The International Planned Parenthood Federation (IPPF) is a global network of 149 Member Associations working in 182 countries, and the world’s foremost voluntary, non-governmental provider and advocate of sexual and reproductive health and rights.

The International Community of Women Living with HIV/AIDS (ICW) is a global network of 149 Member Associations working in 182 countries, and the world’s foremost voluntary, non-governmental provider and advocate of sexual and reproductive health and rights.
DREAMS & DESIRES
Sexual and reproductive health experiences of HIV positive women
Introduction

At the turn of the new Millennium, and for the first time in the 20-year history of the AIDS epidemic, more women than men have been infected with HIV. Globally, women now account for more than 50 per cent of those infected due to a host of socio-political, cultural and biological reasons.

While more and more women become infected, the possibility for HIV positive women to live long, productive, sexually fulfilling lives and to give birth to healthy babies has increased with the expansion of access to anti-retroviral treatment (ARV) care. These developments go hand in hand with a growing demand for sexual and reproductive health services for women living with HIV.

In response, the International Planned Parenthood Federation (IPPF) - one of the world’s largest NGO providers of sexual and reproductive health – and the International Community of Women living with HIV/AIDS (ICW) – the only international network of HIV positive women – decided to explore the specific sexual and reproductive health issues facing HIV positive women in 2004 and beyond. For it is only in understanding these issues that we can develop meaningful strategies, responses and services for women living with HIV, based on a full recognition of their rights, and tailored to the realities of their lives.

These thirteen stories by women from around the world aim to highlight what it means to be a sexually active HIV positive woman. Utilizing the strong ICW network and some of its members, this collection of courageous women’s voices and faces provides insight into what HIV positive women dream about and desire in relation to their sexual and reproductive health. From these stories, the universality of what it means to be a woman living with HIV unfolds and their sexual and reproductive needs become more apparent.

The experiences and observations from these stories provide insight and will inform the design of appropriate and integrated sexual and reproductive health services. For example, positive women need increased access to prevention services and accurate information. Addressing any misinformation (which even exists within some of these stories) is an essential step to curb the epidemic. They also need support in addressing many of the psycho-social issues related to ARV side effects and complications, as well as the freedom to make choices about whether and/or when to have children. Also abundantly clear is the vital role of condoms as a protective method from re-infection and unwanted pregnancies for positive women. It is imperative that access to condoms, including the female condom, become standard in our approach towards meeting the sexual health needs of positive women.

This joint IPPF and ICW initiative is a small step towards realizing the dreams of many HIV positive women for access to appropriate sexual and reproductive health services. From creating safe environments for women to express their sexuality to ensuring their rights to have healthy children, we will be using this as a basis and guide to meeting positive women’s sexual health and reproductive needs.

We are committed to this work as we continue to find new ways of expressing humanity and care in the midst of an unforgiving epidemic and realizing the reproductive rights of every woman - regardless of HIV status.
IN 2003 ALMOST 5 MILLION PEOPLE BECAME NEWLY INFECTED WITH HIV – THE GREATEST NUMBER IN ANY YEAR SINCE THE EPIDEMIC BEGAN.

“WHEN I WAS YOUNGER, NO ONE EVER SPOKE TO ME HONESTLY ABOUT ANYTHING RELATED TO SEX AND SEXUALITY.”
VIOLETA

Violeta was born in La Paz, Bolivia, and was diagnosed with HIV in May 2000. She is currently studying for a MA in Gender, Sexual and Reproductive Health Studies.

“When I was younger, no one ever spoke to me honestly about anything related to sex and sexuality, so I learned most of what I know in secrecy.

When I was 20 years old I was raped. I suspect the two men responsible for doing this also infected me, but they were strangers and I never met them again. Being a rape survivor damaged my self-image for a long time and the impact of that experience on my sexual life was enormous. I felt destroyed and I engaged in sex without any caution or care for myself. I wanted to die. Three years after I was raped I discovered I had HIV.

I have never been pregnant, so I don’t know what it feels like, but I am conscious that for me becoming a mother is more complex than for women who are not living with HIV. Some people have said to me that women who are HIV positive will automatically put their babies at risk. In fact, all pregnancies involve risk, whether the woman is HIV positive or not. HIV does not take away my right to become a mother.

I want very much to have a baby, but I want to be confident he or she will be okay in every sense. One consequence I still carry as a rape survivor is that I am unable to trust men – I simply don’t believe what they say. But I am working on this. I want to make sure I am with the baby and the baby’s father. Then if I fall sick the father will be there to take care of the baby.

I have many fears around having a child, and at the moment I don’t have a partner to support me in this choice. It’s difficult because most men don’t want to be with a woman who might become sick. Traditional gender roles are still quite rigid in our society, so men want someone who will always take care of them and be a good wife. If I ever find a man who is prepared to live with me and to love the baby we would hope to create together, I would consider him a gift from God. The possibility of one day being a mother fills me with happiness, but it feels far from my reach right now. Because of the HIV infection, I am beginning to feel physically weaker.

One of my fears is that my strength will not last until the possibility of getting pregnant becomes a reality.

I think all sexual and reproductive health organizations and family planning clinics have to accept and understand fully how HIV/AIDS affects women. Organizations need to stop the denial and involve HIV positive women in their programmes. They should promote HIV/AIDS awareness for prevention, treatment, care and support for positive women as a matter of urgency.

The future feels uncertain and I do not dwell on it. I prefer to concentrate on the present - I am alive today and I will live today to the full. Tomorrow will bring its own problems. In my ideal future, I dream of being the mother of two beautiful babies, married to a loving husband and working in a relevant HIV organization.”
IN SUB-SAHARAN AFRICA, 15–24 YEAR-OLD WOMEN WERE FOUND TO BE 2.7 TIMES MORE LIKELY TO BE HIV-INFECTED THAN THEIR MALE COUNTERPARTS.

“THE CONSTANT NEED TO MONITOR AND TAKE CARE OF ONE’S HEALTH IS IMPOSSIBLE FOR MOST HIV POSITIVE WOMEN IN NEPAL.”
to survive. In any case, I have become very weak and I’ve also developed an allergy to most of the food I can afford to buy. The constant need to monitor and take care of one’s health is impossible for most HIV positive women in Nepal, including me. Taking proper care of my health is far too costly.

I am afraid of taking anti-retrovirals (ARVs) because they require a life long commitment, and as an HIV positive woman in a very poor country like Nepal there is no guarantee of receiving a permanent supply. There are now 25 people living with HIV/AIDS enrolled in a new Government scheme to provide free ARVs. I can’t buy these drugs myself but if I enrol in the scheme the Government might discontinue it, and then what would I do? Recently my friend – another HIV positive woman – started taking ARVs from the Government. The drugs did not suit her but there was no alternative combination available under the scheme, so now she has to buy different drugs and pay for them herself. She will not be able to do this for very long unless she finds someone to support her financially.

My life changed forever the moment I was diagnosed with HIV. I don’t have any great plans now, but as long as I am alive I want to do something to help other HIV positive women in Nepal. I am sharing my skills in literacy and handicrafts with other HIV positive women, which I hope will help them to generate enough income to survive.

Family planning clinics could help us to access Neviripine, or even other drugs to treat opportunistic infections. They could also raise awareness and empower women like myself, so we can choose whether we want to have children or not and whether we want to sleep with a man or not. It would be good if women in Nepal were able to make these choices.”

ASHA

Asha is 28 years old. She was born in Kathmandu, Nepal, where she still lives. She was diagnosed with HIV eight years ago.

“Most of the HIV positive women in Nepal are widowed and/or abandoned by their family. This means they have a lot to worry about apart from their sexual and reproductive health. Staying alive and keeping safe are their main concerns. In my case, two years after my diagnosis I married an HIV positive man. I am lucky that my husband supports and cooperates with me and that we are able to discuss sexual and reproductive health issues. But sadly we don’t have many choices available to us.

Even though I would like to have a child, I will not. Before, I was frightened that without access to Neviripine to prevent mother-to-child transmission the baby would be infected. Even though Neviripine has recently become available in Kathmandu (although not in the rest of the country), I am still afraid I would have an unsafe delivery because of my poor health. The other problem is that my husband and I could not afford a baby – it is already hard enough for the two of us
“I was sexually abused by my ex-partner and eventually he infected me with this terrible virus on purpose.”

Girls and young women presently account for 60 per cent of all HIV-positive young people.
one of my dreams is for researchers to find ways to eliminate the unpleasant side effects of anti-retrovirals (ARVs). For instance, lipodystrophy has made me feel sexually unattractive. The fat in my body has become distributed in all the wrong places and I hate standing in front of the mirror these days.

After taking ARVs for six years, I am running out of energy. I am unable to do all the things I used to do for my family and I am always worn out by the end of the day. This is very frustrating, especially for my partner who I sometimes feel is sexually starved. I have really lost my appetite for sex, which is also a side effect of the ARVs. It is an awful state of affairs, as I am sure you can imagine.

My biggest dream is for a world free from AIDS. But when I look towards the future it still seems very cloudy, especially if the policy of ‘Access for All’ is not successfully implemented in Africa and the rest of the developing world. It’s not only medications that are needed, but also food to go with them. What is the point of advocating for ARVs if the people taking them are starving?

Currently I am preparing to run the World Marathon in Nairobi which will take place in November 2004. I am not a marathon runner, but when I saw this opportunity to help raise money for my dying motherland, I decided to grab it with both hands. We may not be the policy-makers, but we can show our fellow Africans that we have not forgotten them.

Through everything, I remain positive about life and hope for the best. I have just turned 40, and as they say, ‘life begins at 40’. So my life has just begun – a life so full of HIV and high hopes!"

“MY SON, KIRIL, IS 14 MONTHS OLD. THREE HIV TESTS HAVE SHOWN HE IS HIV NEGATIVE WHICH MAKES ME VERY HAPPY.”
TANYA

Tanya is 26 years old and was born in Herson, Ukraine. She tested HIV positive in 1999 and was married two years ago. She has one son.

"Until I became aware of my HIV-positive status, I never thought of using a condom. If I ever used one, it was always at the request of the person I was sleeping with. Very rarely, with a casual contact, I used vaginal spermicidal suppositories in order to avoid an unwanted pregnancy. Over the years I had two abortions. Each time it never crossed my mind to continue the pregnancy. But times changed and I changed too. I wanted to become a mother. After trying to get pregnant for four years, the doctors told me it would be impossible to conceive without medical assistance.

Even before we were married my husband knew I was HIV positive. The first time we had sex the condom broke and to my surprise I became pregnant. With my husband’s support, I decided to keep the child.

I had been working for an HIV positive people’s organization for two years and knew almost everything there was to know about the use of preventive treatments to avoid mother-to-child transmission of HIV. My research drew on the experience of positive people in other countries and I also consulted the most prominent Ukrainian doctor who specialized in HIV/AIDS. In addition, I found somewhere to have a viral load test, which at the time cost about US$2,450.

In the end, I obtained part of my drug combination in Ukraine and part of it in Germany. I started taking medications in the 25th week of my pregnancy. I also made arrangements to have a Caesarean, which I had in the 38th week of pregnancy. My baby was born with no abnormalities and weighed almost four kilogram’s. He received Retrovir syrup for one week. Because this formula is not licensed in Ukraine, it had to be brought into the country by doctors who were interns in the US.

Today my son, Kiril, is 14 months old. Three HIV tests have shown he is HIV negative, which makes me very happy. I have a normal sexual life with my husband, and we protect ourselves with condoms. Once every six months he gets tested for HIV. So far, he has always tested negative. My husband and I do not plan to have more children because our financial situation will not allow it.

As far as my own sexual health is concerned, I dream of a constant supply of high-quality condoms in order to avoid infecting my husband. I also dream about medication for post-exposure prevention, which would be readily available for HIV negative partners to use if a condom breaks during sex.

Regarding the reproductive health of HIV positive women in the Ukraine, I have three wishes: availability of medications to prevent mother-to-child transmission; universal availability of viral load tests for HIV positive pregnant women; and universal availability of Caesareans for HIV positive women who choose them. I would also like to see family planning organizations running training programmes for midwives and obstetricians as well as developing and distributing information materials, and lobbying for new standards of treatment.”
IN 2003 THERE WERE OVER 10.3 MILLION PEOPLE AGED 15-24 LIVING WITH HIV/AIDS, AND HALF OF ALL THE NEW INFECTIONS OCCURRED AMONG YOUNG PEOPLE.

“AS A POSITIVE WOMAN, PEOPLE SAY YOU HAVE NO BUSINESS BECOMING PREGNANT.”
Rolake was born 34 years ago in Lagos, Nigeria. She was diagnosed with HIV in 1998.

“When I was with my husband I had no rights over my body. I couldn’t negotiate safer sex, even though I knew he was unfaithful and that I would ultimately have to pay the price. Eventually we had to deal with HIV infection. The thought of being labelled an HIV positive divorcee scared me so I stayed for four years in a miserable, unhappy marriage. Finally I had to choose my life and sanity over my marriage and the fear of what people would say. Now I am separated. I made a choice to survive and right now Rolake is the most important person in my world.

When you are positive, doctors make you feel guilty for wanting a child. For years after my diagnosis I was totally confused about whether or not I could give birth to a healthy baby. The thought of having a positive child paralyzed me but I was receiving mixed messages from the health professionals about the risks involved. As a positive woman, people say you have no business becoming pregnant and a single positive pregnant woman is treated worse than a criminal in the health centres. But I really want to have a baby! Now, knowing treatment is available, I have regained my hope of being pregnant some day.

Being on treatment makes you feel less contagious, less like a vector of transmission. It enables you to take back your life. But I am not on anti-retrovirals (ARVs). I don’t need them since my immune system can still cope. In spite of the health improvements I have seen other Nigerian women benefit from, I am not psychologically ready to begin taking medications. If I start, I will need to continue taking them every day for the rest of my life. Because I work in treatment advocacy, I am also mindful of the side effects these drugs can cause.

What do you do about fulfilling your sexual needs and desires when you keep getting gynaecological infections as I do? What makes things worse is that these infections are constantly referred to as sexually transmitted infections (STIs). It makes you feel totally undesirable. With treatment you have fewer episodes and things eventually become normal. You can have healthy, pleasurable, non-violent sexual activity, which is what we all desire.

I am currently establishing an HIV treatment information and advocacy organization in Nigeria. The work we are doing has a very strong gender focus, as there is little or nothing said or done about positive women and HIV in my country. I want to share what I have learned and transfer the skills I have acquired to other positive women.

Family planning clinics in Nigeria should subsidize the female condom, as it gives women the power to take more control over their sexual lives. They should begin to talk about sexuality and family planning for positive women. And they should approach these issues from a balanced perspective, taking into consideration the wider context in which we live our lives. This would include economic, social and gender constraints and how these impact on HIV positive women’s sexual and reproductive health options and choices.”
EVERY DAY AN ESTIMATED 5,000-6,000 YOUNG PEOPLE AGED 15-24 BECOME INFECTED WITH HIV.

“AS A WOMAN LIVING WITH HIV, I WISH THAT PEOPLE WOULD LEARN TO WORK TOGETHER COOPERATIVELY, AND TO TREAT EACH OTHER EQUALLY AND RESPECTFULLY - WHETHER THEY ARE LIVING WITH HIV OR NOT.”
By doing this, we can all take responsibility today for what will happen in the future. We need to realize that although people make mistakes, this is not because they are stupid. Sometimes people just do not have the information they need to make the right decisions – for instance about safer sex. People can learn about such things by asking questions or by being asked questions. But they should be given the opportunity to do this without fear and without feeling guilty for asking. Family planning clinics have an important role to play in making information available for HIV positive women. The information they provide should be easy to ask for, easy to find and easy to understand. It should also be accurate and non-judgemental! These services should be targeted towards HIV positive women, with their specific needs in mind. To make these services more effective, positive women themselves should be consulted during the planning stages.

Women have different bodies than men and there is little information available in Thailand on the potential side effects of anti-retrovirals (ARVs) on women’s bodies. Health care professionals can help us by advocating with the Government for drug trials that look at women-specific side effects.

The future for me is both challenging and mysterious. I don’t know what will happen, but whatever it is, I am prepared for it. When I am strong, I am happy to help and share my happiness with others. But, when I am sick or exhausted, I expect people to offer their shoulders for me to cry on. But I feel that most people do not understand me and think that I’m a bit odd. That is okay, they can think whatever they want to think. If I am odd, so what?”

**OOM**

Oom is 35 years old. She was born in Nonthaburi, Thailand and now lives in Bangkok where she runs an NGO that cares for the children of HIV positive parents. She was diagnosed with HIV in 1986.

“I had my first child four years ago and now I am pregnant with my second. I also have another older child who I adopted when she was a baby six years ago. Personally, I felt very proud when I became pregnant for the first time, even though it was a difficult time for me in many ways. But now my daughter has her own life, which she will be able to lead in the way she wants.

As a woman living with HIV, I wish that people would learn to work together cooperatively, and to treat each other equally and respectfully - whether they are living with HIV or not. We should all learn to overcome our prejudices against people, no matter who they are and what they do with their lives.

We should begin to learn from our mistakes and use these lessons to improve our current activities, services and interventions for women living with HIV.
I DREAM OF HIV POSITIVE WOMEN IN SWAZILAND HAVING THE LIBERTY TO CHOOSE WHETHER OR NOT TO CONCEIVE.

AS OF DECEMBER 2003, WOMEN ACCOUNTED FOR 50 PER CENT OF ALL PEOPLE LIVING WITH HIV WORLDWIDE AND FOR 57 PER CENT IN SUB-SAHARAN AFRICA.
on women, made specifically for us, and available in doses appropriate for women’s bodies and metabolisms.

In Swaziland there are no dedicated sexual and reproductive health services to address the specific needs of HIV positive women. The only available service is for prevention of mother-to-child transmission. Cervical cancer is very common among HIV positive women, and yet in Swaziland there is no effort made to encourage us to go for pap smears. The incredibly high prevalence rate of HIV in my country means this service would be highly appreciated. It would facilitate early diagnosis and immediate intervention, potentially saving many women’s lives.

Family planning clinics and similar service providers must ensure there is a wide range of female-controlled barrier methods easily accessible to women of all ages. They should also ensure their staff is well trained to work with HIV positive women. In the future I hope health care workers become far more informed about the sexual and reproductive health needs of HIV positive women. I want them to have the skills and knowledge to deal with me without being judgemental. They should be equipped to give us all the information we need to make informed choices.

I have three sons. My first one turned 21 in November, number two will be 20 in April next year, and the baby turned nine in August. None of them are HIV positive as far as I know. I plan to live life to the fullest, continuing to contribute to the world’s positive development through my work. I would be happy to see my three boys start their own families one day, and to sit and cuddle my grandchildren.”

GCELBILE

Gcebile was born in 1962 in Manzini, Swaziland. She was diagnosed in 1989 and is currently the Southern Africa Regional Coordinator for the International Community of Women Living with HIV/AIDS.

“In 1989 I applied for an insurance policy and had to be tested for HIV. The test results showed I was HIV positive. My husband passed away in 1998 due to an HIV-related illness, so now I am on my own. I am currently not in a relationship and this is a deliberate choice I have made.

I dream of HIV positive women in Swaziland having the liberty to choose whether or not to conceive. I also dream of HIV positive women having the freedom to engage in sexual relationships if we want to, without fear or criticism from others.

I believe that HIV has an effect on my sexual and reproductive organs and I want to understand exactly what these changes are. I want research done on how HIV effects my menstrual cycle and on how the medications I take affect my sexual desires. It would be great if we had medicines researched
THE OVERWHELMING MAJORITY OF PEOPLE WITH HIV/AIDS - 98 PER CENT OF WOMEN AND 94 PER CENT OF MEN - LIVE IN DEVELOPING COUNTRIES.

“I HAVE NEVER BEEN REJECTED BY A SEXUAL PARTNER BECAUSE OF MY HIV STATUS.”
I don’t believe the fact that I happen to be living with HIV should be a barrier to having sexual relationships. Quite frankly, most men would be extraordinarily lucky to have sex with me regardless of my HIV status!

I have never been rejected by a sexual partner because of my HIV status, but I was fearful about disclosing my status to my current partner when we first starting seeing each other. I chose to disclose to him in a McDonalds car park – I suppose the rationale was that if he did reject me, I would at least have the consolation of a Big Mac Meal.

We always endeavour to use condoms when we have sex. I must confess that the one time we slipped up I became pregnant. So far the pregnancy has gone without incident. I didn’t need to change my HIV medication and because I have an undetectable viral load the risk of transmitting HIV to my baby is less than one per cent. Health care professionals have been very supportive and positive during my pregnancy – I have never been made to feel that my pregnancy was an unfortunate occurrence because I happen to be living with HIV. I plan to have a vaginal delivery when I give birth to my baby. I realize that many women living with HIV opt for Caesareans because it has been suggested that it reduces the risk of mother-to-child transmission even further. However, in women with undetectable viral loads, Caesareans do not appear to offer any additional protection.

I don’t intend to have any more children after I give birth. This has nothing to do with my HIV status - it purely concerns my age. However, it certainly doesn’t mean I’m going to stop having sex!

I think family planning clinics and sexual health organizations can play an important role in addressing the diverse needs of HIV positive women, including sex workers and drug users. They are well placed to act as advocates for women living with HIV, getting important messages across to national governments and the wider society. They can help in the fight against stigma and discrimination by educating health care workers. For instance, I know of some positive women who have been pressured into terminating pregnancies simply because some health care workers are ignorant of the real risk of mother-to-child transmission.

These organizations can ensure that women have access to barrier methods of contraception and they can put pressure on pharmaceutical companies to develop microbicides. They have the potential to be powerful allies, helping empower positive women to make their own decisions in choosing when and how to have children."

Susan is 35 years old. She was born in London, England. She is twice divorced and currently cohabiting with her partner of three years. She has two children aged 10 and 12. She was diagnosed in January 1999 and works for the UK Coalition of People Living with HIV/AIDS.

“I am conscious of the fact that I’m very lucky. I live in a country where I have free access to treatment, unlike the majority of women living with HIV in other parts of the world. I was also diagnosed at a time when anti-retrovirals (ARVs) were available for treating HIV effectively, so I’ve never had to face the feeling that my diagnosis was an inevitable death sentence.

I imagine my dreams and desires regarding my reproductive and sexual health are very similar to women who are not living with HIV. I aspire to have lots of sex in the future, despite gravity and age beginning to have an alarming impact!

I hope that my HIV status does not affect any possible future sexual relationships, although ideally I plan to have a very long-term relationship with my current partner.
HIV/AIDS PREVALENCE IS HIGHEST IN SUB-SAHARAN AFRICA WITH OVER 60 PER CENT OF THE WORLD'S YOUNG PEOPLE IN THIS REGION INFECTED WITH HIV; THE MAJORITY OF WHOM ARE ALSO YOUNG WOMEN.

“I AM CRITICIZED FOR HAVING A DAUGHTER WHO IS HIV POSITIVE. NOTHING IN THE WORLD WOULD MAKE ME MISS THE EXPERIENCE OF HAVING HER.”
On the positive side, I live with a man who respects my opinions and decisions about our sexuality. On the negative side, I am criticized for having a daughter who is HIV positive. People often ask me whether I knew I had HIV when I became pregnant or whether I would prefer not to have had her. Sometimes they ask if I feel guilty for transmitting the virus to her. It seems as if I am on trial when I am confronted with this type of question. But when I am with my daughter and see the sparkle in her eyes, I know there is nothing in this world that would have made me miss the experience of having her. People judge me, but she gives me love, tenderness and understanding.

One of my main desires is to make sure that appropriate, effective and clear information on sexual and reproductive health and rights is available for positive women. For instance, we need knowledge on family planning methods for women who do not want to have children and clear information for those who do want children. HIV positive women also want to know what options exist in our country to ensure a safe pregnancy and delivery. We want to be able to protect our own health and the health of our babies.

Some family planning providers should stop being afraid to offer services for positive women. They should give out specific information about HIV infection for positive people and they should recognize that we are women like any other. We shouldn’t be pressured into getting sterilized. Instead, effective family planning methods should be available to us and we should have access to counselling so we can achieve fulfilling sexual lives. Finally, information on the importance of having regular gynaecological check-ups is vital because living with HIV increases our vulnerability to infections.

Currently I am putting my time, efforts, and financial resources into providing information to the community of people living with HIV/AIDS. There is a huge lack of information out there. Even the most essential facts like where to find HIV health centres or support groups for people living with HIV are hard to come by. I provide information through a free bi-monthly newsletter and a radio programme that reaches 60 per cent of the population in Honduras. I also give technical assistance to the Network of Positive Women, helping them get organized and gain strength. I want HIV positive women to know we can still have hope in our lives.”
GLOBALLY ALMOST ONE-FOURTH OF THOSE LIVING WITH HIV ARE UNDER THE AGE OF 25.

“WE MUST ENCOURAGE (WOMEN) TO REKINDLE THEIR DESIRE WITHOUT FEAR OR GUILT.”
“Positive women have more choices today than when I was diagnosed nine years ago. There are now effective methods for protecting our children from infection and thanks to this, our traditional childbearing culture is being saved. Our mothers and grandmothers can rejoice that their daughters can become pregnant with confidence, pride and dignity – and without guilt, especially now that drugs are available to prevent mother-to-child transmission of HIV.

In South Africa the right to sex for positive women is a complex issue. Many positive women have lost interest in sex. We must encourage them to rekindle their desire without fear or guilt. We should celebrate a new sexual freedom, exercising our right to take control and have sex safely, including with the HIV negative people many of us have as partners.

Where I come from, it is acceptable for men to talk about sex, but women are still very shy. Women must learn to talk about sex without being ashamed or constrained by religious or cultural concerns. For those of us who are educators this poses a challenge. We must try to be less conservative and more creative, making it possible for women to express their sexual experiences with joy, instead of shame.

Family planning for HIV positive women has not been adequately tackled. It is fine to use condoms on a daily basis, but the reality is that they sometimes break. Things get more complicated if you can’t rely solely on condoms. I recently enquired about family planning methods and was prescribed the intrauterine device (IUD). However, the IUD is problematic - it is easy to pick up infections while it remains in your womb. If you don’t live near a clinic where you can receive regular check ups this could be a problem for positive women.

In my experience, reproductive health providers are not helping positive women sufficiently who want to prevent pregnancy. Also, in South Africa there are no pap smear facilities available in these, and we know regular pap smears are important for all positive women. We should assess these deficiencies critically. I’d like to be able to look back in five years and see vast improvements to these services.

When I was diagnosed in 1993 I became very focused. Everything in my life and work was about AIDS. Three years ago I stopped to take a look at my own needs. I gave my work a back seat and concentrated on my own development. It was worth it. In June 2004 I married a wonderful, open-minded man. We have a responsible, adult relationship and he treats me as an equal partner in our marriage and sex life.

I also have a son who is 16. Back when I was diagnosed I explained to him what HIV was, even though he was very young. As a mother, I have always been very open with him. I might have been more conservative if I had not been HIV positive.

After I was diagnosed I said, “God, if you are there, I will do anything. Just give me my life back. I want to have a family again.” Now I have it back. Who would have thought back then that I would be married and living so far from my home? I never dreamed of leaving South Africa, but that’s what love does!”

Masi was born in Soweto Meadowlands, South Africa. She is 34 years old and has one child. She is currently living between the UK and South Africa.

MASI
“MY FORMER SEXUAL PARTNERS WERE HIV NEGATIVE, BUT THEY WERE NOT SCARED BY THE FACT THAT I AM POSITIVE. THIS LACK OF REJECTION WAS A VERY ENCOURAGING AND EMPOWERING EXPERIENCE FOR ME.”
Because of this I chose to terminate the pregnancy. The gynaecologist was visibly relieved to no longer be dealing with my pregnancy, but I will try again sometime in the future if I am still with my partner.

I always carry a supply of condoms in my bag! Condoms are easily available in Belarus. It’s not possible to obtain female condoms, but I don’t like using them anyway. In any case, they are too expensive for women in my country to afford. My former sexual partners were HIV negative, but they were not scared by the fact that I am positive. This lack of rejection was a very encouraging and empowering experience for me.

I am very interested in the challenges faced by discordant couples. What is the point of advocating for ARVs if the people taking them are starving? I have the impression that it’s more difficult for a positive woman in a discordant relationship than it is for a positive man. For some reason, it appears easier to maintain a long-term relationship if the man is the positive partner. This is probably a gender issue – men want a woman who will ‘provide the next generation’. They want to be taken care of – not to do the caring! The woman is supposed to be stable. Men are afraid that a positive woman may fall ill and not be able to provide stability in the home. Because of this and the many other problems they encounter, discordant couples experience numerous psychological problems. I plan to conduct a small study into discordant couples as part of my work.

I have no experience of sexual health organizations or much knowledge of their activities. They are something new to us in Belarus. Unfortunately, the sexual and reproductive health services that do exist focus on the needs of HIV negative women, rather than on those of us living with HIV.

Like many other women, I dream of having a family, of living with someone I love and having children together with that person. But at the same time, it is equally important for me to be successful in my professional life. On the material level, I would like my own home because at the moment I either have to pay rent or live with my parents. And of course, I would like to see my son grow up. Anti-retrovirals (ARVs) are not the key to happiness. They won’t solve all my problems or make all my dreams come true. Even if I live for only five more years I want to live the way I want to live - with or without ARVs.”

Tatiana is 27 years old. She was born in Minsk, Belarus and was diagnosed with HIV in 2000. She works for Positive Movement Belarus.

"Anti-retrovirals (ARVs) are not readily available in Belarus, but as a positive woman, even without access to these medications, I have the right to my own dreams and desires about sexual and reproductive health issues. I already have a son who is 10 years old. He was conceived ‘accidentally’. This doesn’t mean I don’t love him - on the contrary - but he was not planned.

Several months ago I made the decision to have another child. I wanted this very much and so did my current partner, who is also HIV positive. When I spoke to my gynaecologist about our desire to have a child she put up many barriers and displayed a very negative attitude towards our plans. This was extremely distressing for me, but I went ahead with the pregnancy nonetheless.

Sadly, the pregnancy was not successful this time around, but not because of HIV. After routine tests, I was told my child would be born with Downs Syndrome.
“IN THE FUTURE I WANT TO CONTINUE LIVING POSITIVELY TO THE BEST OF MY ABILITIES.”
SHEERIN

Sheerin is 38 and was born in Tehran, Iran, where she lives today. She is single and has no children. Sheerin was diagnosed with HIV in 1989.

“As an HIV positive woman living in Iran, my main desire is to possess the freedom and opportunities I require to maintain my sexual health. These include unrestricted, cost-free access to sexual health services and treatment.

I would also like all positive women in Iran to be provided with up-to-date, accurate and appropriate information and education on sexual and reproductive health issues. These should be tailored to their needs rather than to the needs of women who are not living with HIV.

Although I have never had children and do not plan to do so at this stage in my life, I truly wish for a day when for all HIV positive women in Iran who want to become mothers can do so safely, without the fear of other people judging or condemning them.

It is also my desire that HIV positive women have free access to the latest developments and antiretroviral (ARV) treatments to prevent mother-to-child transmission.

Over the next few years I would like to see family planning clinics and service providers begin to advocate for and provide access to free HIV testing. In addition, they should advocate for clinical monitoring of those who are diagnosed positive. Family planning services should provide the following: counselling, treatment, educational programmes on sexual and reproductive health and rights, and birth control/prevention measures for HIV positive women. These are important holistic areas of work concerning the needs of HIV positive women that are often neglected.

In the future I want to continue living positively to the best of my abilities. I will keep educating myself with up-to-date knowledge on HIV issues and treatment possibilities. In order to do this for themselves, positive women in Iran need easy access to this kind of information. This is relatively simple for me as I have contacts abroad and can speak and read English. However, for other women in my position it is not always so straightforward, and information needs to be made available in our language. I also hope to keep up with my current work which involves helping people living with HIV, and others, in all areas of prevention, treatment education, positive living, counselling, care, support and advocacy.”
Globally young women are 1.6 times as likely to be living with HIV/AIDS than young men.

“One day I hope to have access to anti-retrovirals on a sustainable basis.”
and this in turn has resulted in a loss of sexual desire for me.

I have many plans, hopes and dreams for the future. First of all, one day I hope to have access to anti-retrovirals (ARVs) on a sustainable basis. Having these medications would enable me to maintain my health and thus achieve many of my other dreams, which all depend on me being well enough to keep going. One of my big dreams is to run my own business and be financially independent. If I ever manage to achieve this, then I would like to earn adequate money to buy a house of my own. Currently most of my income goes on renting, but owning my home would give my family and me far more security.

It is also very important for me to see my children educated and to ensure a good quality of life for them. Lastly, I’d like to participate fully in initiatives that educate people about HIV/AIDS. I’d especially like to work with women and girls, as they are particularly vulnerable to HIV in the society I live in.”

AAISHA

Aaisha was born in Sudan, where she still lives. She was diagnosed with HIV in 1998.

“I am a housewife, which is a full-time job for me. In addition to my husband, I have eight children to take care of. We have four boys and four girls, so there are 10 of us in the family all together.

My dream is to be able to have a satisfying, problem-free, sexual relationship without fear. I believe condoms are very useful and can assist women living with HIV in sexual and reproductive health matters. For me, having condoms available and being able to use them with my husband has been a positive experience. Condoms have multiple uses. Not only do they enable you to protect your partner against HIV infection, but also they are very useful to couples for family planning purposes.

But personally I have found that using condoms can sometimes be problematic as well. For instance, after using them, there have been occasions when I experienced a burning sensation during urination. I have also experienced a loss of sexual enjoyment when I use condoms and this in turn has resulted in a loss of sexual desire for me.

I have many plans, hopes and dreams for the future. First of all, one day I hope to have access to anti-retrovirals (ARVs) on a sustainable basis. Having these medications would enable me to maintain my health and thus achieve many of my other dreams, which all depend on me being well enough to keep going. One of my big dreams is to run my own business and be financially independent. If I ever manage to achieve this, then I would like to earn adequate money to buy a house of my own. Currently most of my income goes on renting, but owning my home would give my family and me far more security.

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VISION / MISSION / CORE VALUES

IPPF’S VISION
IPPF envisages a world in which all women, men and young people have access to the information and services they need; a world in which sexuality is recognized both as a natural and precious aspect of life and as a fundamental human right; a world in which choices are fully respected and where stigma and discrimination have no place.

IPPF’S MISSION
IPPF aims to improve the quality of life of individuals by campaigning for sexual and reproductive health and rights through advocacy and services, especially for poor and vulnerable people. We defend the right of all young people to enjoy their sexual lives free from ill-health, unwanted pregnancy, violence and discrimination. We support a woman’s right to choose to terminate her pregnancy legally and safely. We strive to eliminate STIs and reduce the spread and impact of HIV/AIDS.

IPPF’S CORE VALUES
IPPF believes that sexual and reproductive rights should be guaranteed for everyone because they are internationally recognized basic human rights.

We are committed to gender equality, and to eliminating the discrimination which threatens individual well-being and leads to the widespread violation of health and human rights, particularly those of young women.

We value diversity and especially emphasize the participation of young people and people living with HIV/AIDS in our governance and in our programmes.

We consider the spirit of volunteerism to be central to achieving our mandate and advancing our cause.

We are committed to working in partnership.

The International Community of Women Living with HIV/AIDS (ICW) is the only international network of HIV positive women. Our vision is a world where all HIV positive women:

- Have a respected and meaningful involvement at all political levels where decisions that affect our lives are being made;
- Have full access to care and treatment; and
- Enjoy full rights irrespective of our culture, age, religion, sexuality, social or economic status/class and race

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All statistics were sourced from UNAIDS.