attitudes about HIV he is not the only one to be blamed. Our society and the values everybody - many of you out there! - promote also influenced him'.

After a year being single I decided to start dating again (I don't give up easily!). I joined the dating web site of The Guardian: Soulmates I thought that Guardian's readers would be better educated and more open minded than the average guy. In the space of a couple of months I went on several dates and I met 3 guys that I thought could be interesting: they had postgraduate degrees, PhDs, lecturers in arts and politics. I disclosed after the first date and numerous emails. I was pretty shocked when in spite of initial enthusiasm they all decided they would rather not continue seeing me. They all stated it wasn't the HIV, but the change was too sudden to really be ascribed to anything else.

Relationships are difficult and complicated even without HIV, I keep telling myself. I didn't used to be very good at them and possibly that's part of the reason why I got infected in the first place. However, in the past 12 years I have done a lot of work on myself. Through groups with other positive women, counselling, yoga and meditation I believe I have healed and I am ready for an equal and healthy relationship. But I live in a world which is still extremely sick with prejudice and irrational fears around HIV.

For a long time I always refused to really look for an HIV positive partner because, maybe, I am too romantic and I always thought I didn't want my virus to ghettoise my love life. I thought that I need to share more than a little piece of RNA with somebody to experience real intimacy. I think I might soon change my mind... But somehow it would feel like a loss... Why should I allow a virus to limit so substantially the most intimate, and deeply human aspect of my life?



Art by Shaun Askew (shaun@holistic-hamster.com) -
To get involved or for more information
at info@sophiaforum.net or at www.sophiaforum.net

Sophia

Mini Quiz on HIV and AIDS – the bare facts

How did you get on?

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

15 – 10 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?

The government has only just decided it might be a good idea to make sex education compulsory in schools here. We all need to start talking about these things much more.

Mini Quiz on HIV and AIDS – the bare facts

1) What does HIV stand for?

For each question, award yourself

2 marks = fully correct

1 mark = partially correct

0 marks – anything wrong

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 a female condom?

Mini Quiz on HIV and AIDS – the bare facts 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. This can be done in less than 30 minutes in the UK, 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.

Mini Quiz on HIV and AIDS – the bare facts ANSWERS

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 stand 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 ARV’s 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.*

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 you can get pregnant if you are not on the pill.