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# POSITIVELY WOMEN



## The Prevention Issue

The only magazine for positive women written by positive women

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## Guest Editor's Letter

I am honoured to be guest editor of this particular edition of Positively Women magazine. It is a wonderful opportunity to highlight a couple of issues I am passionate about – positive prevention and treatment advocacy – topics that are not exclusive of each other, but very much interlinked.

Prevention is a very topical issue, and not necessarily for the best reasons. On a global level, prevention efforts have been less than satisfactory. Twenty-five years into the epidemic and 20 years since celebrating the first World AIDS Day, more people are getting infected every year, many people living with HIV are dying and many babies are getting infected vertically – all preventable. But even more importantly, positive prevention – what I will define as a set of activities directed at people living with the virus to avoid further transmission – is hardly on the radar of many policy makers. We are dedicating this issue to positive prevention in all its different forms.

Looking towards the future, many people working on HIV are focusing hopes on concept of and framework for 'universal access' to HIV prevention, treatment and care by 2010. It looks very unlikely that this ambitious goal will be reached, but a healthy optimism remains that no one is going to give up on the campaign. The issue of HIV treatment remains an especially critical one, as almost every person living with HIV is going to need it at some stage. Treatment adherence, literacy and advocacy are just as crucial, part of the bigger picture of universal access. I will attempt to make a case to invest in treatment advocacy.

Of course the magazine retains its unique cocktail of articles on personal stories, research, other pertinent issues like violence and male circumcision and how all these issues impact on the lives of women. I really hope you will enjoy reading this special edition of the magazine. Any feedback would be greatly appreciated.

Winnie

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# Positive Prevention – Does Anyone Even Care?

It is a well-documented fact that the majority of prevention programmes have been directed at HIV negative people to keep them from getting the virus. HIV positive people have largely been overlooked conveying an inadvertent message that prevention should no longer be our concern. Yet it is common sense that there is a lot of people living with HIV could do to contribute to prevention strategies.

The challenges around positive prevention are many, but it is not my intention to address all of them in this article. I will just deal with two – one of them being that many people living with HIV and some healthcare workers don't even understand what positive prevention is. I attended a conference in the summer where someone raised a question about positive prevention. The question that immediately followed was from a sexual health worker who asked what 'positive prevention' meant.

An additional challenge is that of providing a definition that satisfies the majority of people, especially people living with HIV, since positive prevention is directed at us. Last August at the Living 2008 Summit, a pre-conference meeting for people living with HIV failed to agree on a definition when it came to discussing positive prevention. Many people living with HIV feel that positive prevention burdens them with the responsibility of HIV prevention yet that responsibility should lie with everyone – HIV positive or not.

For the purposes of this article, I will define positive (or secondary) prevention simply as a set of activities directed at people already living with the virus to avoid further HIV transmission, to protect their sexual health, avoid other sexually transmitted infections and to delay HIV disease progression.

The topic of positive prevention is huge and the arguments for how it should be done, when it should be done and the obstacles are numerous and could fill a book, literally. What I will try to highlight are the principles on which positive prevention is based.

Positive prevention is important because globally, most people living with HIV do not know their status. Furthermore, the majority of people living with HIV have no access to anti-retroviral therapy. From what we know to date, HIV is going to be with us for a long time. It is important that positive prevention initiatives do not operate in isolation, but are expanded and included in mainstream prevention strategies.

It is important that people living with HIV understand that prevention is based on the realities of their lives. Positive prevention is not about blame or criticism but supposed to help people with information and practical skills that promote the confidence to make choices that make sex for them and their partners safer.

Equally important people living with HIV should not have the sole responsibility of reducing HIV transmission. Rather activities directed towards them should promote human rights, right to health and also provide the most effective tools that support people to understand that the responsibility for reducing transmission lies with every one, HIV positive or not.

It is also very important to recognise that important issues like gender inequality, sexuality, harm-reduction, the rights of sex-workers, migration and poverty are considered when initiatives are developed to keep from further marginalising and stigmatising those already marginalised in communities. The prosecution of people living with HIV for transmitting the virus is not helpful, but unfortunately it is something that is getting increasingly common in many countries.

Crucially, positive prevention needs the full participation and meaningful involvement of people living with HIV. We need to be part of planning initiatives in order to make sure that they apply to the realities of the parts of the world we live in.

Winnie

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# Treatment Marries Prevention?

'Treatment marries prevention' was one of the slogans of the International AIDS Conference which took place in Mexico last summer. Does this mean that all our efforts to stop the epidemic should be focused on putting everybody on treatment as soon as possible – as latest World Health Organisation (WHO) papers suggest? Or is there more to prevention? Above all, what does this new focus on treatment as prevention really mean for us who live with HIV?

Treatment has been openly used as prevention for a long time, for example in preventing mother-to-child transmission. This is one of the of the greatest success stories of the epidemic: HIV treatment used during pregnancy gives HIV positive women 99% chances of having an HIV negative baby. However, only about 30% of HIV positive pregnant women in the developing world have access to this treatment, and furthermore, once the pregnancy is over, only 10% will have access to treatments that would allow them to see their children grow up, but that's another story... However, it does demonstrate how treatment-based prevention strategies, which are known to work extremely well, are still not implemented. Prevention is a complex business. So, can treatment really be the main star?

Recently it has been highlighted that HIV treatment is effective in reducing sexual HIV transmission, especially among heterosexual couples where one partner is positive and the other is negative. A panel of Swiss experts last year published a statement saying that the risk of transmission for a couple – where the positive person had an undetectable viral load for

at least six months, was under medical supervision, adherent to treatment and didn't have any other STDs – was 'negligible'.

Recognising that people living with HIV with an undetectable viral load are only to some extent infectious is a big step. This information had been known for a long time, but people were cautious about debating it more openly because of the fear that people living with HIV would act irresponsibly and have random unprotected sex. However, the feedback Positively Women (PW) had from a large number of women living with HIV when discussing this topic gave a very different picture. Women welcomed the Swiss statement as reassuring, but still felt very wary and felt that insisting on using condoms and femidoms was still important. As a member of PozFem UK – the National Network of Women Living with HIV commented: 'I think that after all this time of using condoms ... it does give me a degree of tranquillity and ease in my sexuality – I can relax more because I feel protective and protected ... If a condom broke I would probably feel a bit easier thinking about the Swiss guidelines.'

Moreover, many women who participated in the feedback sessions on Mexico 2008 run by PW recognised the Swiss statement as beneficial in challenging HIV-related stigma. Women felt a huge sense of relief that the statement could be used to challenge the view of people living with HIV as vectors of infection and potentially dangerous.

Another huge benefit related to the recognition of the decrease in infectiousness in people with an undetectable viral load is that at a policy level it implies the promotion of scaling up of testing and treatment as a form of prevention. This is extremely important especially in the developing world where, according to the latest figures from UNAIDS, only three million people are receiving ARVs of the nine million who need them immediately.

However, sometimes there can be too much of a good thing and this seems the case with how this policy recommendation has been taken to an extreme by WHO in a new radical strategy released just a few days before World AIDS Day.

The WHO strategy plans to test everybody for HIV every year in hard-hit areas and put those who are positive immediately on treatment regardless of whether they need it or not. The rationale behind this extreme plan is based on a mathematical model which calculates that by reducing people's infectiousness to very low levels using treatment, the proportion of people living with HIV in sub-Saharan Africa could decrease to 1% in less than 50 years. The authors of the



paper on which the WHO strategy is based include Kevin de Cock the HIV/AIDS director at WHO. The paper was published by the authoritative medical journal *The Lancet*.

Obviously, HIV activists and other human rights organisations have been highly alarmed by these plans.

Marginalised groups like injecting drug users, sex workers, and migrants are particularly vulnerable to the enforcement of those extreme guidelines, especially around testing. Melissa Hope Ditmore, co-ordinator of the Sex Worker Network reports: 'We are all for expanded access to treatment but I'm really concerned about this. Sex workers in Macedonia and Mongolia have reported forced testing at police stations, which has been described as provider-initiated testing. This is the work of the Global Fund in Mongolia. I don't know which agencies are behind the forced testing in Macedonia. Forced testing is a human rights violation. If the police are involved, it's clearly not consensual. We all know that the police are not health care providers. So we as activists need to be vigilant about preventing and protesting forced testing, which has already begun on sex workers.'

The Global Network of People Living with HIV (GNP+) has also raised concerns around possible human rights violations that could be caused by the enforcement of the new WHO strategy.

GNP+ press release 'welcomes the WHO breakthrough in thinking on Treatment as Prevention' but it also highlights the following concerns:

- HIV testing should never be mandatory.
- Treatment commencement must remain the individual choice of the person living with HIV and must consider implications for toxicity and adherence first.
- Feasibility: up to now governments have been unable to live up to their commitment of providing treatment to People Living with HIV (PLWH) who need it to stay alive. How are they going to be able to afford and deliver treatment to all who test positive regardless of CD4 count?
- Criminalisation (sic): current legislation in some cases criminalises the mere exposure to HIV, will increase in testing lead to more criminalisation of PLWH? Increased testing efforts must be balanced with the concerns of PLWH not to be criminalised.

The general consensus among social scientists, activists and doctors at the Mexico conference last summer was that there is no single 'technological solution' to address prevention. What is envisaged is a multi-disciplinary approach to prevention similar to treatment: Combination Prevention.

The cocktail of Highly Active HIV Prevention – as it was named by Professor Myron S. Cohen in Mexico – would have as ingredients: 1) Behavioral change – e.g. partner reductions, use of condoms and femidoms, 2) Bio-medical Strategies – e.g.

microbicides, vaccines, circumcision, 3) Treatment – including ARVS and STI treatment, 4) Social Justice and Human Rights – which of course means challenging stigma and discrimination, addressing socio-economic issues such as poverty, food security, gender-based violence, harm-reduction, xenophobia, homophobia and last, but not least, sexism!

In all of this of course the role of governments is paramount. Leadership from the top is needed in scaling up treatment/prevention efforts as well as a push from the bottom and a strong emphasis on community involvement, especially our involvement as people living with HIV.

It is vital that prevention strategies are designed on the base of strong socio-economic research, not simplistic mathematical models. Everybody in society has a role to play in HIV prevention. As HIV positive men and women we have the knowledge and the experience of what it really means to live with HIV, especially the consequences of stigma and discrimination, which is still what prevents so many of us either being tested, or gaining access to care and support once diagnosed, or disclosing our status or negotiating safer sex when entering a relationship. Because of our in-depth insights into the psycho-social issues related to HIV, it is necessary that we are consulted and fully participate in designing and implementing prevention strategies.

It is essential to involve and protect all the groups who are potentially most vulnerable to HIV. Unfortunately at present the UK prevention strategy doesn't involve women adequately. A lack of a gendered approach in UK policy means that we are not taking into account how women are more vulnerable to HIV because of their anatomy as well as gender inequity. A gendered perspective would make us look at power dynamics between men and women: Do women have power within their relationship to disclose their status and negotiate safe and pleasurable sex? How is women's power in intimate relationships affected by an HIV diagnosis? What process needs to take place for women to acquire more power within this context? And more importantly in the field of prevention: How can more women have access to power and control in their intimate relationships before becoming infected? I believe many HIV positive women (especially those who had access to good psycho-social support) have gone through the process of addressing those questions themselves in order to deal with their diagnosis and are therefore in a privileged position to lead other women so that they can protect themselves.

It is important to acknowledge also that a gendered approach that really wants to change power dynamics between the sexes successfully can't just work with women, but also needs to involve men. To challenge gender roles, men need also to explore ideas of masculinity and how they limit and condition relationships and sex as well as predispose them to risky behaviour.

Silvia

# Fighting Against Violence or Working for Peace

What are we referring to when talking about violence against women? If we look it up in the dictionary, violence is defined as 'to behave in such a way to break someone's resistance or to oblige him or her to behave against his or her will by means of force or intimidation', or also as the 'use of brute force in order to dominate someone.' The direct expression of violence, the physical expression, is easy to spot, but it is only the tip of an iceberg, the core of which is the basis of the relations between women and men, children and adults, poor and rich... in the whole world. What is not so easy to understand is the impact of the subordination of one person to another, especially when our minds are saturated with the multiple atrocities taking place in our daily life. That's why we have to identify the seed of violence as well as tackle violent behaviours. We need to learn what contributes to one person using violence against another: a person only uses violence when

there is the possibility of doing so, that is, when the circumstances place that

person in a position of power, where the use of violence is 'natural'.

On most occasions, it is not even necessary that one person uses direct violence against another; the social context in which one has been born and educated warrants submission to social hierarchic organisations. This is why it is very difficult to talk about violence as a cause of the spread of HIV and why it is not well understood, especially when we introduce the concept of violence beyond its direct physical expression.

In all the institutions that influence our lives, it is mostly men who are in power: family, education, media, politics, religion, legal or economic systems. Women account for half the population in the world, but most of them do not participate in decision-making about issues that affect their lives. All the decisions, rules and models of our societies are adapted to the needs, values and beliefs of the dominant half of the humanity, men. That is what is called 'structural violence' and it is 'structural violence' defined by patriarchy that makes women victims of violence at home, in the workplace and in public spaces.

Not only is it men who are mostly in power; it is also societies and institutions which are being ruled by patriarchal hierarchic conventions. Rules based on the need for someone to be above or under someone else. Rules that are based in 'power over someone else'. Rules establishing that someone has to 'lose' in order for others to 'win'.

Prevention, being in control of our own health, implies

making informed and free decisions. Most women in the world do not take decisions in freedom but under the pressure of fear of being battered, abandoned, humiliated, isolated and stigmatised. In most environments, women grow up thinking that they have less rights to everything because they have always received less. It is only after a radical change in life, they realise what has been done to them. A few days ago, I was interviewing a woman living with HIV for more than 20 years, a woman who had been using drugs for quite a long time and who had decided to stop drug use more than 10 years ago, I asked her what had been the most important decision she had made in her life. She replied: 'To get rid of the violence I have been experiencing from my partner. That changed my life.' She had been making decisions about her life and health, but what she saw as real liberation was to leave behind the torture she had been suffering, which had been undermining her capacities, disabling her to manifest herself and to make informed deliberate decisions about her life.

In recent HIV literature, it has been sufficiently proved that violence against women is a barrier to prevention, both directly and indirectly. Almost everybody can understand the direct link between violence and HIV when they think of rape and the possible effect of transmission of the virus. But the link is not so clear when it comes to imagining a woman not being able to insist on using condoms with her partner or when she cannot even think of the possibility of refusing to have sex with him. It is not as evident that fear of violence is enough to immobilise her; it is not as evident, though it is equally risky, that this may be occurring every day, every time she will need to decide to protect herself but is obliged to accept her partner's decision instead.

Some of the things that happen in conflict zones are an intensification of domestic violence. It is not advisable to think of those as separate environments. It is important that we recognise that they come from the same root and they only differ in intensity or intention (one aimed to conquer an individual and the other as a war weapon to conquer a country). People do not usually think of domestic violence as a kind of war, as a torture. They do not name it by its real name and that is what makes it such a devastating thing: it can happen every day, at any time, in your own home, without the intervention of anyone from outside and it destroys our capacity to self-

defend. If we recognise that this form of violence has the same base as torture, which ends up by breaking the free will of the person, then it is not difficult to understand why some women are not able to use the information they get to protect themselves against HIV or other risks in their lives.

Clearly, we must not forget that the most common victims are women and the most common perpetrators are men. But it is also necessary to bear in mind that this situation is shaped by a model of relationships that situates some individuals above others. We should not be focusing only on the actors but in the play we all represent, in the script that makes us play a certain role. We should start by recognising that the system facilitates this domination, because you are either above or under someone else, it does not allow for equality. The basic fact is that those in power exert violence against those with less power and then, shaped by our patriarchal social structures, it is addressed to women as 'infantilised' parties of society, deprived of their natural power to manage their own lives.

Often, the magnitude of the situation leads us to try to alleviate the tremendous impact of violence. Thus we promote women's empowerment so that they stop being submissive to their executioners. Meanwhile, we keep on moving in the paradigm that allows violence to take place. As long as we do not change this paradigm, our efforts are a drop in the ocean.

Before translating into physical action, violence is a seed sown in people's minds. It starts with rage and fear. It starts with dualistic thought: 'them versus us' or 'them above us'. Aspects and forms of violence are so many; we waste a lot of energy producing changes in specific realities while we do not focus on the core issue: the rules in place. We perpetuate the status quo by adhering to the rules, by recognising a masculine ladder of power and by trying to climb up it. The solution is not to climb up the ladder, but to change the rules of our relationships.

**MariJo**

# Personal Story

## Fran

Chris, my husband, played the trombone in the military band. He was very, very good; he played it like a trumpet. I had a keyboard, a nice professional one, and we used to improvise together and he wrote songs. He was playing in the band in 1985 in Deal, Kent when they had that bombing. He got a piece of his instrument stuck in his neck. He was rushed to hospital and given a blood transfusion.

Some four years later, my son Matthew became very ill. He had a bad chest infection that couldn't be got rid of, didn't respond to antibiotics, very high doses for such a small baby, and it just got worse and worse until he got pneumonia. He died, aged two. Nobody knew why; further tests were done; eventually someone suggested he be tested for HIV and he was found to have died of AIDS. So then obviously, we were both tested and were both found to be HIV positive. In the UK, they started in late 1985 to have blood product screening as the norm (only months after Chris's transfusion).

We went over to live in Belfast because Chris's parents lived there, his family was from there, and he wanted to be with his family. One Saturday morning, we were doing our weekly shopping in the Shankill Road. Suddenly there was all this shouting and four men came running across the road with pieces of wood and things in their hands and attacked both Chris and myself; a young man cracked me across the head, and he split my head right open, and they broke Chris's arm. It was because of the HIV. They also killed two people in our street because they were gay.

One evening, we came home to find all the windows had been smashed, the front door was wide open and everything wrecked. They'd written on the wall '24 hours'. Chris, having grown up in the Troubles in Northern Ireland, knew exactly what that meant, that if we hadn't gone in 24 hours, they'd come back and kill us. That was purely because of the HIV. We had to leave everything behind. I had a motability car at the time and we just stuffed a few clothes in there,

stayed the night in the police station for our own safety, and then caught the first ferry to England at seven o'clock in the morning.

We decided to come back to Dorset, where Mum and Dad lived. We thought Dorset would be the safest place to be. We were housed very quickly, we were both beginning to get ill with all the stress, and we got the house I'm still in, in Bridport. We didn't envisage any troubles down here, but my goodness, were we wrong.

The TV programme we agreed to take part in was entitled 'HIV and AIDS in the West Country', and it was all about prejudice and unfamiliarity with the problem, and about how dangerous people thought people with HIV were, and how difficult sufferers were finding it because people were so, so ignorant about the disease. There was a gay couple, a gay man, and Chris and I involved. Chris and I were interviewed, how he became HIV and everything.

Then all hell broke loose. We started getting bricks through the windows, dog excrement through the letterbox, windows being kicked in, people not giving a damn about anybody seeing them. Some of the residents here got a petition together asking the Housing Association if we could be removed from the place because we were 'threatening' their health, and they wrote to the MP saying that we shouldn't be allowed to live in the 'community'; he wrote back agreeing, saying we should be in secure, secluded accommodation.

We were having a cup of coffee in a café in Bridport, and suddenly all these police officers appeared as we were just about to leave, and they said, 'Please leave now'. I looked at the manager and I said, 'I'm terribly sorry but I don't know what we've done wrong'. He said, 'We don't want you in our restaurant because it will damage our business if people know that we are serving people with a contagious disease'. And the police escorted us out of the restaurant.

I have an electric buggy that I get around in; I can't walk any distance at all because my illness has

attacked my respiratory system. Over the past three years, I've had three completely written off in Bridport, specifically because of being HIV positive, the last being in 2007. Just recently, April 2008, the lights and electrics were smashed.

A friend of mine has two pre-school children. Her four-year-old son especially liked to ride in the buggy. Sitting on my knee and going slowly, he was perfectly safe. Somebody phoned the Social Services anonymously and said I was doing things to him to give him HIV. My social worker then came, saw me, and said I wasn't allowed to mix with that family. This was a few months ago. The mother said herself, 'Stuff the Social Services, you're a very good friend of mine and as far as I'm concerned you're no danger to my children at all.' I chose to ignore it too. It was completely ridiculous; someone's total ignorance; just the word 'HIV' or 'AIDS' meant that you were... scum.

Chris got very little support from his family. He was really ostracised. It made him a very angry person, and he did very silly things, that you wouldn't normally do if you were well. But he got HIV-related dementia. I looked after him at home for three years. The illness took him over very quickly; he was too late for the modern medication that I take, for instance, this anti-retroviral treatment. It had only just reached this country at that stage. But the dementia was really very serious with Chris, until I had to have him sectioned and put into hospital. He died in 1997.

After Chris' death, I had the most horrendous car accident, and I did it on purpose. I thought about doing away with myself quite a few times. But then I thought, 'No, I'm not going to. God gave me life and I've no right to take it away.' I'm belligerent! I say to him up there, 'No, I'm not going yet!' I believe there's something else for us all, I do believe in something after death, because if there wasn't anything after death, then what would be the point of our lives, you're not just born; live; die and that's the end of it, because that's senseless, pointless. We're in a transition in this world and this is just part of the journey. I don't think our future is exactly laid out, but I do think we're guided.

I was about 17 when I started experimenting with class A drugs, and I've had a problem off and on ever since really. Life seemed a lot easier on drugs. But you can't stay high all the time. You come down to reality with a bang after three or four days, and then it wallops you in the face. And Bridport is absolutely rife with drugs, it's easier



to get drugs in Bridport that it is to get a roll up. And all the faces become familiar very quickly. It's just a question of walking round the corner to someone's flat and buying a bag.

But this time I was going crazy, I was poisoning my brain, I couldn't think straight, I didn't know where I was, I didn't know what I was doing, I was all over the place. Because I'm so frail now, physically I just couldn't handle it. And I had started to inject again, which I swore I'd never do, so I thought, 'No, knock this on the head.' I got a lot of support from CADAS. I went to Mum's, I didn't take any gear with me and I went through three days of horrible things like diarrhoea, excessive sweating and not being able to sleep at night. But then it settles down, it's out of your system in three days. The time after, that's difficult. The doctor at the Hughes Unit gave me some medicine to help with the side effects of coming off the smack. And I just stayed out there like a hermit and Mum looked after me and fed me and everything. It's such a relief.

I think it's as simple as choice, it's as simple as that. No one was forcing me to use class A drugs; I chose, like an alcoholic to be off my face on smack. It's difficult to be straight because it's so painful, because I miss Chris so much; he died 11 years ago now.

**Fran**

# How Many Women Does it Take to Change the Research Agenda?

Over the last 25 years information about HIV has come pouring in from many different research projects around the world. Understanding the structure and life cycle of HIV has allowed the development of drugs that have changed the face of HIV therapy. There are now 20 different drugs available and more in development. Getting a drug from the test tube to the person living with HIV is a long process, involving research, clinical trials, monitoring, regulation and licensing authorities and approvals. But developing the active ingredients for a new medicine is only a part of the story. There are questions to be answered about how powerful it is, what's the best way to use it and when, how safe is it and what are the side effects? And what about the people who will take the medication – will it work in the same way for everyone? Are there differences between people and population groups that will have an impact? Will all those who should be able to use it be able to get proper access? What about age? What about ethnic background? And what about sex?

In the parts of the world with the technological and medical infrastructure to develop anti-HIV drugs and hold sophisticated clinical trials, the majority of those living with HIV have been men. Most of the available data has been drawn from male dominated studies. Indeed, in some of the early studies, the sex of participants in clinical trials isn't even mentioned and maleness is taken for granted. If there is information about

women, the numbers tend to be small and the data gathered by chance rather than specifically designed to find out about women's needs. But worldwide, HIV is now affecting more women than men and the information gap needs to be filled.

Despite an increasing appreciation that gender is a key issue for transmission and prevention of HIV, far less attention has been given to factoring it into the medical aspects of HIV research. What are the differences between men and women that might matter? The proportions of body fat and muscle, the hormonal and metabolic variation in the ways that drugs are handled by the bodies of men and women are a few of the most obvious differences that are likely to be important in medication trials. These factors are especially important for medications where there is a very specific range of blood levels needed for it to work properly and in those that are likely to be affected by other medications (e.g. contraceptive pills or HRT) which might change their metabolism. The ways in which women's lives are structured in relation to those of men include things such as their role as carers for others, economic independence, access to education and literacy, health seeking behaviour, social support, mental health and spiritual values, are harder to research and capture. But they are likely to have a substantial influence on health, well-being and clinical outcomes in HIV.

But to get to the information that is needed there are two important considerations. First, the right questions must be asked and second the research must be designed in a way that will give useful answers to the questions.

Some questions may be about ways that certain medical problems affect women living with HIV differently from women without HIV, and for this sort of research it's important to have enough women in both groups to make comparisons. Examples here may focus on issues that are 'women specific' such as malignancy of the cervix and the important factors may include different approaches to treatment in women with HIV compared to those without. HIV related differences in bone disease, blood pressure, breast cancer and cardiovascular disease all come into this category of research, which may need large numbers of women with and without HIV to be studied over long periods before the differences are properly understood.



Another sort of question is about the ways in which HIV affects women and men differently. For this sort of study there need to be enough men and women in the groups who are comparable in other ways (e.g. age, other medical problems, treatment history and so on) to be able to make valid comparisons. HIV is a long-term condition and these sorts of studies need to be maintained over long periods. If only small differences are likely to be discovered then the numbers of people that must be included to make the study statistically robust will be large. One way around this is to merge the information from a number of similar studies to make sure that enough people are included.

When the research question is about a drug treatment, the issues will be both whether the drug works and what side effects and problems may be encountered. When addressing the question 'does it work?' – it's important to ask to what it is being compared. In today's world trials of a new agent will be carried out in comparison to ones that already have a track record, and so the question may be does it work as well as or better than the medicines we are already using? Alternatively the question may be is it safer or easier to take or have different side effect profile? For these answers to be relevant to the people who are going to use the drug the study group must be big enough and diverse enough. Nevirapine is a good example of a drug, which has differences in side effect profile between men and women. However, the early trials in the 1990s had too few women in them for the differences to become apparent. It was only once the drug was being used by large numbers of people in 'real life' that the sex differences were seen and properly understood. In contrast the GRACE (Gender, Race, and Clinical Experience) study, which has been designed to assess gender and race differences in the power, safety and side effect profiles Darunavir in the USA has enrolled 287 (67%) women and 142 (33%) men with the intention of looking specifically for gender-related issues.

Particularly difficult to research is the issue of safety and effectiveness of HIV drugs in pregnancy. There is clear evidence that the way many drugs are metabolised in pregnancy is different and needs to be better understood. Concerns about toxicity to the baby mean that it's very difficult to design and get approval for research studies in pregnant women. However given the major role that anti-retroviral medication has played in reducing mother-to-child HIV transmission it is vital that good data is collected to give women with HIV the best possible advice on what drugs to use during pregnancy. A fine balance exists between the dangers to the baby of conducting a well designed research study and that of treating women with drugs that have not been properly evaluated in pregnancy. A majority of the information that is available on drug therapy in pregnancy comes from the anti-retroviral pregnancy registry, which carefully collects anonymised routine information from women with HIV who are treated with anti-retroviral drugs in pregnancy. The findings so far are very reassuring and do not suggest that there are excessive risks to babies exposed to ARVs in the womb.

Ideally, HIV clinical trials today need to include enough women to deliver data on the safety and efficacy of drugs for women at all stages of their lives. This is all much easier said than done. Barriers exist to including women in clinical trials. Following the recognition in the 1960s that drugs given to pregnant women could cause birth defects in their babies, women of child bearing age were specifically excluded from clinical trials just in case they became pregnant during the study. By the mid 1990s this position had shifted and the emphasis was on ensuring that women were properly represented in drug trials by giving information about possible risks and ensuring adequate contraception was used during clinical trials. These concerns persist today and in some studies there is still a requirement for women to use two different forms of contraception if she is to enrol in a drug study.

Being in a research trial is time consuming. There are additional medical follow ups, appointments may be longer, more frequent investigations may be needed. Women with responsibilities for caring for children, and with multiple jobs to provide enough money to live on, may find it particularly difficult to carve out the additional time. For women to be able to take part, research studies must have flexibility about appointment times and follow up visits and the costs of child care and travelling expenses need to be factored into the budget as a matter of routine.

Women with HIV may be more socially isolated than men and so ensuring that women are aware of the studies that are happening is also a challenge. There is evidence from the USA that women, once enrolled in a study, have a higher dropout rate than men.

There are benefits for contributors to research studies. Quite apart from being involved in moving the knowledge forward, participants usually have an opportunity to learn about the research topic in greater detail and to find out information that they might otherwise miss out on. People in drug studies are monitored frequently, with more investigations and with great thoroughness. In certain situations the only way to get access to a new type of medication may be through a clinical trial.

Women make up a majority of people living with HIV in the world. Designing gender equality into clinical research for HIV is becoming more frequent and needs to become automatic. The needs of particular women must be properly considered, for example women of older age. Research councils and funding bodies must make sure that the research questions relevant to women are properly resourced and supported to deliver high quality relevant information. Ensuring that women with HIV are represented on steering committees and regulatory research boards will help ensure that the issues are not overlooked. Organisations such as Positively Women and its membership are crucial to help inform the research agenda about the work that needs to be done, and to support and empower women with HIV to engage with the research questions that need to be addressed.

Dr Jane Anderson



# Report Review

## NAT's HIV ...all grown up?

I received the latest National Aids Trust (NAT) report with a question as a title: *HIV ...all grown up?*

I commend the report for having a wide scope including prevention, treatment, testing, poverty, stigma and discrimination and much more. It is very pragmatic and not only has it included priorities for action, but also more specifically: four things we want to see, in four years' time for each heading. However, as I turned one page after the other my initial sense of approval and admiration lessened considerably. Page after page it seemed that the reality of women living with HIV was not included in those challenges. Women are mentioned about three times, but only as an appendix as in: African men and women.

In the final page the report claims: 'We listen to people living with, and affected by, HIV and those who support them and we put the needs and rights of HIV positive people at the heart of everything we do.' So did they listen to women? Why should they listen to women?

Well maybe because 35% of people living with HIV in the UK are women! Women's infection has grown enormously in the past 10 years. In 1997 women accounted for only 25% of new diagnosis while in 2006 they had reached 40% of new diagnosis (HPA 2007). Doesn't this ring any alarm bells?

I am not aware of any consultation of women living with HIV by NAT to find out what were our challenges and recommendations. Since I am deeply involved with most organisations of women living with HIV in the UK I think I would have heard about it.

If such a consultation had taken place, areas, which would greatly benefit from a gendered approach, might have included:

### Prevention

It is widely acknowledged that women globally are more vulnerable to HIV because of their anatomy as well as socio-economic and cultural circumstances: especially gender inequities and gender violence. A gendered approach wouldn't just benefit women, but also men. Understanding how gender roles make both men and women more vulnerable to HIV needs to come at the centre of the debate around prevention in the UK.

### Testing

Testing HIV positive and disclosure to a partner can be extremely difficult for women who can often experience violence rejection and abuse as a result.

More research is needed in this area. But can generic testing and supporting services offer appropriate protection and support to women vulnerable to abuse and violence?

### Stigma and discrimination

Stigma and discrimination don't exist in isolation, but are often multilayered. Homophobia and racism have been acknowledged to play a central role to compound HIV-related stigma and discrimination, but so does sexism – and this needs to be more widely acknowledged.

### Treatment

Research around HIV treatment has been carried out mainly on men, most clinical trials only include about 20% of women. Consequently women often experience more side-effects than men. There is a need for more investment in treatment research that will benefit women and that looks beyond vertical transmission.

These are just a few ideas around some of the headings used by NAT in the report, but almost every section could include a gendered perspective.

I understand that consultations are not always easy, but I wonder if NAT could at least have used the PozFem UK's report *Women, HIV and Sexual Health in the UK* as a reference. This report was produced by HIV positive women this year during a consultation to review the National Sexual Health Strategy. The report gave as a key recommendation that the approach of the strategy should be gendered in line with UK laws around equality and in line with international recommendation such as Millennium Developmental Goal 3 on gender equity.

It makes me extremely sad and angry that influential leading organisations such as NAT – that holds as one of its strategic aims equitable access to treatment, care and support for people with HIV – appears to have totally ignored PozFem UK's recommendations and how gender issues impact on the whole society.

There is a lot more to be said but I would really like to hear from other people living with HIV how they feel about the report *HIV ...all grown up?* Do you think it reflects your challenges and experiences? Speak up! Otherwise others will do it for you.

### Silvia

To download a copy of the PozFem UK report: *Women, HIV and Sexual Health in the UK* visit: [www.poz-fem-uk.org](http://www.poz-fem-uk.org)

To download NAT's report *HIV ...all grown up?* visit: [www.nat.org.uk](http://www.nat.org.uk)



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

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

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

# The Female Condom



[www.femalehealth.com](http://www.femalehealth.com) [www.postalcondoms.co.uk](http://www.postalcondoms.co.uk)

# The Opportunities in Treatment Advocacy

I will start by stating the obvious – HIV treatments have given many people living with HIV a lifeline. On a personal level, if it wasn't for anti-retrovirals (with all their side-effects), I am not sure that I would be alive to write this article.

Few other patients of any disease have been as instrumental in getting treatments on the market and learning about the science behind those treatments like HIV patients have. Very few other diseases have patients as knowledgeable about their chronic illness and the treatments as those with HIV. Whatever you may want to call them – HIV treatment activists, treatment advocates or community treatment advocates, they are invaluable and they are quite thin on the ground in the UK. There are even fewer women treatment advocates.

It is important for people to be pro-active in their health, but HIV treatments can be complex. Just the names of the different medications alone put some people off. I have heard people identify the tablets by colours – and that's absolutely fine. However, there has got to be a support network of people within the community who are willing to learn about clinical trials, research and how treatments work in the body to be able to support those who are only interested in their individual health. Other people living with HIV with the experience of taking treatments are best placed to do this work and can make a very big difference, if supported.

You do not have to have a scientific background; you do not need a degree in medicine. What you need is to want to be challenged, to read and understand clinical trials, research and putting in the time to learn. Being a treatment advocate is hard work and it demands dedication. Learning how treatments work, why resistance happens in patients, and how to manage side-effects requires reading information over and over with numbing repetition. HIV is a fast-paced field. There is always new information coming out and one needs to stay on top of it all the time. You have to be able to interpret the research in a non-technical language that an ordinary patient can understand. It is extremely important that the information that the patients receive from an advocate is correct. Nothing is more important than this.

With the 2010 Universal Access To Treatment Campaign in full swing, there is no better opportunity to invest in treatment advocacy than right now. With more people needing and accessing treatment the role of a treatment advocate is critical.

In the UK, most of the treatment advocates are men. I can barely name five women treatment advocates. Yet women living with HIV are in a good position to pursue this role, as a voluntary service or as a paid job. Women living with HIV, many also caring for children and young people living with HIV can support their families better if they are knowledgeable about treatments. For many people from other countries who are currently living in the UK but hope to go back to their countries of origin at some point in their lives, treatment advocacy is a transferable skill. Treatment advocacy is a stepping-stone to other careers, but it is also a job in itself.

The best example of how revolutionary treatment advocacy led by HIV positive people can be is The Treatment Action Campaign (TAC) of South Africa. TAC is a grassroots organisation led by people living with HIV, which steered a campaign to make sure HIV treatment was provided by the government to those who needed it. TAC took the South African government to court when they reneged on their commitment to provide HIV treatment. TAC has won (and lost) some battles but their campaign continues and they have grown rapidly.

One interesting aspect of TAC is its membership. TAC is made up mostly of women, many living with HIV and with little or no formal education. The members have had to learn everything they could about HIV treatments, laws governing patents and to interpret clinical trials in order for them to be able to discuss and debate these issues with government officials and pharmaceutical companies' representatives in meetings and in court. It took determination and tenacity for members of this organisation to learn and teach other members so that they could all move forward together.

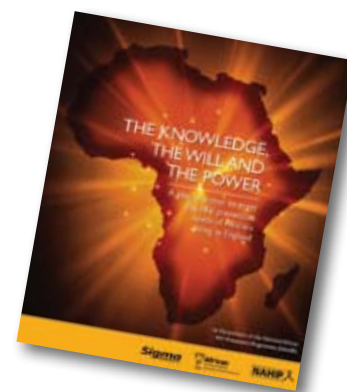
Many TAC members continue to support HIV positive members in their communities in South Africa and have built a formidable network of treatment advocates unmatched anywhere else in the world.

Surely, this is a model that can be adapted and or replicated in other places, like the UK? It is important to invest in treatment advocacy, the opportunities are there and they need to be utilised.

If you are interested in becoming a treatment advocate call HIV i-base on 020 7407 8488.

Winnie

# The Knowledge, the Will and the Power



On 27 March 2008, the African HIV Policy Network (AHPN) with funding from Department of Health for the National African HIV Prevention Programme (NAHIP) launched; *The Knowledge, The Will and the Power: a plan of action to meet the HIV prevention needs of Africans living in England (KWP)*. This planning framework was developed by Sigma Research and informed by NAHIP partners as well as other stakeholders. The planning framework is a statement of vision, a statement of the way the partnership works to reach their aim of reduced HIV acquisition and transmission.

Based on the epidemiology of how HIV is transmitted sexually through populations KWP identifies priority groups for interventions targeting Africans. As we all know, effective targeted health promotion is not about treating all African people as one audience, who all have the same prevention needs – Africans are a diverse population covering over 54 countries and 800 different language groups and varying cultural practices.

With this in mind, KWP sets out the best use of whatever finite resources we have by working in priority order starting with those who are most likely to be involved in sex that leads to HIV transmission. The first priority group are people diagnosed with HIV – not because people living with HIV have more responsibility than others for prevention, but because they have more opportunities for involvement in sex that could lead to transmission. The second priority group are partners of people living with HIV. The third priority group are people with multiple sexual partners. The fourth priority group are partners of people with multiple sexual partners and the fifth priority group are all other sexually active African people living in England.

Effective health promotion is not about making people feel bullied or chastised for the choices they make, it is about helping to ensure that they have the Knowledge [information to understand how HIV is and is not transmitted, where to get an HIV test, how to access male and female condoms, what is PEP and how to access it] ensuring that people have the Will [to want to reduce their risk of acquiring or passing on infection, to value themselves and those around them, to understand and believe that the benefit of staying well far outweighs any costs involved] ensuring that people have the Power [to access well planned and well resourced interventions, to disclose their HIV status, to negotiate safer sex and to say no to sex that puts them at risk of further infection], in order to reduce the likelihood that they will get or indeed pass on HIV. This is the core element of

the NAHIP partner's ethical approach to influencing HIV prevention behaviours.

In order to increase the Knowledge, the Will and the Power, the plan sets out aims that will influence individual Africans considering sex, service providers' capacities and approaches and decision makers and policy planners' capacities to act to reduce HIV prevention need amongst Africans.

The planning framework also helps agencies to understand what is happening with HIV prevention locally – to understand the structure of the NHS and where responsibility lies.

It also clearly sets out the importance of commissioners not only building strong relationships with local organisations and having up-to-date local data on HIV prevention need, but the importance of commissioners ensuring that they commission health providers who know and understand how to address HIV prevention needs of their African population.

The plan embodies a commitment to partnership and will, hopefully, support all those who are concerned with HIV infection and who have the capacity to influence it. This is key because when all's said and done, prevention is for life – and it is lifelong and as such it requires a committed and sustained response.

NAHIP will deliver a series of trainings to complement the Knowledge, the Will and the Power.

For more information and for copies of the planning framework please contact: [www.ahpn.org](http://www.ahpn.org)

**Angelina Namiba, Programme Leader – NAHIP.**



# A Testing Time



Going for an HIV test is possibly one of the most terrifying things you will ever have to face in life. For those of us who already know our status, at least we'll never have to endure that particular torture again, although obviously there are the ongoing day-to-day afflictions and persecutions associated with this particular disease, mentally and physically, as well as socially. At least we know our status, unlike the alleged third of the people living with HIV in the UK who remain undiagnosed. Most HIV transmission occurs from people unaware of their status, therefore diagnosing the undiagnosed is a major public health issue for the UK.

I remember all too well the horror of receiving my own positive diagnosis and that was only thanks to a homeopathic doctor who had enough medical insight and awareness of the signs of HIV to send me for a test. My own doctor, even though I had been presenting what I know now to be the classic signs of HIV infection for quite some time, failed to pick up on the fact that I might be HIV positive because I was classed as being in a non-risk category – whatever that's supposed to mean and it's a ridiculous term anyway, as there is no such thing as a non-risk category – in reality we are all at risk.

The day I received my diagnosis was the most traumatic day of my life and yet there was no counsellor immediately to hand, or direct access to any HIV support group. From that day forth, I vowed to train as a counsellor so I would be able to offer that necessary and vital support to other newly diagnosed people. I now work as a volunteer pre- and post-test counsellor on the POCT rapid 60 second HIV testing team at Body Positive North West. There are arguments both for and against this form of rapid testing, as the results are instant and therefore potentially life shattering in a very short space of time. In only 60 seconds, if the results of the test are reactive, that client's life will be changed forever and from that moment on, things will never be the same for them. Major decisions will have to be made, more or less on the spot, such as who to tell or even whether to tell anybody as the decision

to disclose could affect so many things, family relationships, career etc. For those reasons, as it is such a traumatic and life-changing event, it is vitally important that the correct procedures be in place, such as counselling and ongoing support.

The main arguments for undergoing the rapid testing is it that it cuts out the agonising two-three week wait, depending on the clinic, and the client will find out their status there and then, which reduces the risk of ongoing transmission. Before the test, the client is offered pre-test counselling and made aware of all the facts and the pros and cons of taking the test, but the fact is also stressed that if they consent to take the test there is no going back. For that reason, they are always asked to sign a consent form. If the test turns out to be reactive, the client is immediately referred the following day to hospital for the full Venus blood tests and screening for other STIs. If the test turns out to be non-reactive, at least that person knows that they have taken a very brave step and that by acting responsibly by finding out their status and with the benefit of regular testing, they are at least trying to ensure that they will remain HIV negative. In an ideal world, everyone would undergo HIV testing as part of their regular health checks and this would greatly help in reducing the spread of HIV.

For the 21st Anniversary of World Aids Day, Body Positive North West has instigated the Green Ribbon campaign. The concept of the Green Ribbon was first seen in Botswana to promote being tested for HIV and living positively with the outcome, regardless of the result. The Green Ribbon was intended to remove some of the stigma and negative associations with the Red Ribbon. The Go4it! Campaign aims to promote HIV testing, encourage people to take the test and live responsibly with the outcome, as well as educate about life with HIV and availability and improvements of treatments. Wearing the green ribbon does not denote your HIV status, it is simply an acknowledgement that you are aware of and promote HIV testing. The green ribbon raises the profile of the actual HIV test,



highlighting that there are things people can do to improve their health.

Barack Obama in the early days of his presidential campaign, on a visit to Kenya publicly took an HIV test with his wife in order to lessen stigma in association with testing. The most important thing, according to Obama was the control that comes with knowing their HIV status.

'If a US senator can get tested and his wife can get tested, then everybody in this crowd can get tested. Everybody in this city can get tested', Obama said.

If I hadn't taken an HIV test, I wouldn't be alive today. As it was, I very nearly died from AIDS-related pneumonia and had I died, no one would have ever known I was HIV positive. This continues to happen, especially to women of a certain age who are not classed in the stereotypical high-risk category and who are in long-term relationships, but whose partner per chance is unfaithful. Likewise, until doctors become more aware of the classic signs of HIV infection and promote regular HIV tests for everyone, this will continue to happen.

Adrienne

## New ActionAid campaign to tackle violence against women and HIV and AIDS

A girl born in South Africa has a 50% chance of being raped. Combine this with the number of South Africans living with HIV – currently more than 5 million – and the risk of HIV infection is extremely high.

Across the world, the threat of violence prevents women from refusing sex or insisting on the use of condoms, even when they suspect their partners are HIV-positive. Many women also face violence and abandonment on disclosure of a HIV positive diagnosis.

The UK government has just launched a seven year strategy for tackling AIDS in developing countries. In that strategy, they acknowledged that widespread violence against women increases their risk of HIV infection, but they haven't said what they're going to do about it. Now it's time to move them from acknowledgement to action, and you can help.

ActionAid wants to collect 2,876 shoes, one for every woman who contracts HIV around the world each day. These will be developed into a sculpture which we will present to the government on International Women's Day in March, to highlight both the scale of the problem and the numbers of people who are concerned.

Help ActionAid to reach our target by sending a shoe to: **put your foot down, ActionAid, Hamlyn House, Macdonald Rd, London, N19 5PG.** Please put your name and address on the back of the package.

No spare shoes? Take part online at [www.actionaid.org.uk/putyourfootdown](http://www.actionaid.org.uk/putyourfootdown)

Put your foot down on violence against women and help to end HIV and AIDS.

**act:onaid**



ActionAid/Nicolas Axelrod

# Charter of Rights of Women Seeking Asylum

In the UK, we have seen gender-sensitive practices develop in the criminal justice system for women who are victims of rape, domestic violence or honour crimes. Unfortunately, women who enter the country seeking asylum, have not seen the same gender-sensitive practices develop around the handling of their claims. And the forms of violence which women often face, such as rape, domestic violence, female genital mutilation or forced marriage, often do not fit well within the definition of a refugee in the 1951 United Nations Convention on Refugees. Ensuring fair treatment for women who are claiming asylum means that the Refugee Convention needs to be interpreted in a gender-sensitive way.

Women seeking asylum in the UK face a system, which does not often fully understand their gender-sensitive situation and therefore, needs. The new Charter of Rights of Women Seeking Asylum is an initiative from the Refugee Women's Resource Project at Asylum Aid, which seeks to set out the Rights of Women Asylum Seekers. The aim is for a major cultural shift within the UK Border Agency (UKBA) to consider gender issues in every facet of the asylum process – it covers the asylum determination system, accommodation, welfare, detention and removal. Suggestions range from providing female caseworkers and interpreters to making sure that women with children are provided with childcare during asylum interviews and are not expected to make long complicated journeys to report to the UKBA office. Additional actions suggested in the Charter include that the UKBA should undertake gender impact assessments in relation to all asylum policies, train their staff to improve the quality of decision-making in relation to women's claims and end the detention of families with children.

The UKBA has made some movements in the right direction with their Asylum Policy Instruction on gender issues adopted in March 2004. But the implementation has been inconsistent, implying that gender is still not fully appreciated as a major factor which needs to be considered in attempting to

create a fair asylum system. In addition there is, too often, a disconnection between the policy and the operational parts of the UKBA, particularly on gender issues. To ensure women's rights are recognised it is essential to create a gender-sensitive culture within the UK Border Agency as a whole.

Currently a multi-layered strategy is being developed to promote the Charter. This includes using the Charter as the basis for discussions with the UKBA through formal stakeholders' meetings and informal negotiations, setting up a Google group to provide a network for feedback between people working on the actions suggested in the Charter and holding a series of workshops to discuss with practitioners how to cooperate on promoting these issues. In addition organisations are being asked to endorse the Charter and, in doing so, commit themselves to promoting those actions which are within their sphere of influence (e.g. an NGO working for detained asylum seekers would promote the actions to do with detention). Positively Women was one of the first organisations to endorse the Charter.

The Charter has struck a nerve with 120 organisations endorsing it so far, including; Amnesty International UK, Liberty, Oxfam, Positively Women, Refugee Council and the Women and Girls Network. The official launch of the Charter showed the true interest and concern within the community surrounding these issues. It was held in Parliament with over 80 people attending including individuals representing the Equalities and Human Rights Commission, the British Red Cross, Oxfam and Amnesty International UK. Helen Bamber OBE was the guest speaker and Neil Gerrard MP, chair of the All Party Parliamentary Group on Refugees, hosted the night.

The Charter's goal is to make the asylum process both more understanding of women's needs and fairer in its decisions regarding them. The number of organisations that have endorsed the Charter and the extremely successful parliamentary launch show that there is recognition in the community of the need for this kind of reform of the asylum process.

If you would like to learn more about the Charter or if your organisation would like to endorse it, please go to [www.asylumaid.org.uk](http://www.asylumaid.org.uk).

Shawna Spoor  
RWRP volunteer



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**Life is complicated enough.  
Talking to your doctor may help you manage  
your HIV regimen better.**

# Infectiousness

One of the hottest HIV topics of the year has been the infectiousness (or otherwise) of people taking effective HIV treatment.

It takes two for a new HIV infection to occur, and it's pretty obvious that one of those people has to be HIV positive and the other HIV negative. But what's often less obvious (and, until this year, talked about) is the extent to which someone with HIV is infectious.

A better understanding of infectiousness could enable some people to make informed decisions about the risks of unprotected sex. This is an important issue for many people, possibly because they want to conceive, or they find safer sex difficult for one reason or another, or simply because they desire closer physical intimacy and the sexual pleasure that can come from that.

A number of factors affect how infectious someone with HIV is. One of the most important factors is the amount of HIV in your body – your viral load. Basically, the higher your viral load, the more infectious you are. As part of your routine HIV care, your blood viral load will be monitored at regular intervals. The amount of HIV in other body fluids – such as breast milk or genital fluids – is related to the amount of HIV in your blood.

Viral load is highest just after you're infected with HIV, so the risk of you passing on HIV to somebody else is highest at this time. Many people aren't aware that they have HIV at this stage.

Assuming you don't start any HIV treatment, your viral load reaches another peak after you've had HIV for a long time and are starting to become ill because of it.

During the period in between these peaks (which is likely to be several years long), your viral load is lower and so is the risk of passing on HIV to someone else. But having another sort of infection, including a sexually transmitted infection, can cause temporary increases in your viral load, potentially increasing your infectiousness.

HIV treatment lowers viral load in the blood as well as other body fluids – including genital fluids. Most doctors, researchers and public health experts therefore agree that HIV treatment can reduce infectiousness.

But there is currently a lively debate about just how infectious somebody with an undetectable viral load is.

In January, some senior HIV doctors in Switzerland issued a statement saying that a person taking HIV treatment who has had an undetectable viral load – the goal of HIV treatment – for at least six months should not be considered infectious to their HIV negative heterosexual partner provided that they were monogamous, took their HIV treatment properly and did not have any sexually transmitted infections.

There are two bodies of evidence used by the Swiss to support their statement. The first shows how HIV treatment can help prevent mother-to-child transmission of HIV. Studies have shown an extremely low rate of a mother having an HIV positive baby if she is taking HIV treatment during pregnancy and delivery and has an undetectable viral load.

The second set of evidence came from studies that have looked at the risk of HIV transmission in heterosexual couples where one partner is HIV positive and the other HIV negative. These studies showed that the risk of HIV transmission was related to the positive partner's viral load, and that there was a negligible risk of transmission when the HIV positive partner was taking HIV treatment and had an undetectable viral load.

Debate about the accuracy and implications of the Swiss statement is still ongoing, but a consensus appears to be emerging. Most doctors and researchers would agree that HIV treatment with an undetectable viral load does significantly reduce the risk of HIV transmission occurring.



However, there are few people prepared to say (at least publicly), that HIV transmission cannot occur in the circumstances outlined by the Swiss.

There are a number of reasons for this. First of all, there have been a small number of case reports of HIV transmissions occurring in exactly the circumstances in which the Swiss said it couldn't happen.

Then there are some concerns about the different effect of HIV treatment on viral load in the genital fluids of men and women. HIV is much more likely to be found in the genital fluids of women with an undetectable blood viral load than in the semen of men with an undetectable viral load. So it's a lot less certain for women than men – even if they have an undetectable viral load in their blood – that HIV is also undetectable in their genital fluids and that they are therefore less infectious.

What's more, there are still unanswered questions about sexually transmitted infections. Many women (and men) with HIV have chronic herpes infection and herpes can be active without causing symptoms.

Although the Swiss stated that their findings were limited to heterosexual couples, that leaves an unanswered question about the sort of sex they imagine heterosexual couples actually have? Did they mean solely vaginal sex, or were they being more realistic and acknowledging the range and variety of 'heterosexual' sex? If the couples in the study only had vaginal sex, then anybody engaging in other penetrative sexual activity may be placing their partner at greater risk than they realise. There is currently very little information about viral load, infectiousness and the risks of transmission through anal sex. Researchers are often reluctant to ask heterosexuals if they have anal sex, but when they have, they have found that quite large numbers do have anal sex. So it's possible – at the very least – that many of the heterosexuals included in the research into viral load and infectiousness were having unprotected anal sex.

A question nobody has so far addressed is the issue of treatment, viral load and the risk of HIV transmission from injecting drug use.

And now the statement is out here and the debate taking place, how should we as people with HIV react to it? Some have welcomed it as de-stigmatising. For example, there's widespread agreement that only a tiny number of new HIV infections originate in people taking HIV treatment. This goes some way to busting the myth that people with HIV are walking vectors of disease.

Others have also welcomed the statement because it's an acknowledgement of what they are already doing and is a sign that doctors and researchers are realistic about the concerns of people with HIV.

Reduced infectiousness could also be a real motivation to start treatment, or to maintain high levels of adherence for other people.

But not everyone has had this reaction: for example, some people have real concerns that it may make negotiating and sustaining condom use with partners harder.

You may well be left with questions or concerns about infectiousness. Positively Women can be a good source of support and their phone line (020 7713 0222, Monday-Friday, 10am-1pm and 2pm-4pm) provides an opportunity to discuss your concerns with other HIV positive women. Your doctor or other staff at your HIV clinic will also be able to answer questions.

You may also want to discuss the possible implications of the debate about infectiousness with your partner, a discussion that is likely to be especially important if your partner is HIV negative and you're thinking about stopping using condoms. Although there haven't been any prosecutions for reckless HIV transmission for a couple of years, such a prosecution may still be possible if you don't tell your partner you have HIV, have unprotected sex and transmission occurs.

Condoms, when properly used, can provide excellent protection against not only against HIV, but most other sexually transmitted infections and safer drug use can help prevent the transmission not only of HIV but other blood-borne infections, most notably hepatitis B and hepatitis C.

No HIV conference is now complete without a session on treatment and infectiousness and medical journals publish studies, which are informing this debate. It looks set to rumble on for some time. You can keep up to date with the very latest developments by visiting [www.aidsmap.com](http://www.aidsmap.com).



# Personal Story

## Michelle

I was 21, three months pregnant and it was five days after my wedding. I returned to the antenatal clinic for the results of routine blood tests, was whisked into a side-room and surrounded by staff. I wasn't expecting what I was going to be told, but I kind of knew in the pit of my stomach what they were going to say: HIV positive.

After that, I don't remember much more of the conversation I had with them that day, I remember their faces, where we were all sitting, what else was said was all a blur.

Irrational thoughts then set in: Where did this come from? Could I have my child? Was I going to die? Was my husband going to die? Was my baby? This is all that went round and round my head. They were telling me it wasn't so, but fear of the future and the unknown occupied my thoughts – if only I knew then what I know now!

I remember crying all the way home, through the front door and collapsing at my husband's feet. Confused. But he was there for me, he was fantastic. With the help of a great Health Advisor he went out and got tested that day. Thankfully, he was negative. Even though we knew he would have to go back in three months, the relief was still intense.



Reality hit me when I was attending my clinic for bloods, starting medication, saying something at work, being pregnant and trying to maintain a 'normal' relationship with my husband. The nurses at my HIV and antenatal clinics were fantastic. I owe a lot to my midwife, Joyce Simpson. She explained that I could do everything I used to do. She said that my baby would be okay and my husband could stay negative. If it wasn't for their support and almost non-reaction to me being HIV, I don't know if I would have coped as well. Even then, it all got too much and I clicked into autopilot – just getting through day by day until my baby arrived.

Going into labour was one of the scariest things that has ever happened to me. I was not sure how people were going to react when I told them I was HIV positive. The staff were pretty good, I didn't encounter discrimination – just misunderstanding. There were no gowns or masks, no caesarean section, I was treated the same as anyone else delivering a baby. Staff were more unsure how they should be, rather than reacting badly to me. I thought, professionals were more interested how I, a white heterosexual English woman could possibly be HIV positive without something bad having happened to make it that way. Having to explain, that was the hardest thing for me to do, I know I didn't have to yet sometimes I felt obliged to do so.

I didn't really think or deal with anything until five months after the birth of my son – who was delivered safely, naturally and negative. Postnatal depression set in and things went downhill from there. Looking back, I think that it needn't have been that way if I hadn't shut myself off and had actually spoken to others I would have discovered the support available to me. But thanks to the combined support from my GP, Selly Oak Hospital and THT Birmingham, I slowly started to get back on track. Fortunately, it was easy to access these services through my clinic and I was able to meet other positive women and positive mothers, which was one of the best things I could have done. I should have done it sooner.

I remember waiting for the results of my son's 18-month blood test. I knew that the test would be negative but, I wanted to hear the words come out of the paediatrician's mouth. I wanted to hear that my son wouldn't have to go through any more tests. It would just be me living with the virus, just me, I could cope with that.

Then I fell pregnant again. It was a surprise. The few times we were intimate, we were completely protected. The thought of transmitting HIV to my husband was worse than being positive myself.

Once again he got tested, and once again, thankfully, he was negative.

Everything then started all over again – it was back to medication, lots of bloods, scans and appointments, not being able to forget about me and my HIV. In June 2005, my daughter was born, naturally and HIV negative. At this point, I finally started dealing with my HIV properly. Hoping that I would never have to go through such an experience again – two kids, married, perfect package – I thought.

A month before my daughter's first birthday, I discovered my husband had been having an affair and had had a baby with another woman. Fear hit me all over again, but now I was on my own. I felt like I was the only one in this situation – a single HIV positive white woman, with two kids. I wondered if I would ever find anyone to love me again.

This started a whole new chapter in my life, I had never experienced living with HIV as a single person. Disclosure and rejection were never something I had to go through on my own. My family and my ex had been fantastic, I didn't want to have to go through it all again, but it was the choice that I had made – I had to.

Two years on and I am enjoying single life. I have been on dates, met men and told a few about my HIV status although sometimes I tend to clam up before it gets to the point of telling them. I come up with excuses, and reasons why they wouldn't be right – I am my own worst enemy. I know some people choose not to tell and I understand why. Those kind of thoughts have gone through my head many times – about how much easier it would be to just pretend HIV wasn't there.

I keep saying to myself that anyone who is worth the time wouldn't be phased by HIV. I am aware that it's not only decent men who can accept you as you are. I've learnt that you don't need to just stay with the first person that comes along because you think you won't get anybody better. There are good men who have reacted badly and bad men who haven't been bothered at all.

On the whole though, it's been a far better experience than I thought. I had imagined that I would be single forever – that everyone would run a mile once they had found out about my HIV status. But as the hysteria around HIV died down, people are more willing to listen and learn about HIV than to turn and run at the first mention of it. Even over the five years since I have been diagnosed, the public reaction to people with HIV, especially

women, has got better. It's not always assumed that we must have been sex workers or have slept around to be positive.

The last five years since diagnosis have probably been the hardest of my life. But I keep thinking – I'm 26 and life has just begun. I started treatment recently, which has rattled me a little. So many 'what ifs?' – I have been round and round in circles with the same thoughts. But I know now that I have no control over the past. HIV will only stop me getting on with my life if I let it. Words or comments from others can't – unless I allow it to – and I won't.

**Michelle**

Pick up a copy of  
**Positive Nation** today!



Or visit [www.positivenation.co.uk](http://www.positivenation.co.uk)  
[info@positivenation.co.uk](mailto:info@positivenation.co.uk)

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# Personal Social Health

'Personal, Social, and Health Education (PSHE) and Citizenship helps to give pupils the knowledge, skills and understanding they need to lead confident, healthy, independent lives and to become informed, active and responsible citizens.' Department for Education and Schools.

What is one of the most important things as a parent we want for our children? A fair and equal education ... Is this too much to ask in the twenty-first century? You would hope not, but it is evident that this is not the case, especially in relation to PSHE lessons. One of the failings has been that when this was introduced in September 2000, it was only as part of the non-statutory National Curriculum, not compulsory; however, schools did have to provide sex and relationships education, drugs education, careers education and opportunities for work-related learning. In September 2002, citizenship education became a statutory part of the National Curriculum in secondary schools. Unfortunately though, schools are not even meeting these basic needs with our children. Teachers are not required to have a separate teaching qualification to teach this subject, but some experience of life and a good sense of humour are indeed useful! How many teachers feel comfortable and capable of teaching such a diverse subject and talking to their pupils about sex and relationships? Very few. We expect the teachers to have an open attitude and be careful not to judge their students, but at the same time be an appropriate role-model for our children, and in the UK, teachers are expected to follow (and encourage students to follow) some kind of moral code and live respectable lives.

Schools take on the responsibility for the choice of resources and teaching strategies for the delivery of PSHE, which are appropriate for the age range and cultural identity of their pupils, including bringing in professionals from the sector and guest speakers. However, all secondary schools must have an Sex and Relationship Education (SRE) programme, which includes teaching about HIV and other sexually

transmitted infections, but then we have to be mindful that parents have the right to withdraw pupils from part or all of SRE, except for those elements that are included in National Curriculum science.

Taking all this into account, we then start to face the unfairness of the education system. We need to be asking for PSHE to be made statutory, with guidance and instruction to bring professionals in from the voluntary sector, so that impartial support can be given where appropriate, but education is delivered by the most appropriately educated individuals in their 'field'. We would not expect a dietician to facilitate a lesson on mental health, so why should we expect a teacher of English to facilitate a PSHE class which could include anything from healthy eating, bullying, smoking, alcoholic drinking and illegal drugs, adolescent development, relationships and sex; mental health to resilience?

I was very disappointed in the standard of education in relation to PSHE that my eldest son received. His school had opted to teach everything 'in-house' and not invite or allow professionals in to co-facilitate or support staff in delivering these lessons. What then further irritated me was the standard of the education then delivered was so poor, that after quizzing my son I was dismayed that he had not had any in-depth lesson on HIV and was unaware of the transmission routes. After looking into this further, it became evident that this was very similar with schools across the borough yet after further investigation, I found that a neighbouring borough treated their PSHE education more seriously and gave their pupils the best possible education.

Wolverhampton Healthy Schools Programme is a nationally accredited programme, which aims to help schools: reduce health inequalities; raise standards; promote social inclusion; and support children and young people in developing healthy behaviours. The programme works with schools to fulfil the PSHE Curriculum using four core themes:

# h Education – Is it Fair?

- 1 **PSHE** including **Sex and Relationships Education** and **Drugs Education** (including alcohol, tobacco and volatile substance abuse);
- 2 **Healthy Eating**;
- 3 **Physical Activity**; and
- 4 **Emotional Health and Well Being** (including bullying)

Once a school has signed up to the programme, there is a team of specialists who are available to: provide staff and governor training; advise on policy development; create links between partner agencies and the school e.g. theatre companies at the YMCA.

([http://www.wolverhampton.gov.uk/education\\_learning/schools/healthy](http://www.wolverhampton.gov.uk/education_learning/schools/healthy))

'In Wolverhampton, we positively encourage the development of SRE in schools as we believe it helps develop skills and confidence to enable young people to lead a healthy lifestyle and develop positive relationships. It also enables young people to discuss this important issue with parents.'

([http://www.wolverhampton.gov.uk/education\\_learning/schools/healthy/sex\\_relationships.htm](http://www.wolverhampton.gov.uk/education_learning/schools/healthy/sex_relationships.htm))

England has the worst record of teenage pregnancy and sexual ill-health among young people in Western Europe. Surely, we should be looking at examples of good teaching practice and if PSHE was integrated into the National Curriculum naturally, it would then be accepted and would not become an issue. We need to be looking at good examples across the country and advocating to get these implemented into all local education systems to ensure fair and equal education is delivered throughout the country.

**Tina**

Positively Women's *Schools Pack* addressing HIV, stigma and discrimination will be launched in February for more information see [www.positivelywomen.org.uk/schools.html](http://www.positivelywomen.org.uk/schools.html)

## Got what you need?

**Do it Right**  
Africans making healthy choices

Everyone has different needs and wants. Everyone rates what's essential to them in relation to what benefits him or her the most.

Today, it has become more essential to think there are common needs for a common benefit for all. To embrace the fact that, we are who we are because of other people. What is essential and of benefit for all, is reducing transmission of sexually Transmitted Infections and HIV.

## Do it right Competition:

For a chance to win any of this months £25 or £15 or £10, High Street shopping vouchers and campaign merchandise for runners up, tell us what you think Kobana and Janice are talking about in this conversation? (First 3 correct answers Win!)

**Kobana:** That dress looks really nice on you.

**Janice:** Thank you. It's nice to be appreciated.

**Kobana:** [Laughs] You know I appreciate you. Come here let me show you.

**Janice:** Mmmm... OK, but I hope you have what you need this time.

**Kobana:** What do you mean?

**Janice:** You know what I mean.

**Kobana:** No I don't.

**Janice:** Don't play games Kobana; we've been over this before.

**Kobana:** Woman, what are you talking about?

To submit your answer please;

Visit [www.doitright.uk.com](http://www.doitright.uk.com) and watch the complete video of Kobana and Janice, and submit your answer at [www.doitright.uk.com/forum](http://www.doitright.uk.com/forum).

**COMPETITION CLOSING ON: 31 MARCH**

For confidential information and advice on and sexual Health services, Please visit [www.doitright.uk.com](http://www.doitright.uk.com) or call free 0800 0967 500.





# Male Circumcision

In 2006 three African clinical trials in Kenya, Uganda and South Africa, in which HIV negative men were circumcised, were disbanded when preliminary results indicated that the circumcised men were up to 60% less likely to become HIV infected after sex with an HIV positive woman than the men who were not circumcised. The United Nations (UN) has added their voice to the call for male circumcision programmes to be rolled out, especially in Africa and other resource-poor countries (UNAIDS and WHO 2007) and in June 2008 the World Health Organisation (WHO) convened an expert meeting to discuss the implications of scaling up male circumcision as an HIV prevention method. Prior to that meeting, the AIDS Vaccine Advocacy Coalition (AVAC) organised a civil-society consultation in Mombasa, Kenya, on 22-23 June 2008 to discuss the gender-based and woman-centred issues associated with such a move. International Community of Women Living with HIV (ICW) urges that any further move to scale up male circumcision takes seriously the recommendation for further consultations with women (and HIV positive women in particular) regarding the gender and rights implications of any move to introduce male circumcision for specific population groups. Our concerns and recommendations are outlined here in brief.

Reducing the number of new infections among men would mean that fewer women would be exposed to HIV over time and this is something to celebrate. However, ICW members do have concerns about the way male circumcision is being promoted as HIV prevention and the possible impact on women's sexual and reproductive health and rights (SRHR), as well as on comprehensive approaches to HIV prevention. As happens all too often, how women fit into the story has been left hazy. Although WHO/UNAIDS recommendations formally recognise the complexities of generalised calls for male circumcision, how does that recognition work out on the ground?

Women's rights groups have also raised concerns about the impact of male circumcision on men's sexual behaviour and perceptions. Will men believe that if they undergo circumcision they are not at risk of HIV infection and can have multiple sexual partners and penetrative sex without a condom? Will circumcision be one more excuse for men to engage in reckless, non-consensual sex or to not use condoms? We

already know that women face high levels of sexual abuse and struggle to negotiate sex on their terms.

Discussions and programmes on male circumcision are leaving out a consideration of women's subordination to men and how women are often unfairly blamed for infecting their partners when they are first in the family to have an HIV test.

ICW member – *My husband, through whom I was infected, was circumcised because he is a Muslim. The danger about this new message about male circumcision protecting against HIV is that, even though it might provide some protection, it most certainly didn't protect him or me.*

*Once more, I can see that if women are tested positive at antenatal clinics it will be all too easy for their husbands to declare that they are circumcised and therefore could not possibly be the source of their wives' infection. Health workers are already reporting the emerging crisis of violence against women after an inadequately supported positive diagnosis in the antenatal setting, which is also resulting in danger for their unborn babies. Unless handled extremely sensitively, the male circumcision = HIV negative mantra is going to become yet another enormous barrier to disclosure among men and to care or support for their HIV positive female partners.*

If male circumcision is one of a number of ways in which men and women can protect themselves from HIV infection, fine and good. Nevertheless, we must always look beneath the surface of new developments or the results of studies, and ask how will this affect women? Will women's control over their lives be increased? Will it lead to better health for women? Will it enhance or add to equality between men and women? We do not want male circumcision to be the 'quick fix' that draws enormous donor resources, while addressing structural causes of women's HIV vulnerability remains the marginalised 'hard issue' that no one addresses.

ICW member from Namibia [on hearing male circumcision discussed on Namibian radio] – *It provoked a large number of public responses with male callers wanting to know more about male circumcision as a means of preventing transmission of HIV. I feel that if male circumcision is seen as a 100% effective prevention method for men there is a danger that men will not practice safer sex. This could cause distress for women and girls and increase their vulnerability to HIV and male violence. The blame game is going to be intensified, gender relations are*



# and the Impact on Women

## an ICW response

*going to deteriorate, women's decision-making ability, not just regarding safe sex but on quite a number of issues affecting women, is going to go back to zero, old harmful traditional cultural forms are going to be re-introduced. I am saying all this because when I was listening to the callers most of their concerns were illustrated by questions like, is it going to be safe to engage in sex with more than one woman? Can I impregnate a woman living with HIV and not contract the virus? All the callers were in favour of circumcision for their personal selfishness without thinking or taking into consideration women's views on the issue and what the negative aspects and experiences for women and girls are.*

ICW member Swaziland – *We finally, finally have our men using condoms, we women are finally able to negotiate safer sex, and this male circumcision is coming in with all this money and will wipe away our progress because of how it is being understood.*

### An ICW Response to the Issue of Male Circumcision

If male circumcision forms a part of a prevention approach that supports women's SRHR, then there is reason to be optimistic. Such an approach should be backed up by resources so that women and men, including HIV positive women and men, can be thoroughly consulted over what a comprehensive approach should look. Here are some suggestions from ICW:

- Comprehensive HIV counselling as part of the circumcision procedure that addresses issues such as sexual responsibility and women's rights to safe, consensual, satisfying sex.
- All campaign and information materials to highlight the importance of women's sexual rights and to be clear that male circumcision does not replace the importance of sexual responsibility, including condom use.
- Comprehensive and gender-sensitive sexuality education for women and men that addresses SRHR.
- Support for women's economic rights, for example, inheritance, access to resources and employment opportunities.
- Programmes to address violence against women.

- Monitoring by civil society organisations (which includes women's rights groups) of the impact of male circumcision on HIV positive and HIV negative women.

The Community Response to the Question of Male Circumcision from AfriCASO, SWAA and NAP+ includes:

- No vertical programmes should be implemented. Circumcision should be implemented as part of a holistic approach to treatment, care, prevention and testing and should include transformational sexuality counselling and access to condoms. In other words circumcision must not be presented as an end in itself but part of a prevention and care consortium.
- The potential negative effects of circumcision programmes should be monitored, especially the way in which women are treated sexually as a result of men having undergone circumcision.

(African Council of AIDS Service Organisations (AfriCASO) [www.africaso.net](http://www.africaso.net), Society for Women Against AIDS in Africa (SWAA) [www.swaainternational.org](http://www.swaainternational.org), The Network of African People Living with HIV/AIDS (NAP+) [www.rapnap.org](http://www.rapnap.org)).

### References:

- UNAIDS and WHO, 2007, New Data on Male Circumcision and HIV Prevention: Policy and Programme Implications
- Documents produced by Civil Society for the Mombasa meeting 2008
- Lawrence K. Altman, 2008, Male Circumcision No Aid to Women in Study, New York Times

### Other useful resource:

- Rochelle Jones, Friday August 3, 2007, 'Women's rights perspectives on circumcision and HIV prevention', Resource Net Friday File, Issue 336
- Marge Berer, 2007, Roundtable: Male Circumcision for HIV Prevention: Perspectives on Gender and Sexuality

This resource is a work in progress so please get in touch with us if you have any comments or would like to make any additions.

ICW  
[www.icw.org](http://www.icw.org)

# Can safer Sex and Sexiness ... Come Together?

## Positive prevention from The Pleasure Project

Can sex with a condom be sexy? Can a female condom be a sex toy? Can you skip penetration for other, more mind-blowing pleasures? What better way to find out than to read sexy blogs and stories, watch sexy films, and read titillating websites to learn some new tricks to spice up your (safer) sex life.

While safer sex campaigns and education have focused almost exclusively on the negative potentials for sex, some progressive folks have been doing things with a sexy, exciting, fun, naughty and downright dirty approach to (safer) sex for years.

The Pleasure Project ([www.thepleasureproject.org](http://www.thepleasureproject.org)), a non-profit organisation with offices in the UK and India, works to eroticise safer sex around the world through education, research and advocacy. In its efforts to spread the word about the potential of sexy safer sex, the organisation has collected 47 examples of people who are making safer sex sexy through sex education

programmes, campaigns, media, and other initiatives. They have published these case studies in *The Global Mapping of Pleasure: A directory of organizations, programmes, media and people who eroticize safer sex*, 2nd Edition, which is available on their website at: [www.thepleasureproject.org/section6/](http://www.thepleasureproject.org/section6/)

Here are some excerpts from The Global Mapping of Pleasure, which might just give you a few ideas for how to add some sexiness to your (safer) sex life.

### Sex Blogger Selina Fire says safe sex is kinky sex [selinafire.blogspot.com](http://selinafire.blogspot.com)

*'He got on top of me and we rolled on a condom. I helped him put his dick in my wet pussy and he did his hard driving, fast fucking – slam! slam! slam! It felt so good and hard, so deep. Nice to feel so well filled.'*  
– Selina Fire, from the blog story 'Lovers' Posse and more Summer Parties'

Selina Fire is a sex blogger and writer with a difference – she writes hot, outrageous, filthy stories about her life, and knows how to make safer sex hot without it being a big deal. Her sex blog is 'Sex in the City – The Real Version,' through which she tells the tales of 'A 48-year-old New York City woman's sexual adventures.' She also writes a column for Penthouse Forum magazine, and last year dedicated a whole column (April 2007) to ideas for kinkier safer sex, including mutual masturbation, tit sex, fisting, getting her partner to come on her face, and exhibitionism. Selina writes about safer sex in such an arousing way that you cannot fail to see how it can be sexy and how much she enjoys it.

### Steamy lesbian safer-sex porn from Fatale Media

Email [nan@fatalemedia.com](mailto:nan@fatalemedia.com) or [christi@fatalemedia.com](mailto:christi@fatalemedia.com)  
[www.fatalemedia.com](http://www.fatalemedia.com)

*'Instead of using the thick dental dams that were recommended for oral sex, why not have fun with wrapping your partner up in Saran Wrap?'*  
– Nan Kinney, Fatale Media

Fatale Media produces and markets lesbian erotica, including 'Safe is Desire', a safer-sex lesbian film described as 'raw lust and passion with a heart'. According to Fatale Media President,



Nan Kinney, 'Fatale's goal has always been to portray images of sexuality that mainstream adult producers overlook, so exploring and eroticising safer sex for women fit perfectly with that goal.'

Kinney said that Fatale wanted to show that safer sex techniques don't have to be a turn-off; they could be a turn-on. For example, instead of using the thick dental dams that were recommended for oral sex, why not have fun with wrapping your partner up in Saran Wrap™ [cling film]? Or, changing the condom on your strap-on makes it easier to switch from anal sex to vaginal sex and barely miss a beat.

## Hot instructional films for hetero couples: Modern Loving I and II

Director Suzanne Noble  
www.passion8.com

*'Slowly and carefully tear open the packet ... learn to love the sound of the tear...'*

– Suzanne Noble, *Modern Loving I and II*

Modern Loving I and II are erotic instructional videos for heterosexual couples that show real couples trying out different sexual techniques and positions as a way to help viewers improve their sex lives. The Pleasure Project provided condom consultancy on-set to ensure that the sex is always safe but the film is still sexy. Scenes include a woman masturbating with a female condom; a man using a female condom for anal sex with his partner; a man going down on his partner using a dental dam; various examples of male condoms and lube; and a multitude of non-penetrative, super-sexy techniques. The safer sex in the films is a beautiful coincidence and a subliminal message: that safer sex is sexy.

In Modern Loving I, the films narrator instructs: 'If you fancy trying the female condom, ask your man to give you a hand ... The outer ring stays on the outside and rubs against the clitoris for extra impact. Your man also gets off by feeling the inner ring rub against the head of his penis.'

## 'Cliterature' and sexpertise in Scarlet magazine

www.scarletmagazine.co.uk

*'If men were made to feel that using condoms made them better in bed (because women can let go and enjoy themselves without fear of pregnancy and STIs) then they would be more inclined to use them ...'*

– Sarah Hedley, Editor, *Scarlet magazine*

Scarlet is a national women's lifestyle magazine that incorporates an erotic fiction section (Cliterature) which aims to promote a safe and full sex life for women. The Cliterature section prints readers' sexy confessions, erotica book extracts and original erotic fiction from the world's leading writers, designed for bedtime reading. The magazine also features sex toy reviews, 'sexpertise' (sex tips) from leading sex educators, and profiles of iconic female sexual adventurers, such as Anais Nin and Germaine Greer.

According to Scarlet's Editor, Sarah Hedley, 'We do not feel that lecturing people about what they already know, or scaring

www.positivelywomen.org.uk

them with STI statistics is effective in changing the way people view safe sex ... As house policy all erotic fiction stories feature condom use. It's referred to in an evocative language that invites the reader to be aroused when they hear the crisp, enticing tear of the condom packet, the naughty, sharp twang of rubber... We don't gloss over it – we enjoy it. We indulge in it. By eroticising condom use, the presence of condoms becomes part of sex-play, rather than a problem.'

## Secrets to great sex for teens from Coalition for Positive Sexuality

www.positive.org

*'... suck, kiss, touch, bite, fondle, nibble, squeeze, and lick someone's body, nipples, calves, toes, neck, ass, dick or vulva ... jerk yourself or each other off, dry or using lots of lubricant ... kiss for a long time, using lots of tongue ... have sex in front of mirrors, or watch each other jerking off ... look at sexy pictures and videos...'*

– from [www.positive.org](http://www.positive.org)

The Coalition for Positive Sexuality (CPS) is a grassroots, not-for-profit, activist organisation which provides teenagers with candid sex education materials via its website. With the message 'Just say yes', CPS's website advises teenagers that 'There are lots of safe and fun ways to get off, which you probably won't learn in school!' It provides practical, sexy information about how to have great sex (if you want to) that is also safer sex.

The website also covers condom usage, use of plastic wrap for oral sex, and other contraception and safer-sex information, and provides a forum for questions and answers. And CPS has cheeky, sexy posters and information booklets. One features three teenage girls whispering to each other, with the strapline 'The secret to great sex ... water-based lube'.

the  
pleasure  
project.

The Pleasure Project ([www.thepleasureproject.org](http://www.thepleasureproject.org)) is an international education and advocacy organization working to eroticise safer sex by building bridges between the health sector and the sex world, and helping to develop the evidence base for a sex-positive approach to safer sex. The Pleasure Project provides training, consultancy, research and publications for sexual health counsellors, NGOs and others who want to take a more sex-positive approach to their work, and it helps erotic media producers to incorporate sexy safer-sex into porn films and other media. The Pleasure Project started in 2004 and, among other achievements, has mastered the art of erotic condom demonstration.

# Breastfeeding and the Prevention Issue

## Between a Rock and a Hard Place

Coming from a stint in a developed country that has far advanced in the care and treatment of people living with HIV, I found myself beset with so many questions from affected people, hoping for a cure. Are we not all living on hope, nursing hopes of a cure against so many odds? Beginning with the joyful tidings, it is commendable that with the advance in medicine, people living with HIV can have children who are HIV free. There was a time when we were so occupied with bare survival, that a desire for procreation was considered an obnoxious luxury.

I remember the first time I saw an HIV positive baby. His mother did not have a clue what the baby was suffering from, and she spent tireless efforts trying to breastfeed him and nurse the wounds which broke out in his mouth, throat and all over his body. I had a baby about the same time and it was heart-rending to see an infant who never once smiled in his short life of seven months. Breastfeeding on its own was hazardous because of the sores in the baby's mouth. The mother opted for milk supplements, but these didn't help much because the poor baby could not hold them down. He almost always vomited after being forced to drink the milk: due to the pain and stress, his mother would pour milk into the baby's mouth between cries and gulps for air. It was very distressing to watch and I vowed never to have another baby myself, although my own baby was growing normally. I do not know if I already had HIV at the time, but there were so many cases around our locality, that I was expecting a positive diagnosis any time. However, over the years I decided to have another baby, and mercifully my children have grown up well.

I have read about the recent advancements in safe breastfeeding for children with HIV positive mothers, but I am afraid this is still way beyond the reach of many mothers in the developing countries. Many women are still not able to attend health care facilities largely because

of poverty. Faced with a delicate challenge of balancing the family budget between the various household needs, and accessing antenatal care, many a woman would consider it selfish to choose an antenatal visit. What with the demands for sanitary materials, special diets, and transport costs which the family might otherwise save. These attitudes particularly prevail if the pregnancy appears 'normal'. In this way many mothers come to the point of giving birth without knowing their sero-status. This increases the chances of HIV infection. The leading newspaper in Uganda (New Vision November 3, 2008), reported the advent of repackaged Nevirapine, to help prevent mother-to-child transmission. This will be distributed in kits for mothers to give their infants in case they deliver outside a health facility.

Dr. Edward Bitarakwate, technical director of the Elizabeth Glazer Paediatric AIDS Foundation (EGPAF), a United States organisation operating in Uganda, says a formulation of Nevirapine syrup is given immediately after birth and this reduces chances of transmission by 50%. The syrup comes with a kit consisting of a foil paper to protect the medicine from sun rays. The bottle is amber, also to protect the medicine from the effects of sunlight. The foil paper has instructions for use, scribbled in English. The kit comes with a cap which is closed after drawing the syrup from the bottle, to avoid wastage and contamination. He says the required dose is drawn using a syringe from its bottle, put in foil paper, sealed and given to the mother to take home. It should be given within three days.

While these efforts to save lives are highly commended, I can still envisage many children missing out. It will still be a luxury for HIV positive mothers to have children, because many are still giving birth normally. Considering the economic factors keeping many mothers from accessing antenatal care, how many women shall know how to handle these Nevirapine kits? It is reported

that every time the Nevirapine is removed from its packaging, its shelf-life reduces by about two months. The dispensing health facilities target to give it to mothers at 32 weeks, assuming that they will deliver at between 36-42 weeks. This raises questions of proper storage, under the care of an expectant mother. How accurate can she project her expected date of delivery? Some mothers do not disclose their status to their spouses because of the need for social and economic security. Even the well-to-do are stigmatised when they do not breastfeed, so they have to put up an appearance of breastfeeding. Care-givers have been known to abandon their jobs once they discover that the mother does not breastfeed, fearing to catch HIV. In a nutshell, the stigma and uncertainty are still there, but it is so wonderful that there are chances of bearing healthy babies in this generation. Many of our predecessors were not so fortunate, hopefully this shall put an end to any pity parties and we can celebrate the joy of motherhood.

I have learnt of Stephen Gerrard, a chemical engineer from Cambridge University, who has helped devise a shield that can disinfect milk as it leaves the breast. The 'simple' nipple shield prevents HIV transmission from a breast-feeding mother to her child. The device uses a detergent used by biochemists to denature proteins for analysis. A layer of cotton-wool soaked in the chemical is added to a conventional shield and this deactivates the virus. The layer deals with the virus without having to go through heat treatment, which is the normal treatment to deactivate the HIV virus. Mr Gerrard, together with a team of five others, was assigned the task of creating a practical design for heating breast milk to de-activate the virus. Rightly, they established that this may be too lengthy a process for many women in developing countries, and many of them do not have proper facilities for heating breast milk. They were spot on with the conclusion that: 'We were concerned that using our nipple shield could be stigmatising, since it would identify a mother as HIV infected,' said Mr Gerrard. 'We're considering marketing it as a way to deliver medicines or micronutrient supplements to aid breastfeeding. For example, they can also be used for iron or iodine deficiency.' My humble submission is, congratulations! Thank you for giving some children a new lease of life. I can't wait to see this shield in Uganda!

Liz





Cate's Column

Recently I was asked, in an interview, what my dreams for the future are. I found myself stumbling over my words and grasping for something to say. I mumbled something about having a home again (it being the most pressing item on my agenda as I am currently homeless!) I went on to mutter something about wanting more grandchildren (which isn't necessarily true, if it happens that's wonderful but I don't exactly dream of it) before I was prompted to mention my forthcoming book! (Which will be available by the time this goes to print.)

The interview staggered to a close and away I went into my world, somewhat bewildered that, given a fairy godmother moment of dreams, I was left spluttering the first random things that came into my mind. It has bothered me ever since – why couldn't I come up with anything? Is it that I don't have any dreams? Or have I had so many dreams shattered that I have become too cynical to believe in them any more?

It seems to me that the concept of dreams is only really accessible when we're in a reasonably good place. It takes energy and imagination to look beyond the immediate concerns of our lives into the uncertainty of the future and find it exciting and teeming with possibilities.

Word count tells me there are 229 words in my document so far – it's taken me 229 words to say I'm depressed again. Perhaps as much as anything it's the time of year; endless grey and diminishing light, yet another World Aids Day with ever more people being diagnosed and the list of those who

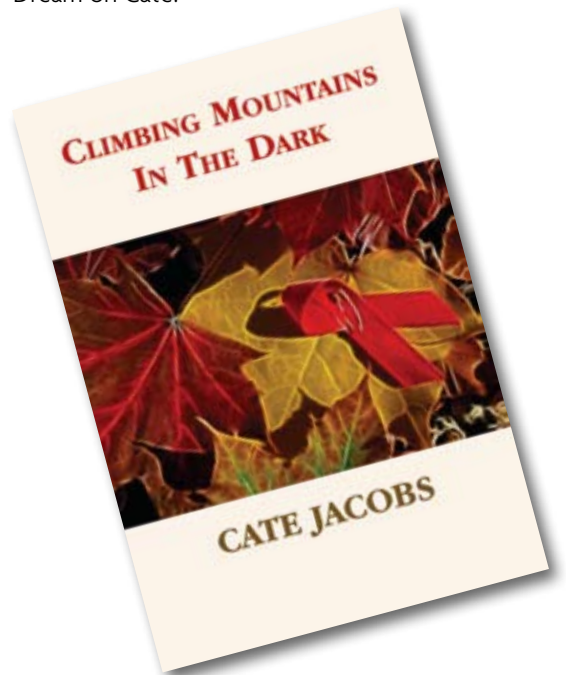
have died has become so long, that a once familiar roll call of friends has become a litany of strangers.

Protect and Respect – what do I dream of? Ironically I don't dream of a cure; I don't think they'll find one. They're looking in the wrong places. A cure can only come about by eradicating the virus and it seems to me that the only way that is going to be remotely possible is through prevention – but have we missed the boat on that one? Here we are 30 odd years on, still bashing on about condom use. Who listens and perhaps more to the point, who uses them? It would seem from the rapid increase in the numbers being diagnosed with STIs generally, that very few are.

Yes, I dream of a world without HIV but I doubt it will happen in my lifetime or the next. Until condom use and safe sex is second nature for everybody, nothing will change.

As our children grow up, we teach them all manners of things we believe are necessary for them to be acceptable and successful members of society. A lot of that teaching boils down to the ability to learn to take responsibility for themselves and to live independently. In many ways, it starts by learning to tie your own shoe laces. There we are it's as simple as that – we wear shoes when we leave the house and we need to wear condoms when we're having sex!

Dream on Cate!



We are proud to announce that Cate's book, published by HEADLAND, ISBN no 978-1-902096-52-0, is now out! You order it through any book shop or directly from the publisher.

# Mexico 2008

## – universal action now!

The theme for this year's international conference called for all of us to take whatever action we could, now. Not tomorrow or the next day but now. The venue for the conference was enormous and able to accommodate all 25,000 of us quite easily. Every morning there was a plenary session. Although I missed Bill Clinton, I saw quite a few speakers. To be honest not all the speakers were interesting, but certain speakers stood out for me. The first one was a young South African girl who has kept an audio diary. This diary has been played on radio stations throughout South Africa and has helped her and thousands of others come to terms with life after HIV. Another remarkable, young lady (probably not even old enough to buy a drink) has been living with HIV since birth and campaigning for most of her life.

Several speakers spoke about the need for harm-reduction strategies and needle-exchange as tools of HIV prevention. Very few programmes exist worldwide in spite of the fact that they have been shown to significantly reduce the risk of HIV transmission. Such programmes are urgently needed in areas where there is a significant increase in HIV infections among intravenous drug users.

Another worrying trend is an increase in HIV infections among men who have sex with men (MSM). There is also a growing phenomenon in certain countries towards criminalisation of same sex relationships. Prosecutions and arrest have led to imprisonment. This in turn may also lead to substance abuse, which increases the risk factors, which may lead to the transmission of HIV. It's a situation that just keeps getting worse instead of better.

Last, but by no means least, is the continuing additional worldwide prosecutions of HIV positive individuals for putting partners and/or offspring at risk. In many cases the prosecutions occur even when said partner or offspring does not become infected and refuses to press charges. It is clear that some governments and judicial systems consider HIV positive individuals as criminals. Amazingly, health workers and campaigners are being tarnished with the same brush. In France, AIDS campaigners have been placed on a police blacklist. In Iran, two doctors who were due to present papers at the conference were arrested and unable to attend the conference. At the time of the conference, their whereabouts were unknown.

But there was plenty of encouraging news too. Southern Africa is experiencing its highest fall in new HIV infections. Despite what is going on in Zimbabwe, apparently there are fewer new infections than in previous years. The lecture on the subject was a little too academic for me, but I understood enough to reach that conclusion.

[www.positivelywomen.org.uk](http://www.positivelywomen.org.uk)



In other sessions from the conference, it is official, women and men are enjoying sex. Several workshops and lectures focused on women's rediscovery of sexual pleasure and their newfound ability to negotiate for sex on their own terms. Although inequalities still exist, they must not blind us to the existence of other types of sexual relationships where both parties come away smiling. Now all we need to do is use some of the skills developed in the pursuit of such relationships to get both men and women to add protection to the equation.

When it came to news about the young generation it was reported that children and young people want to know more about sex, relationships and STIs including HIV. Some are showing an interest in teaching others what they have learned. We must take advantage of this interest. If we play our cards right, one of them may even hold the answer to the holy grail of HIV treatment (a vaccine or a cure). Although many studies are being carried out, the nature of the virus has made the development of a vaccine a very tricky operation.

There are more treatment and prevention options available to HIV positive and HIV negative people and, many new anti HIV medications have fewer side effects. Although new methods such as microbicides are still in the experimental stages; successful interventions have greatly reduced the risk of mother-to-child transmission during pregnancy and birth. Sperm-washing is also available in some countries such as the UK. This means that HIV positive couples and sero-discordant couples can now choose whether to have children in much the same way as other couples do. Although these developments have come too late for those who were diagnosed many years ago and have reached the end of their reproductive cycles, it brings new hope and optimism to newly diagnosed people who may still wish to have families.

Roll on 2010, Vienna is the venue for the next international conference. Vienna is only a train ride away from the UK. Maybe I should get in touch with Eurostar now and see if I can get a good deal...

**Desdemona**

# WHAT'S HAPPENING AROUND THE UK?

## BATH

Women's HIV support group. Monthly on Fridays.

Contact Stuart on 01225 444 347

## BIRMINGHAM

ABPlus run a women's support group on the last Friday of every month.

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

Terrence Higgins Trust offer one-to-one peer support for positive women.

Contact Michaela on 0121 694 6440

## BRISTOL

Terrence Higgins Trust runs a multicultural women's group, monthly on Saturdays.

Contact Bonnie on 0117 955 1000.

## CARDIFF

Terrence Higgins Trust runs an African women's group on the last Thursday of every month 1-4pm and a women and carers' group every second Monday 11am-1pm.

Contact Lorraine on 02920 666 465

## CORNWALL

Kernow Positive Support (KPS) runs a peer support group meeting monthly and a women's group every third Thursday.

Tuesday and Wednesday 10am-1pm there are drop-in appointments for HIV positive women, one-to-one also available at other times by appointment.

Contact KPS on 01208 264 866 or 01872 262 221 or visit [www.kpsdirect.com](http://www.kpsdirect.com)

## COVENTRY

Terrence Higgins Trust runs a peer support service for HIV positive women.

Women's social events are also organised.

Contact Kate or Leillah on 02476 229 292

## DUNDEE

Body Positive Tayside run a women's group every Monday 11am-2pm.

Contact Kim on 01382 461555 [www.sol.co.uk/b/bptayside](http://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](mailto:info@plpea.org.uk)

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

Contact Joe on 01473 692 616

## EASTBOURNE

Terrence Higgins Trust run African women's group monthly.

Contact Caroline 01323 649 927

## EAST SUSSEX

Support services available from Terrence Higgins Trust.

Contact Dawn 01323 649 927

## EDINBURGH

Isis runs a group for HIV positive Women every Tuesday from 1-3.30pm at Waverley Care, Solas.

Contact Maro on 0131 661 0982

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 0131 661 0982 or visit [www.waverleycare.org](http://www.waverleycare.org)

Positive Voice provides advocacy and support from other people living with HIV.

Contact on 0131 652 0754 or visit [www.positive-voice.org.uk](http://www.positive-voice.org.uk)

Positive Help provide practical support for people affected by HIV and AIDS.

Contact them on 0131 558 1122

## ESSEX – SOUTHEND-ON-SEA AND THURROCK

Terrence Higgins Trust Safe Haven run an African women's group monthly.

Contact Winnie on 01702 340 791 or 07766 428 355

## GLASGOW

Terrence Higgins Trust Scotland provides services across the west of Scotland for people living with HIV, including welfare rights advice, one-to-one support and a positive women's group.

Contact them on 0141 332 3838

## HAMPSHIRE – ALDERSHOT

Positive Action run a monthly support group for women infected or affected by HIV.

Contact them on 01252 345 019 or email [info@positiveaction.org.uk](mailto:info@positiveaction.org.uk)

## SOUTHAMPTON

Positive Action run a support group for women infected or affected by HIV monthly on the first Wednesday.

Contact Kate on 02380 225 511

# WHAT'S HAPPENING AROUND THE UK?

## LEEDS

Terrence Higgins Trust have one-to-one emotional support. Every second Monday 6-8pm, children welcome.

Contact Becki on 0113 246 9272

## 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](mailto: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

**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](mailto:losman@positivelywomen.org.uk)**

## BEDFORDSHIRE – LUTON

Bbpositive HIV positive women's support group. Wednesdays 2-5pm. Food and refreshments available.

Contact them on 01582 484 499 or 01582 485 448 or visit [www.bbpositive.com](http://www.bbpositive.com)

## MANCHESTER

George House Trust HIV run a positive women's support group and African service on alternate Tuesdays.

Contact Lynda on 0161 274 4499

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

Contact on 0161 882 2200

## STOKE ON TRENT

Esprit runs a women's group for HIV positive women. Fortnightly on Wednesdays from 11.30am-4pm.

Contact Rosie on 01782 201279

## SURREY

Positive Action runs a monthly support group for women infected or affected by HIV on the first Wednesday of the month.

Contact them on 01252 345 019 or email [info@positiveaction.org.uk](mailto:info@positiveaction.org.uk)

## SWANSEA

AIDS Trust Cymru runs a monthly women's group 11am-3.30pm on the last Wednesday of the month.

Contact them on 01792 461 848 or visit [www.aidstrustcymru.co.uk](http://www.aidstrustcymru.co.uk)

## WOLVERHAMPTON

Terrence Higgins Trust runs a support group for African HIV positive women, monthly on Thursdays.

Contact Jane on 01902 711 818

## LONDON – POSITIVELY WOMEN'S SERVICES

### Support Groups:

#### Cara – Ladbroke Grove

Weekly group for HIV positive women. 11.30am-3.30pm.

Call 020 7745 7257 for details.

#### Positively Women – Islington

Monthly support groups:

- Tuesdays for Lesbian, bi-sexual and transgender HIV positive women
- Thursdays for HIV positive women
- Parenting groups for HIV positive parents

Call 020 7713 0444 for details or crèche booking. Or see [www.positivelywomen.org.uk/supportgroups.html](http://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:

- Weekly general support
- Monthly newly diagnosed support
- Immigration support
- Evening and daytime session

PW – call 020 7713 0444

### Outreach one-to-one sessions:

Homerton – call 020 8510 7996

Royal Free Hospital – call 020 7794 0500

### Complimentary therapies:

Weekly appointments for massage, homeopathy, shiatsu and cranial sacral therapy.

PW – call 020 7713 0444



Awareness. Understanding. Commitment



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