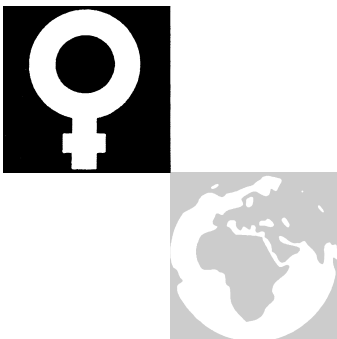


A Positive Woman's Survival Kit



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ICW Membership Form Evaluation Sheet

A *Positive Woman's Survival Kit* is based on the shared experiences of women living with HIV around the world. However, we are not all the same. We have different opinions and approaches to life, work, relationships, religion, politics **and** HIV/AIDS. *The Survival Kit* reflects this.

The information presented in this kit is published as an education resource. It does not indicate that ICW necessarily endorses any of the treatments or therapies described.

Introducing A Positive Woman's Survival Kit



Hallo, Shalom, Jambo, Dzień Dobry, Sawat-Dii, Guten Tag, Hey, Konnichi Wa, Namaste, Sat Sri Akal, Chemchor, Yasas, Salaam Alikhom, Zdrast-Viytye, Hola, Bonjour, Makadii: **Welcome to A Positive Woman's Survival Kit.**

You can read *The Survival Kit* all at once or choose sections of special interest to you. The first part of the kit focuses mainly on the voices of positive women. The second part consists of Fact Sheets which provide you with more information on specific subjects. You can add your own notes to the kit.

Sharing information across borders

The Survival Kit has been produced by and for women living with HIV and AIDS. We have involved positive women from all over the world in the process of creating The Survival Kit. Many of these women have been living with HIV and AIDS for a long time and have much to share.

This kit is primarily aimed at women in countries with few resources therefore we chose not to focus on treatments which are not widely available.

A Positive Woman's Survival Kit is part of an ongoing process. The 'Fact Sheets' included here are only a beginning. In the future we aim to produce more 'Fact Sheets' on subjects of interest to positive women. These could include information on common opportunistic infections; TB; how to cope with diarrhoea and many others. Be sure to fill in the evaluation form included with *The Survival Kit* and give us feedback on what you would like to see.

'Meeting other women sharing our experience helps remind us that we do belong - that we are not alone.'

Maria, diagnosed
1987, Uganda

'Thank you for accepting me as a member of ICW I have shared all the information, educational articles and newsletters with my other friends. We want to form an association for women. We have fear of much discrimination, stigmatisation and isolation in our communities but are strong enough to struggle with the problems. Can you send us the experiences of other similar groups?'

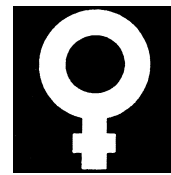
HIV positive woman, Ethiopia

We hope the kit gives you the confidence to begin to ask your own questions. Positive women all over the world are drawing inspiration and strength from each other. *The Survival Kit* is part of that process. We hope it encourages you and helps you to lead happy and healthy lives.

**Share the kit with other women.
Let it inspire you.**

If you don't understand something you read, find the courage and ask someone about it. There is no such thing as a 'silly question'. Everyone learns by asking questions and no one knows all the answers.





The International Community of **Women Living with HIV/AIDS** (ICW)

What is ICW?

- ICW stands for the International Community of Women Living with HIV/AIDS
- ICW is an international network run by HIV positive women for HIV positive women
- Any woman living with HIV can become a member.

ICW was founded in Amsterdam in 1992 in response to the desperate lack of support and information available to HIV positive women worldwide. Our aim is to improve the situation of women living with HIV through self empowerment and to provide accurate and accessible information.

'My life changed from the moment I went to the meeting. The impact of meeting other positive women who were not letting the virus rule their lives and who believed we could work in our individual countries to network with other HIV positive women and break down isolation was huge.'

Linda Reed, diagnosed 1988, Eire

ICW:

- Reaches out to HIV positive women around the world
- Unites HIV positive women around the issues that affect us all
- Ensures that HIV positive women are visible and that all our voices are heard
- Acts as an information resource
- Challenges discrimination, stigma and abuses of HIV positive women's rights
- Encourages self empowerment and self sufficiency.

'Receiving support from others, thinking positively and being smart, keeps me going.'

Scovia, diagnosed 1990, Uganda

'Do I look like a figure or a statistic? I am a person, a woman living with HIV.'

Bridgette, HIV positive, Zambia



World AIDS Conference, Amsterdam 1992

HIV positive women across the globe are actively involved in all of ICW's work.

Join Us!

ICW membership is free to all HIV positive women. Fill in the membership form included in the kit and send it to the London office.

Getting more Information

If you want more local information or if you want to get involved in ICW's work, please get in contact with your region's Key Contact.

A list of current ICW Key Contacts is available from ICW London Office.

Some international and regional AIDS organisations are listed in Fact Sheet 10.



Key contacts in Cape Town 1995: Claudia, Dorothy, Daniela, Bev, Winnie (deceased), Esme (deceased), Linda, Yolanda and Jeanne

ICW:

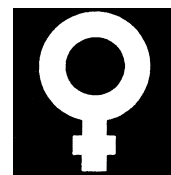
- Works with 15 Key Contacts, HIV positive women whose task it is to organise and network in their regions. The regions are: Africa, Asia and the Pacific, Europe, Latin America and the Caribbean, and North America
- Facilitates international information exchange via our quarterly newsletter, ICW News
- Organises international meetings for HIV positive women
- Supports HIV positive women in setting up self-help groups
- Facilitates an International Speakers Service which provides expert HIV positive women speakers for conferences and the media
- Advocates for the participation of HIV positive women in service development, research and policy making.

'There are no words to describe the power of bringing together HIV positive women. When I met other women facing this disease, just like I was, I realised I was not alone.'

Antigone Hodgins, diagnosed 1990, USA

'During the summer of 1992 an International AIDS Conference took place in Amsterdam and one night towards the end of the coverage on TV a miracle happened. There on the TV were a group of women, all living with HIV, standing in front of the world saying they existed and were going to do something about the invisibility of women in the epidemic. These were the founders of ICW. I wanted to crawl inside the TV and touch them.'

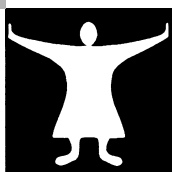
Martina Clark, diagnosed 1992, USA



ICW Twelve Statements

To improve the situation of women living with HIV and AIDS throughout the world:

- 1 **WE NEED** encouragement and support for the development of self-help groups and networks.
- 2 **WE NEED** the media to portray us realistically and not stigmatise us.
- 3 **WE NEED** accessible and affordable health care (conventional and complementary) and research into how the virus affects women.
- 4 **WE NEED** funding for services to lessen our isolation and meet our needs. All funds directed to us need to be supervised to make sure we get it.
- 5 **WE NEED** the right to be respected and supported in our choices about reproduction. This includes the right to have children and the right not to have children.
- 6 **WE NEED** recognition of the right of our children and orphans to be cared for and of the importance of our role as parents.
- 7 **WE NEED** education and training of health care providers and the community at large about women's risk and our needs. Up-to-date, accurate information concerning all issues about women living with HIV/AIDS should be easily and freely available.
- 8 **WE NEED** recognition of the fundamental human rights of all women living with HIV/AIDS, particularly women in prisons, drug users and sex workers. These fundamental rights should include the right to housing, employment and travel without restrictions.
- 9 **WE NEED** research into female infectivity, including woman to woman transmission, recognition of and support for lesbians living with HIV/AIDS.
- 10 **WE NEED** decision making power and consultation on all levels of policy and programmes affecting us.
- 11 **WE NEED** economic support for women living with HIV/AIDS in developing countries to enable them to be self-sufficient and independent.
- 12 **WE NEED** any definition of AIDS to include symptoms and clinical manifestations specific to women.



"These twelve statements were agreed at the first meeting of ICW in Amsterdam in 1992. It was the first time that HIV positive women had come together globally and expressed their needs. They are the foundations on which ICW was built."

Jo Manchester, founder member

Dealing with an HIV Positive diagnosis



I have just found out I am HIV positive. What does this mean?

HIV stands for Human Immunodeficiency Virus. Being HIV positive means you are infected with this virus. Your body reacts by producing HIV antibodies. Antibodies are developed in the blood when your body fights viruses like HIV. These antibodies can be detected by a blood test. If a test shows that HIV antibodies are present, then you are HIV positive.

HIV is found in an infected person's blood, breast milk, semen and vaginal fluids, and menstrual blood. During unprotected sexual intercourse, HIV can pass from someone's infected blood, semen or vaginal fluids directly into another person's blood stream, through the mucous membranes lining the inside of the vagina, penis or rectum. HIV can be transmitted by HIV infected blood transfusions or contaminated injecting equipment or cutting instruments. It can also be passed to a baby during pregnancy, delivery and breastfeeding.

It is frightening to find out you are HIV positive. Many of us found it hard to believe at first, especially if we felt healthy when we were diagnosed. Some women learned about their HIV status a long time after they had stopped injecting drugs. Others of us were told while still injecting drugs. Sometimes we found out after our partner became ill or died. Others discovered they were HIV positive only when they started to get ill. Sometimes our children started to get ill at the same time.

'I tested positive in 1993 after my husband died. Along with the massive shock, I also felt a huge mixture of other feelings including shame and embarrassment. I cried a lot during this time. I thought I was dying.'

Liza Enriquez, diagnosed 1993, Philippines



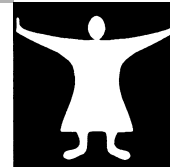
'When the doctor told me I was so shocked I wanted to end my life.'

Diana, HIV positive, Malaysia

'I obviously was not a gay man. I had never been an injecting drug user, nor had I ever had a blood transfusion. What I was to learn, however, is that engaging in unprotected sex with a man who had been a close friend my entire adult life, I became infected in 1985 at the age of fifty.'

Jane Pecinovsky Fowler, 63 years old,
HIV positive, USA

Not all of us discovered we were HIV positive voluntarily. We may have been tested without our knowledge or against our wishes. Our positive status may have been revealed to other people either maliciously or carelessly.



'About six months after the accident I became very ill. I was admitted to another hospital where they tested my blood. I know now the test was positive but no one told me. I was discharged and told everything was okay. But after three days the police came to my family's home in the middle of the night and arrested me. The police gave my photo and a statement to the newspaper and in the morning a crowd gathered outside the prison.'

Ruby, HIV positive, Bangladesh

Until we were able to find out more about HIV many of us were too frightened to let anyone touch us or to talk about it.

'To be honest, up to this day I do not know how I felt. I think at that time every sense in my body froze, especially the sense of feeling, because there was no pain, no anger, no tears, nothing. I was just numb. I suppose I still thought it was not true.'

Petudzai, diagnosed 1992, Zimbabwe

I became a drug addict at the age of seventeen. Two years after kicking my habit, I began to relax and think about starting a new life. Then I got my HIV diagnosis. It was a shock.'

Oom, HIV positive, Thailand

Patricia, Argentina; Giovanna, Peru



Even if you're ill now, it does not necessarily mean you always will be. Some of us have been severely ill and recovered our health. Once you know you're positive, there are ways to improve your health and feel more in control of your life.

'When I first met my husband we didn't seem to have a care in the world. But now AIDS is always there in the back of my mind. We make plans and then I think, God what are we doing this for? And he'll say, you can't think like that. You've got to make plans for the future.'

Pat, HIV positive, Uganda

If I'm HIV positive does it mean I have AIDS?

Being HIV positive does not automatically mean that you have AIDS. AIDS stands for Acquired Immune Deficiency Syndrome. It is used to describe a group of infections and diseases. These may include weight loss, fungal infections, diarrhoea, pneumonia and certain cancers. If your immune system is weakened by HIV these conditions may develop.

The period between infection with the virus and the development of the first symptoms of AIDS can vary greatly. It can take anytime from a few months to more than fifteen years. In some wealthy countries, there are new drugs which are helping some people to stay well longer. Unfortunately, these drugs are not available around the world. Even in these countries, like the USA, not everyone has access to them and they don't work for everyone who takes them. For some people the side-effects are hard to bear.

'Through involvement in the project, people, including myself, often forgot they were infected and felt happiness.'

Agnes, diagnosed 1990, Uganda



Getting to know
each other

'When I took the protease inhibitors, my T-cell count went up and my viral load started going down, and I felt better than I ever had before.'

Nora, diagnosed 1987, USA

'For me quality of life is number one. At this point I don't want to deal with the side-effects. I look at friends and others who are on these regimens and watch them go through so many changes. I hear the vomiting. I see the fatigue, I listen when they talk about nausea, depression, high cholesterol, diabetes, high triglycerides, lipodystrophy.'

Nilda Rodriguez, diagnosed 1986, USA

Sometimes there are contributing factors which play a part in the development of AIDS, like not being able to eat well enough or suffering from high levels of stress.

But there are steps we can take, no matter how small, to enhance our health, stay well and prevent illness. Our lives are worth it!

'It has brought my family and friends closer together and showed me the strength my husband has.'

HIV positive woman

Will my feelings ever change?

No one who receives an HIV positive diagnosis reacts in exactly the same way. However, women who were diagnosed some time ago remember experiencing a whole range of feelings, including shame, anger, guilt, fear, sadness and depression. At first your emotions may be very intense. Try not to panic. Gradually these intense emotions become more manageable. Instead of being overwhelmed by an HIV diagnosis, you begin to **live** with HIV.

'Today the virus and me, we are living together equally. All of us have to struggle with life, but some of us have a higher mountain to climb.'

Idar Maria Lorenz Lopez, diagnosed 1990, Brazil

Occasionally the panic returns, especially when you are isolated or ill. If it happens try to find someone to talk to who you feel safe with.

'When I heard about my HIV status, I wanted to commit suicide to spare my family from worrying about my health. But then I thought it would hurt them even more. And after all, why die sooner, I loved living too much. I'm glad I'm still here. HIV is a part of me and even if it's not always fun living with it, life is still surprisingly beautiful.'

Isabelle Defeu, HIV positive, Belgium

If you are feeling alone and isolated, remember you are not the only one. There are thousands and thousands of women like you who have gone through the same emotional upheavals. Many are now living productive, healthy lives.

Lynde, Beatrice, Martine



'I try to face things bravely and stand on my own two legs but sometimes I feel I can't and then I feel like committing suicide. My boss said not to cry. He said there are many people like you and they are facing this situation bravely. I didn't believe him.'

'Then my boss encouraged me to come to this conference. I saw so many people, the same as me, laughing, smiling, living well and working together. I used to think I was the only person suffering for HIV. I have now been so inspired. I want to make sure what happened to me never happens to anyone again.'

Ruby, HIV positive,
Bangladesh



Disclosure

2

Anyone who has ever received an HIV positive diagnosis faces difficult decisions about telling people about their HIV status.

Making decisions

It can take time to come to terms with a positive HIV diagnosis. Don't feel you have to rush into coping or telling people. You may not tell anyone at first and then find people you feel you can trust. You may tell only the person closest to you. Even if you have the urge to tell people right away, it's a good idea to wait a bit and think about what the consequences might be. Some HIV positive people are able to be completely open about their HIV status. Others aren't. Whatever the case, in some situations it is better to be cautious.

'Around the time you first get tested positive, you're bursting to tell people. I told the wrong person, when he was very drunk he told his girlfriend, and she, in turn, other people.'

HIV positive woman

Unfortunately, for many HIV positive people, the choice of whether or not they disclose their status is taken out of their hands. Any involuntary disclosure is a breach of confidentiality.

'My reason for going completely public with my sero status was, in a way, to save myself from hiding a secret which a number of people already knew; a public secret, in fact.'

The late Elizabeth Ofwono, HIV positive, Uganda

*Colette Moussa, HIV positive,
lecturing nurses about AIDS
Central African Republic*

Being HIV positive is no reflection on your worth as a human being. HIV is a virus and nothing to be ashamed of. Unfortunately, there are still far too many ignorant and prejudiced people in the world who judge us for being HIV positive. ICW is totally opposed to any discrimination and stigmatising of positive people and committed to challenging it wherever it exists.

'I remember very well thinking (at the time I found out my HIV status) I didn't do anything strange or wrong, everybody has sex – so why should my family or friends judge me? HIV is not a consequence of misbehaviour, it's only a virus that can make me ill. I could have had an accident, cancer or something else, but my fate gave me this virus. I'll have to live with it.'

Isabelle Defeu, HIV positive, Belgium

Being able to confide in a few close friends or relatives who can give comfort and share our feelings has often lessened a sense of isolation. For many of us, meeting other positive women was very important. We could trust and understand each other. We could share information and experiences. Also in some countries there are organisations which can provide confidential support for women who have just discovered their HIV status.





Ex-sexual partners

It can be hard to tell an ex-sexual partner about an HIV diagnosis. It will depend on what kind of relationship you had in the past and have now. Do they know anything about HIV and HIV testing? It depends too on what you want an ex-partner to know about you. Will they want to hear what has happened to you? Talking to other positive women about how they handled telling ex-partners may help you make the best choice.

Helpful Hints

To help you decide who you want to share the news of your HIV status with, make a list or think about all the people who you might tell.

For example:

- mother or father
- partner
- children
- close friends
- colleagues at work
- religious or spiritual guide
- people from your place of worship
- support groups or HIV organisations
- political organisations
- class mates in school or college
- teachers.

Think about each person or group. In each case, what are the advantages or disadvantages of disclosing your HIV status?

- What would the consequences be for you if your HIV status was generally known?
- Would your community or friends support you?

'At first I only told my father who did a lot of research and found out I could still live a long time. I was so surprised because I thought I was dying.'

Liza Enriques, HIV positive, Philippines

'I tried to get him admitted to a school. But the school authorities threw him out the moment they realised that his mother is HIV infected.'

Selvi, HIV positive, commercial sex worker, India

If you are going to tell someone, try practising how you will break the news to them. What will you say? Try to imagine what kind of responses you will get once you have shared your news.

'I haven't told my mother because I'm so far away and I don't want to tell her over the phone. She's just lost her mother and sister to cancer. I told some friends first and it turned out they weren't prepared and I had to give them support. So with my mother I think I should be with her and not just send her a bomb.'

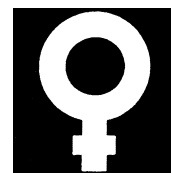
Ale, diagnosed 1998, Argentina

Sometimes there are parts of our lives besides HIV which other people find difficult to accept.

'I think that when positive women learn that I'm a lesbian they sometimes withdraw a bit. But then they learn to accept me. It doesn't make a lot of sense to many people, but lesbianism is a reality in Africa.'

HIV positive woman, Africa





Juliet from Uganda

It was hard for any of us to predict exactly how our families, friends or community would react to an HIV diagnosis. Some have been extremely supportive. Others have been rejecting or abusive. Some have changed their negative response and become supportive once they've got over the initial shock. On the other hand, some of us have told our family and close friends and to our surprise, we discovered we had to give them support because they were so shocked and distressed.

'Well, not a lot of people knew and the people who didn't know and found out I was positive and pregnant at the same time, they were a bit shocked. You have to educate people when you tell them stuff like that, you can't just give them the news and then leave them in the dark. You've got to have a network and back people up so they've got someone else to talk to about their feelings.'

Cathy, 21, diagnosed 1995, Australia

It helps to remember that for most of us, disclosure is not an 'all or nothing' situation. Going completely public is different from telling your closest friend, your mother, or your partner. If you want to be completely open consider the possible repercussions and build up a strong base of support.

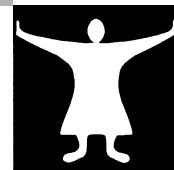
No one can pretend telling others our HIV status is easy and there are no simple set of rules to follow. Follow your instincts and take your time - *you are not alone*.



Daria from Brazil. HIV positive since 1986

'Before disclosing to anyone, prepare yourself. I couldn't go outside because everyone would stop and ask questions. I didn't know how to answer.'

The late Auxillia Chimusuro, the first woman to be publicly out as HIV positive in Zimbabwe.



3 Staying Healthy

Taking care of ourselves and our loved ones

Women often take better care of others than themselves. But survival depends on taking care of yourself too. We can learn how to take care of ourselves by caring for our bodies, nurturing our minds, and maintaining our emotional or spiritual health. Maintaining and valuing our own health is good for us and our families and children.



ICW members in Zimbabwe

'I don't find it easy to take care/make time for myself - I tend to put my children and partner's needs before my own. But I have realised to be able to care for them properly and to be able to continue doing the work I'm doing with ICW and the HIV positive women in my country, I have to take care of myself first. If I get sick I'm no use to anyone.'

Linda Reed, diagnosed 1988, Eire

Women often are treated as second class citizens and taught they are less worthy than men. Learning to value ourselves is part of developing self esteem and finding our strength as women.

'I used to see the world in black and white. Now I see it in colour. I have developed skills and deepened friendships.'

HIV positive woman, Peru

'In Uganda there are so many women living with HIV/AIDS who cannot support themselves financially. They struggle to earn a living while having so many orphans to look after. This is so difficult for working class women. All these difficulties mean women may be forced to find a man to support them.'

Anna, diagnosed 1993, Uganda

Specific needs

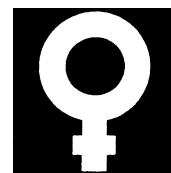
We need to focus on the specific needs of different groups of positive women. We all have the virus but we have different needs.

'I'm a lesbian and I hope that our health and the different issues we face are taken into account. I still think there needs to be more known about woman to woman transmission.'

Hazel, HIV positive, USA

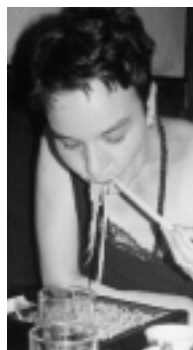
Viv, Giovanna and Leigh





The necessities of life

We know that nutritious food can help maintain healthy bodies and provide vital energy. Where money or food are scarce, it may be hard to meet the basic nutritional necessities of life. However, you don't need fancy foods to have a healthy diet.



Claudia eating

'In the developing world the golden rule is "Did your great grandmother eat it? If she didn't, you should probably avoid it." It must be harder in the west where there have been generations of junk food, fat and sugar. But anywhere the rule is, "Eat whole, eat natural".'

Lynde Francis, HIV positive nutritionist, Zimbabwe



Dipuo feeling good

'A lot of people don't believe I am positive because I actually look healthier now than I used to. I eat vegetables and I also now use garlic and ground ginger. It's important to cut down

on drinking and smoking. It's not easy but I have cut down and would like to stop altogether. I now try to exercise and do yoga.'

Dipuo, diagnosed 1992, Botswana

SEE FACT SHEET NO 2
Tips for Eating Well
for advice on good nutrition

Rest is restorative. It helps to combat stress. If it's possible, try to take some time out for yourself during the day. It's not easy to find time to rest if you have children and it is probably impossible if you are working. If you can manage it, try to have a short time during the day when everyone is quiet. Perhaps your neighbours, friends, or partner could look after your children occasionally.

'I go to bed very early every night. When my daughter comes home from school, we eat well. I've tried to take the stresses out of my life. I walk every day. It hasn't been difficult. Stress is the biggest thing that will make you feel sick, and HIV really is a lot about stress, I think. You've got to be well to be able to fight things.'

Marlene Diaz and daughter Margaretha, both diagnosed positive 1993, USA

It is true that laughter is healing. Studies have proved it! So let yourself laugh. Look for the funny side of things. Watch children play and get pleasure from their laughter.

'I work so hard for other people and their problems never rest, so I have to be really strict with my rest time. I take the phone off the hook. I used to feel guilty until I got burn-out. Now I know it's not just for my benefit. It's for their benefit too.'

Lynde Francis, HIV positive, Zimbabwe

Exercise is beneficial and helps to reduce stress. Swimming, walking, dancing, cycling or yoga are all good forms of exercise. If you have never exercised before, start slowly by walking and stretching. In fact, walking and gentle stretching are excellent exercise.

'Dancing keeps your body and your mind happy.'

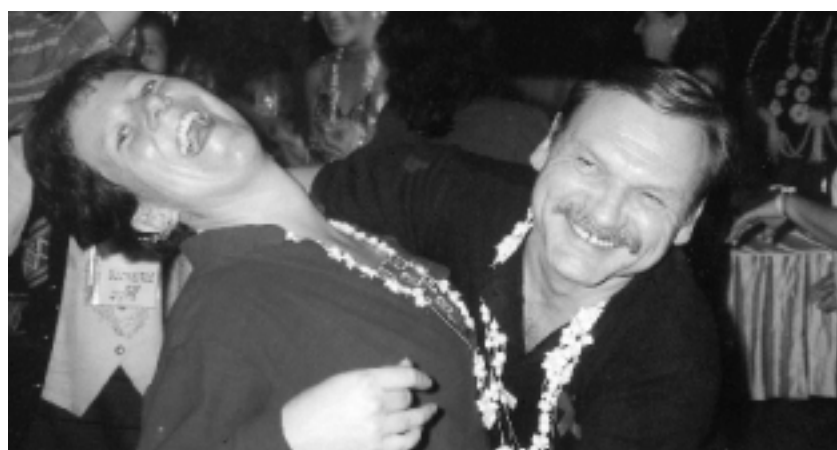
Ale, diagnosed 1998, Argentina



Mercy laughing



Marina from Brazil dancing



Jo and Wojtek dancing



Martina relaxing

If you do hard physical work already, you are probably doing plenty of physical exercise. In that case, try to find a few minutes a day to quietly relax and stretch your tired muscles.

'When my body feels tired, instead of pushing myself hard, I stretch my body slowly – this helps my energy flow again.'

Ale, diagnosed 1998, Argentina

For many women, traditional, alternative and complementary approaches to health and healing are an important part of staying healthy.

These include things you can learn to do for yourself like meditation and relaxation techniques. Other approaches include massage, aromatherapy, reflexology, acupuncture, and using herbs. Spirituality is another source of strength and healing for many positive women.



Blanca walking

There are no guarantees of success from holistic treatments, traditional therapies, or from western medicine. We choose the treatments and approaches available and the ones we feel are best for us. We have to work with what we have and find the ways which work for us.

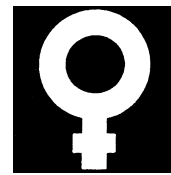
*'Why must it be the doctor **or** the traditional healer – I find some things work from both, but you can never tell one about the other. If they worked together it would benefit the patients. As it is, I've had to work out the balance for myself but it's really helping – herbs counteract the side-effects of some of the drugs.'*

Priscilla, diagnosed 1994, Zimbabwe

Some health professionals have very strong views about what treatments you should have. Remember that it's your body and your life. It's important to feel confident about any decisions you make. Ask questions and if possible talk to other positive women about their treatment experiences.

'Parents have the right to make treatment decisions for their children and treatments should never be mandated.'

Marlene Díaz and her daughter Margaretha,
both diagnosed 1993, USA



'I have more faith in holistic medicine/way of life than conventional drug therapies although I use both. It makes perfect sense to me to use a holistic approach both in living and medicine. We are more than just physical and mental bodies - we have emotional and spiritual needs. I truly believe that I would not be here today were it not for meditation and the complementary therapies.'

Linda Reed, diagnosed 1988, Eire

Sometimes 'miracle cures' are suggested to positive people. Sadly, there are people who want to make money out of AIDS by offering expensive and useless 'cures'. At this moment no one can promise a cure. However, there are many valuable traditional, alternative and western medical treatments which can help maintain and regain health.

'As we are not welcome in some hospitals, we must go to the few that will accept us. Bed space, however, is limited. Sometimes we turn to "black magic" treatments as a last resort and are cheated.'

Oom, HIV positive, Thailand

If you're going to see a health practitioner you don't know, take a friend with you for support and take a list of questions you want to ask.



Good Friends

- Ask how long the person has been practising. Are there any side-effects associated with the proposed treatment?
- Can the new treatment be started if you are already on other medications?
- Ask about the length of time you should expect to use the treatment?
- How much will it cost?

If a health practitioner refuses to answer your questions, think again about whether you want to start the treatment.

'We are nearly in the year 2000. It is time for a new medicine which is more humane. We are bodies, souls and minds and there are many options we can follow to rebalance a depressed immune system.'

Marina, diagnosed 1996, Brazil



ICW get together, Geneva 1998



4 Pregnancy, Childbirth and Breastfeeding

When you receive a positive diagnosis the question of whether or not you can have children is frequently one of the first things which comes into your mind. It can be confusing and difficult to think it all through, taking into account what you want as well as what everyone else is telling you. We can reassure you that positive women all over the world have faced very similar emotions and decisions.

Deciding about pregnancy

Can you be HIV positive and have babies?

Being HIV positive does not mean you cannot have children. Nevertheless, a decision to have a baby is likely to be more complicated when you are HIV positive. Some women want children more than anything else in the world.

'The grief of not having a child has always been greater than the grief of having HIV.'

Rebecca Denison, HIV positive, USA

In many communities children are considered an integral part of family life and many people believe that women's role in life is to bear and raise children. Not having children may draw disapproval. Considering not to have children when you're HIV positive may be difficult in the face of tradition.

'I was afraid if I refused to get pregnant, my husband would beat me, divorce me, and take another wife. So I got pregnant.'

HIV positive woman, Zimbabwe

Maybe you would rather not have a child when you're trying to cope with HIV yourself. Maybe you just want to wait for a while and see how you feel then. These are all valid and possible options for positive women.

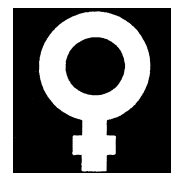
It's important for women who do not want to become pregnant or have more children to be able to discuss birth control with their partner.

'All women should be free to have a baby if that's what they want. But it should work the other way too. For myself, from the age of sixteen I knew I didn't want to have children. Some of us just choose not to have them and that should be respected.'

Ale, diagnosed 1998, Argentina



Rebecca (HIV+) and her negative twins, Sophie and Sarah, with Antigone



Getting pregnant

For women who do want to become pregnant or have more children it is important to understand how pregnancy can affect positive women, the risk of the baby being infected and what may reduce the risk of transmission to the baby.

'I live in a joint family with my in-laws who always wanted a child in the family. My husband is only twenty-seven. I got ill after a blood transfusion and since then my husband has been very nice and kind to me and we understand our situation. But we and the whole family want a child. I was told that unsafe sex is dangerous for my husband and probably my child would be HIV positive, but nobody can tell for sure. I often wonder how long do we have to follow this safer sex?'

Pramila, HIV positive, India

Some positive women with HIV negative partners, have been using their partner's sperm to get pregnant without having to have unsafe sex. The man ejaculates in a condom or clean jar. The woman (with or without her partner's help) puts the fresh sperm into her vagina, as high up as possible. Some other positive women and their partners decide to try for a baby but have sex without condoms only at the times they are most fertile. (This is in the middle of the cycle, 14 days from the first day of a period). In this case it is important to be clear that there is still a risk that the man may become infected with HIV.



ICW women in Acapulco, Mexico (2 of whom have since gone on to become mothers)

It's not just a matter of making decisions about the future. Many positive women find out they are positive when they are pregnant. If you have been in this situation you'll know how hard it can be. Perhaps you were pressured against your will to have an abortion or even to get sterilised. If you went through with the pregnancy it may have been a stressful time – learning to cope with your own HIV diagnosis and worrying about the health of your unborn baby all at the same time. Women do not always get the support they need.

'My husband and I are both HIV positive. We went to the doctor when I was three months pregnant. The doctor recommended a termination because my husband had a low T-cell count. He said the baby would be deformed.'

HIV positive woman, Thailand

Annie Bungeerthy/Panos Pictures



Cecilia, Peruvian HIV positive mother and her negative daughter

There are no simple answers to all these questions and situations. Some positive women don't have much of a choice anyway. But it is better when we can weigh up the situation and our feelings in the light of non-judgemental information and then make a decision which suits us. Whatever we decide we need support and help.



Will a positive woman have a positive baby?

HIV can be transmitted from a woman to her baby. However, transmission does not occur in the majority of babies born to HIV positive mothers. Current information suggests that two-thirds of babies born to HIV positive mothers are *not* infected with HIV.

'In 1989 when I was pregnant my test came back positive. I had my baby, Vaurice LaMon, and he was beautiful. Unfortunately my baby was positive and went on to develop AIDS and eventually he died when he was three and a half.'

Monica Johnson, diagnosed 1989, USA

Recent World Health Organization (WHO) material suggests that the risk of HIV transmission from mother to baby is roughly as follows:

- Two-thirds of babies born to mothers with HIV are not infected at all
- Of the remaining one-third of babies who *are* infected, two-thirds are infected in the womb or at birth
- The remaining one-third are infected through breastfeeding.



Monica Johnson, USA

There is evidence that the risk of transmission increases if the mother's health is not good or she has symptoms of AIDS. If you are pregnant and are going ahead with the pregnancy, or if you have decided to get pregnant, the better you are able to treat yourself during the pregnancy the better the outcome will be for you and the baby.

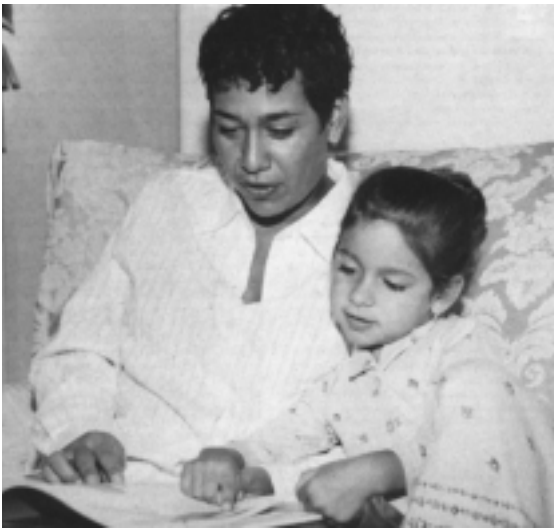
'If we really want to take care of children we need to figure out ways to take better care of the health of the mothers.'

Rebecca Denison, HIV positive and mother of negative twins, USA

Many positive women have found that talking to other positive women about having children has helped them think through their feelings. Some women, if they have a choice, have decided not to take the chance of having a positive child. Others have weighed up the possibilities and decided to go ahead. While the majority have children who are not HIV infected, some children will be HIV positive. This is a hard reality. But it is not one which necessarily negates the decision to have a child.

SEE FACT SHEET NO 3

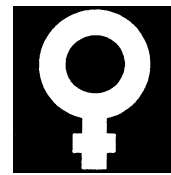
Reducing mother-to-child transmission of HIV.



Marlene and Margaretha

'I found out I was positive eight months into my pregnancy. I knew nothing of HIV or AZT and was in shock. My daughter, Margaretha, is five years old and has HIV. At one point she was diagnosed with AIDS. I had hoped the odds would be in my daughter's favour, that she would not have to struggle with this virus.'

Marlene Diaz and her daughter Margaretha, both diagnosed 1993, USA



vaginal delivery and recovery time takes longer. A planned caesarean is different from an emergency caesarean, which is undertaken when the mother's or the baby's life may be in danger. This procedure does not give added protection against HIV.

'I had to make a choice whether or not to take AZT for my unborn child. I had to elect for a C-section to deliver my baby and then had to think about whether to breastfeed or not. My husband and I discussed all of this so he could be involved.'

Bridgette, HIV positive, Zambia

How will I know whether my baby is HIV positive ?

All babies are born with their mother's antibodies. It may take up to 18 months or longer before you know if your baby is HIV positive or negative.

Many positive mothers say that the best thing to do once the baby is born, is to concentrate on the baby's physical and emotional well being. Also, staying as healthy as you can will help you to look after a baby and allow you to enjoy your new child's uniqueness.

Treatments during pregnancy

There are several techniques including drug treatments which may lower the risk of mother-to-child transmission of HIV.

ICW advocates for all pregnant positive women to have access to up-to-date treatments. In the meantime, the harsh reality is that deep inequalities exist between what treatments, information and care positive women in different countries can access.

Childbirth

What about childbirth?

Up to two-thirds of infected babies become HIV infected while in the womb or during childbirth. A planned (elective) Caesarean Section (CS) may reduce transmission during delivery but this is a very expensive procedure that is not available to most positive women. CS is also a more dangerous procedure for women than a



Ruth, HIV positive mother and her negative daughter, Sarah



Breastfeeding

Does being HIV positive mean I shouldn't breastfeed ?

This is a very difficult question. There are no easy answers and a lot depends on your circumstances.

Some babies have been infected with HIV through breastmilk. It is suggested that approximately 10 out of 90 babies born to HIV positive mothers will be infected through breastfeeding.

Positive women need information about the risks of breastfeeding and of not breastfeeding. Breastmilk is free and nutritious and it protects children against other infections. Breastfeeding is recommended for positive women in situations where appropriate alternatives are not available. Positive women need research and information to know what these alternatives are so they can decide for themselves.

'My baby was put on AZT at birth, but no one told me not to breastfeed.'

Mercy Makhalemele, HIV positive, South Africa



Otilia, HIV positive,
Zimbabwe.

What we do want is non-judgemental and helpful information and discussion of what our real choices are. If you do not want to breastfeed you need to be able to answer questions like:

- What substitutes for breastmilk will you be able to find or afford?
- Is it possible to clean equipment well enough to prevent infections?
- Can you make sure your water is sterilised?
- Is it possible to prepare baby feeds hygienically?
- Will the alternatives you have access to provide enough nutrition to avoid malnutrition?

It is clear that the positive women who are faced with the hardest decisions about breastfeeding are those who live in developing countries, where resources are not necessarily plentiful and poverty is common.

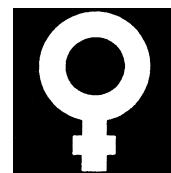
Nevertheless, some positive women in developing countries are confident they can find nutritious alternatives to breastmilk to give to their babies.

Women are looking at new alternatives and exploring older solutions which were used in the past when a woman was unable to breastfeed. They are using things like goat's milk or 'paps' which are made from ground beans like soya or grains like sorghum. Women want research into whether they can express breastmilk and then get rid of the virus by boiling or refrigerating it. Would the breastmilk still maintain its goodness?

Other women have decided that breastfeeding is still their best option. Whichever way you choose to feed your baby must be respected. You are doing the best you can for your baby.

'For two days I did not breastfeed. But each time I looked at him I knew it was not enough. How could I say to myself I was a mother while I was not breastfeeding. That's when I decided to breastfeed. I told the nurses about my decision. They tried to talk me out of it but I had already made my decision. I breastfed him and there were no problems. The only problem I had was with people who knew my HIV status.'

Otilia, HIV positive, Zimbabwe.



WHP Photo by L. Gubb



Ethiopian woman and her children

If you decide not to breastfeed you may face criticism from family and friends as well as from medical personnel. In some situations, if a woman does not breastfeed, people may ask why and wonder if she is HIV positive. However, if your partner or family knows your HIV status and understands the risk to the baby, they could help by supporting your decision. You could also try to get support from a doctor, midwife or a friend who could help explain that there are medical reasons why you shouldn't breastfeed.

It may not be easy to decide whether to breastfeed or not. But it is our choice to make and our right to decide about what is best for our baby.

'I'm not trying to find a scapegoat for my daughter's positive status. I just wish I'd had the information I have now. I would have done things differently. Positive women want to have babies responsibly. We need more conclusive studies to know the full story.'

Marlene Diaz and daughter Margaretha, both diagnosed 1993, USA

'In the hospital the nurses tried to force me to breastfeed my twins. I had to explain my status which I did not want to do. Then my mother-in-law came in and made a fuss. There's a belief that if you do not breastfeed it means the baby is not your husband's. My husband supported me and said as I was going back to work straight away we had decided it was easier. The twins are a year old now and thriving.'

Primrose, HIV positive, Zimbabwe

SEE FACT SHEET NO 3
Reducing mother-to-child transmission
of HIV for more information

5

Communicating with our children



Globally, most positive women have children or will have them in the future. We who are living with HIV and looking after children have to cope with our own health and the well being of our children. Some of our children are also positive.

Among all the practical necessities of daily life, we have to decide whether or not to tell our children about our HIV status. If we do tell them, how can we help them cope with HIV in a world which is often hostile and stigmatising. Positive women are confronting these problems and coming up with ideas about how to talk to children about life, death and HIV. Here are some of the questions we faced and the answers we came up with.

Should I tell my children I am HIV positive?

You are not alone on this difficult journey. Many women living with HIV/AIDS have children and have pondered this question. We have no easy answers except that we know it is very important that children are able to talk with people they feel safe with.

'For us as mothers living with HIV/AIDS the most delicate spot is our children. We are confused as to how to prepare our children for the changes ahead of them. We don't know how, when to do it. We are always grappling with the burden of secrecy on top of our physical sickness.'

Scovia, HIV positive, Uganda

I want to tell my children but I don't know where to begin.

Our children need accurate information presented in a way they can understand. But how and when to tell our children is our choice. Some women talk to their children on their own. Others talk to them together with their partner.

'I have definitely avoided talking about death with my son. If I had to go into the hospital and they told me something really serious was happening, that would be the time to talk to him. But I realise we should be prepared and maybe it's a good idea to introduce him to the idea when I'm really well.'

Maggie, diagnosed 1988, Britain

What if I am asked questions I cannot answer ?

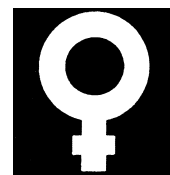
It is perfectly okay to say you do not know the answer to a child's question. You can explain that information about HIV changes all the time. We are all learning about it constantly. Also, sometimes children ask embarrassing questions about sexual matters or intimate body parts. Some women may feel uncomfortable with such questions. Try to answer them simply and honestly – your children only want to understand.

'Children know exactly what is going on, they don't ask you tricky questions because they don't want to know the answers. Children just accept things. I talk to her directly all the time.'

HIV positive woman, Australia



Australian positive mother
with her negative
daughter



It might be helpful to ask yourself questions like:

- How do I think my children are feeling?
- What do I think my children's most important physical and emotional needs are?
- What can I do to help my children cope with my diagnosis?

For many parents, telling children about their diagnosis does not happen all at once. Younger children in particular may need time to digest very simple things about AIDS and about your situation. Often children will let you know when they are ready to hear and learn more. They will start asking questions and bringing the subject up, even if it's in a roundabout way.

'I find it easy to speak to forums, to international meetings and political leaders about living with HIV. However, I found it very hard to speak to my own children - in fact it was one of the hardest things I ever had to do. Children are always left until last. I hadn't spoken to my daughter about my status when she said, "Mummy, I hope there is a drug for HIV in 7 years." I was really taken aback. Our children are the last to know and we take it for granted that they don't and can't understand what's going on. But they do. They suffer stress and anxiety just like adults.'

Beatrice Were, HIV positive, Uganda

Many parents choose not to tell their children or do not have the opportunity to do so. The children discover their parent is HIV positive when they get ill. No matter how much things have changed, in many places an HIV diagnosis is still seen as equalling a death sentence. It's not surprising in these circumstances that children might associate a parent's HIV diagnosis with death.

Where can I get support if I need it?

If you know or can make contact with other positive parents, it could be useful to talk to them about their experiences with their own children. Also, many ICW Key Contacts have children and would be able to talk to you about their own experiences.

'As a single mom it is challenging to take care of myself when I have to care for my child who is also positive as well. I am fortunate to have close family and friends who know our status and help out. I have learned that by reaching out.'

Marlene Diaz and daughter Margaretha,
both diagnosed 1993, USA



Lisa and Marise

'I ended up not telling my daughter for about one and a half years. She already knew about her father. She knows now but it was really hard for her.'

HIV positive
woman





6 Memory books & boxes

One of the ways some positive women are dealing with the possibility of death is by concentrating on practical plans. We've sorted out our wills. We've planned our own funeral and where necessary the funeral of our partner. We've made arrangements for our children to be looked after by relatives or friends.

Many of us have also thought about how important it is to make sure we leave our children intimate reminders of our lives together. More and more positive women are creating 'memory books' and 'memory boxes' for their children to have if they die. A memory book can be a simple scrap book or note book; a memory box can be whatever container you have handy.

'We carried out an assessment of the children about what they wanted to know and asked the mothers what their fears were in relation to their children knowing. As part of this we devised the memory book. It is a book which records our lives. The mother does it together with the child and this gives them an opportunity for dialogue. It contains good things about yourself, your life and your spouse. It also contains your vision of the future. What will happen when you get sick and what plans you have made for your child.'

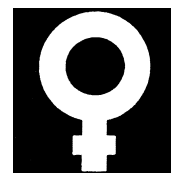
Beatrice Were, HIV positive, Uganda



Taking time to write and reflect

You can put anything you want to into a memory book or box.

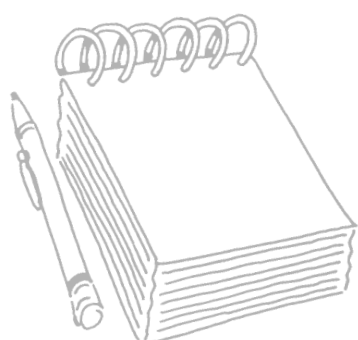
- You can include photographs with little descriptions of who is in the picture and where and when it was taken
- If you have access to videos and tape recorders you can make a special audio tape or video with messages on them
- You can write poems and stories.
- You can include a trinket or little baby toy
- Some women include 'family trees' which record information about their children's relatives and ancestors.



Personal note books

Some of us have started keeping notes about our children as they grow up. These notes record thoughts and feelings as we watch our children grow.

One way to start your imagination working on things you want your child to remember is to recall memories and thoughts about your life and your child's life. The following list may give you some inspiration.



We are all unique. Our children and loved ones are all unique. The ways in which we can support each other, share our experiences and gain strength are many and varied. We hope the idea of 'memory books' or 'memory boxes' will inspire you to think about how you and other positive women in your area might want to deal with issues of grief and loss.

'Evaluation of this project has shown that children are very eager to get involved and the mothers are much happier having this dialogue with their children.'

Beatrice Were, HIV positive, Uganda

- Our family came from...
- Your grandparents' names were...
- These are some of the jobs our family did...
- I was born in... Your father was born in...
- When I was growing up this is what it was like...
- Our family values and traditions were...
- You walked when you were...
You first talked when you were...
Your first words were...
- Your favourite foods were...
You didn't like to eat...
- When you were little you loved to...
Your favourite book, game, cartoon character, TV show were...
- I always laughed when you...
- I always remember the time...
- I hope you never forget the time...
- Here is the most important advice I would like you to remember when you are grown up...
- I want to tell you how much I love you...

Relationships



Partners, children, friends, parents, brothers and sisters, ex-partners, work mates, colleagues – we all have a range of relationships which HIV can impact upon.



The late Milly with Jacob,
the love of her life

'I love him but I have to admit I've also gone through periods of feeling such anger at him too. I was such an innocent, I didn't have a clue what he was getting up to. So it was a shock too. That's why it's been so helpful to talk to other HIV positive women who've gone through the same thing.'

HIV positive woman, Scotland

'Sometimes I joke and say I'm now married to AIDS. We live together, we do things together. We talk to each other every night.'

Pimjai, HIV positive, Thailand

'We find it difficult to talk with husbands, friends, or relatives about our health condition. Some of us feel frightened of being rejected after revealing our situation.'

Bernice and Neris, HIV positive, Venezuela

Finding out you are HIV positive and pregnant

Some of us were diagnosed when we were pregnant. Then, not only did we have to cope with our diagnosis and worry about the baby's health, we also had to deal with talking to our partner. Although many negative partners of positive women are caring and supportive, others are angry and accusing. If it's available, counselling for both partners can be helpful.

When a partner is ill first

In many other situations, women have only found out about their HIV status when their partner was ill or died. The question then is not how to tell our partner but how to cope with his or her death, our own recent HIV diagnosis, and possibly a child's diagnosis as well. All this at a point when everything seems to have crumbled in front of our eyes. When the news of a partner's HIV status becomes a source of gossip, any chance of privacy is often lost. We know this is the experience of thousands and thousands of other women.

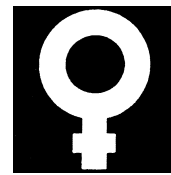
'It was in 1985 after I gave birth to my last boy that I started seeing my dear husband experiencing some difficulties in life and some funny symptoms in his body. On 31 May 1986, my husband died just like that. I remained confused, not believing, in tears all the time, only to be told by the doctors that the next person to go would be me.'

Jennifer, diagnosed 1988, Uganda

There are situations where a man is HIV positive but either does not know it or will not confront the truth. His wife may be infected by him. If she gets ill first she may end up being the one who is tested.

'The majority of HIV positive women get the virus at home, not on the streets: they get it in their own beds.'

Giovanna Torres, diagnosed 1995, Peru



'Sometimes if a woman tests for HIV first, the husband will then refuse to. He'll say, "I'm not ill." I think it's very important to try to get couples to test together.'

HIV positive woman, Africa

Unfortunately some positive women have been rejected by their partner or family, perhaps even found themselves without a home. Some women who know they were infected by their partner, have still been rejected by him and his family when they were diagnosed with HIV. But not all partners and families are rejecting, even if they are shocked and upset at first. HIV positive women are coming together with positive people all over the world to fight against the stigmatisation of people living with HIV. We are all worthy of respect - women, children, and men.

'Unfortunately, discrimination against women is still widespread in my country. Women will look after husbands who are dying but if a woman is diagnosed and tells her husband she may be abandoned.'

Martine Somda, HIV positive, Burkina Faso



Martine Somda

'I was dumped by my husband in 1993 after I got very sick and was told about my status. He did not expect me to be positive, since he had bought a second wife into our matrimonial home. He said I was a whore and jealous and that's why God punished me by having the virus. He used to make me sleep outside in the open with my children.'

Anna, HIV positive, Zimbabwe

'Sometimes people hide behind their fear of telling because they assume they will be rejected. They decide it's easier not to put themselves in that situation. I believe it's not a healthy thing to hide and cut off from things completely. In the future you will come across men who you are attracted to and when they find out you're positive, yes, they might walk out the door. What are you going to do then? If they do walk out it's just as well, because they're not worth knowing. There is also the possibility they won't walk out and you'll never know unless you overcome the fear of rejection.'

HIV positive woman, Australia

Violence

It is sad that sometimes an HIV diagnosis appears to provoke abuse and violent behaviour from family members or, if they know, neighbours. If you are being battered you may be able to get support from a local women's organisation. It is never right for a woman to be beaten. It is never right for a woman to be treated violently because she is HIV positive. None of us are to blame for being HIV positive. None of us deserves to be treated violently.

'They were all shouting things I could hear. They wanted to burn me alive, shoot me, kill me. Someone shouted out that I should be kept in a glass room which I could never leave and where everyone could see me.'

Ruby, HIV positive, Bangladesh



Anger

A lot of women find out they are positive before their partner. They are shocked because they have always been faithful to their partner.

'I feel disappointed and angry at my partner's dishonesty. He was my only sexual partner. I went for a test when I found out he had many outside partners.'

Diana, HIV positive, Malaysia

'One of the reasons why I got married was because I thought it was important to make a public statement. A lot of people thought it was absurd that two people who were HIV positive were getting married, because marriage is future stuff. A lot of people that were there had been to funerals over the years and it was quite a change. A celebration of life and future.'

Fiona, HIV positive, Uganda

'I never would have imagined I'd be in a relationship with a woman and now that I am, I'm happier than ever. Life is full of surprises.'

Andrea Skopp, HIV positive, USA

'I got married to a negative guy three years ago and we adopted a son.'

Nira, diagnosed 1986, Israel

'I resolved to get married to a fellow HIV positive partner. We were married and I am so faithful to this relationship because we understand each other very well. My parents, too, are very happy because they never expected me with AIDS to find a partner and one to marry me. The people in my village are still mesmerised about my marriage.'

Sarah, diagnosed 1988, Uganda



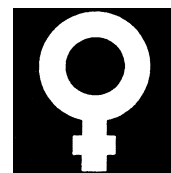
Friendship

New Happiness

No one pretends that life is easy when you are HIV positive, but neither is it always gloomy and negative. None of us would choose to be infected with HIV. Nevertheless, an HIV diagnosis can help us re-evaluate our lives. We treasure stories of joy, our own and others, even when we are going through a hard patch. After an HIV diagnosis many women believe they will never have a relationship. These feelings can change. Some of us have found a new loved one. And friendships, old and new, are often the mainstays of our lives.

Happiness





Martina, Jecenia and Cindy

'I haven't done drugs for two years because I want to live. My lover has custody of his two kids. They call me mommy. I stopped because of these children. I want to be able to take care of them. My lover is positive. We both just happen to be HIV positive. If he was and I wasn't, I would still be with him..... I'm a really lucky person. I have a good man. I live so much better now than I did before.'

Sugar, diagnosed 1991, USA

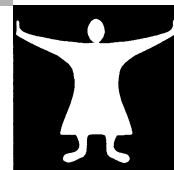
'me sex is not the most important component in love. Understanding, support, caring and the desire to live meaningful and respectful lives are even more important.'

Beatrice Were, HIV positive, Uganda

'Richard has been a pain to my former in-laws. After the death of my former man, his relatives believed my brother-in-law had an obligation to inherit me as his wife. He was an unsuspecting boy of seventeen whose understanding of AIDS was very low. In fact, the clan and he in particular, believed I was responsible for the death of my husband. They believed I "bewitched" him. I am privileged to have disappointed my relatives and in-laws through my "stubbornness". I have reaped happiness I am sure I would never have found otherwise. The relationship I have now with Richard who is also living with HIV, has shown



Beatrice and Richard



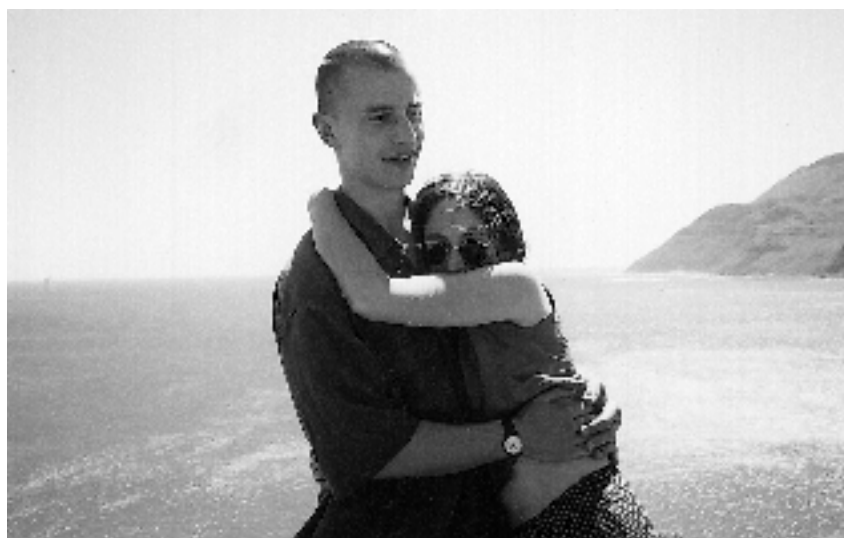
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Sex and Sexuality

Many women welcome sex and find it pleasurable. But for many others, sex is unwanted and may be forced on them. In many communities women are discouraged or even prevented from talking openly about sex or their sexual health. Learning to be more at ease when talking about sex can help women to begin to define what it is they want and need.

'Men don't realise women can have sexual pleasures. It is seen as unnatural and even dangerous if a woman tries to talk about sex.'

Martine Somda, HIV positive, Burkina Faso



Kate and Steve

'When I found out I was infected, I thought I'd never have sex again. I've been through a lot now and have a wonderful relationship. I wish I'd been able to have a bit more hope when I first got diagnosed.'

Jo Manchester, diagnosed 1986, Britain

What about sex?

After being diagnosed, women may have many different responses. Sex may be the last thing in the world we want to think about. Some women never lose their sexual desires. Others are relieved they can say no to the sex they never enjoyed in the first place. In fact we all have changing feelings about sex depending on who we are, are partners, our health, how old we are, and whether we have children.

'Even when I am physically well which is most of the time, occasionally I feel as if the virus has taken over my body and it makes me feel undesirable, especially when I have vaginal infections and am tired.'

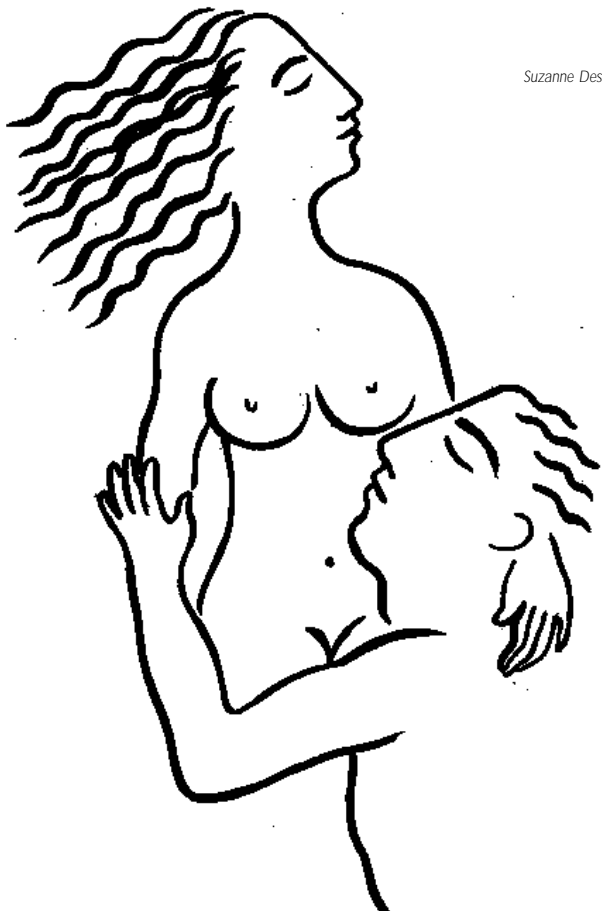
Philippa, diagnosed 1986, Britain

'I've always been very, very careful even before my diagnosis. In the 80s my girlfriends and I used to go out with condoms hung on our earrings. It was part of being modern. In fact, not many things have changed in my sexual life since I've been positive.'

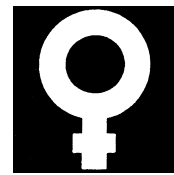
Ale, diagnosed 1998, Argentina

Intimacy

Many women associate sex with a desire for intimacy with another person. You may achieve this by holding your loved one, and being held, or by stroking and kissing each other. This kind of sensuality can provide a great deal of emotional fulfilment as well as comfort and intimacy.



Suzanne Desbiens



I'm worried about infecting my partner - what are the risks?

It is harder for a positive woman to infect a man or another woman than for a positive man to infect a woman. Many of us now have long term partners who continue to test negative. Nevertheless, a man can be infected through having unprotected sex with a positive woman. This is almost always through having vaginal penetrative sex (where the man puts his penis into the woman's vagina) without a condom. The presence of other sexually transmitted diseases, oral infections, or menstrual blood may increase that possibility. Whatever the circumstances, practising safer sex prevents transmission of HIV and has the bonus of protecting you from other sexually transmitted infections.

'I think it's really important to remember I'm more than a virus. I remind myself that my lovers are lucky to have such a unique woman in their lives.'

HIV positive woman, Britain

Many positive women would like to talk with their partners about their sex life. Are there ways to explore new ways of being sexual together? What can stay the same? Although it may not be easy to start talking about sex, once the ice is broken, it can bring a couple closer together.

'HIV is the best thing that ever happened to our marriage. He never used to come home and we only had sex when he was drunk. Now we actually talk and safer sex has opened new things for me sexually like touching each others bodies.'

Tatenda, HIV positive, Zimbabwe

'It's as important for me to say what I fancy sexually as it is to let someone know I'm HIV positive.'

HIV positive woman, Britain

'There is some bitterness in my attitude to previous partners. It is a common lament: men in Botswana use women. They are only interested in the sexual aspect. Once they are satisfied, women are dumped. Since this is a common problem, it is extremely important that we women learn to insist on condom use. This is an easier option than trying to change attitudes.'

Dipuo, diagnosed 1992, Botswana

What is safer sex?

Safer sex means preventing infected semen from entering a partner's body through unprotected vaginal or penetrative sex. Unprotected means sex without a condom. It also means preventing vaginal secretions from entering your partner's body through unprotected penetrative vaginal sex. Infected menstrual blood contains HIV and you may decide to avoid oral sex during your period or your partner's if she is HIV positive. Oral sex is when a partner licks or sucks the other's vaginal area and clitoris or



when someone sucks a man's penis. But by far the most common way for HIV to be transmitted sexually is through vaginal or anal penetrative sex without a condom.

'I've always found oral sex more satisfying. Though for a long time I used to worry about this, because of all the emphasis that's placed on "intercourse". Now I don't. After all, it's just one of many types of sex and now it happens to be safer too!'

HIV positive woman, Britain

There are many pleasurable and safe ways to get sexual pleasure. Kissing gently, kissing with intensity, licking sensitive places, learning how to bring a partner to orgasm with your hands and fingers, whispering sexy stories, exploring how to pleasure yourself when you are alone, holding and stroking your partner when he or she masturbates (stimulating genitals), slow and sensuous massaging, reassuring cuddling and words of love – all these are wonderful sexual acts! Starting a sexual exploration can lead to much more pleasure and fun.

Safer sex is about looking after and caring for ourselves as well as our partners.

It is important to protect yourself from other infections which could weaken the immune system. But sometimes it's hard to get it right. Safer sex is an ongoing process. If you don't succeed once, think about how you can succeed next time.

If you are not using any other form of birth control, safer sex with condoms can prevent an unwanted pregnancy. As positive women, we want to make informed choices about if and when we get pregnant.

SEE FACT SHEET NO 6

For more information on male and female condoms

Female condoms

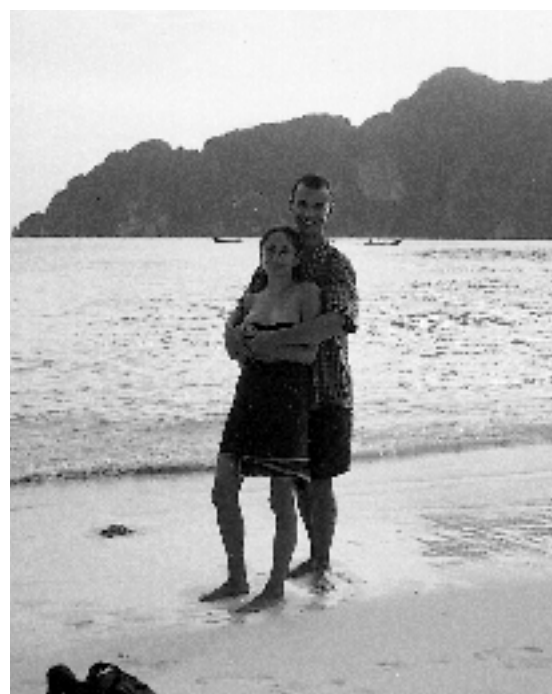
We hear about male condoms most often. But there is a newer form of condom developed for women to use. It's called a female condom or femidom. The good thing about female condoms is that women can be more in control of their use.

'We found it wonderful to be able to fall asleep together and then go another round without having to get up and change it. My husband's really happy with it and he doesn't have to worry about losing his erection and all that.'

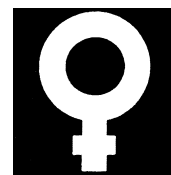
Tatenda, HIV positive, Zimbabwe

'When I saw it I thought "Oh no, this looks like a big plastic sock – it'll never fit!" But it was explained that it has to be big enough for any penis, not my vagina. Once it's all crinkled up inside it's fine.'

HIV positive commercial sex worker, Zimbabwe



Kate and Steve



Practising safer sex also means you don't run the risk of being re-infected with a different strain of HIV. This could mean that the level of the virus in your blood increases. Some strains of HIV are resistant to certain anti HIV drugs. It might mean these drugs would not be effective if you wanted to take them in the future.

'We were together before I got my diagnosis. At first I wasn't able to talk about sex with him – he acted as if there was no problem because we're both positive. I got fed up but I care about him and I wanted to stay a family for the kids. I brought home some leaflets about re-infection and he took those seriously. He started using condoms after that.'

HIV positive woman, Scotland

Safer sex reduces the risk of contracting other sexually transmitted infections (STIs) like herpes, chlamydia, genital warts, hepatitis B and C, syphilis, and gonorrhoea. STIs may have more serious consequences for positive women. Safer sex also helps protect against the sexual transmission of thrush which can be passed back and forth between partners.

'It's so wonderful to have protection that I control myself. It's different when you have to rely on him to use something – sometimes they change their mind at the last minute and you could get beaten up if you insist. With the female condom it's there from the start and I feel safe. I haven't had an STD for a year and I know I'm not infecting my clients.'

HIV positive commercial sex worker, Zimbabwe

Condom problems

Some men may tell you they can't stand using condoms. They may claim they dislike the way they feel or say that if they don't use a condom it proves how much they love you. Some partners may accuse you of not trusting them or suggest that you may have been unfaithful if you talk about using condoms. As positive women we've heard all these excuses and justifications. We want to protect ourselves and our partners but they should behave with respect towards us too.

'Sometimes I just get sick and tired of hearing about my responsibilities all the time. What about my partner's?'

HIV positive woman, USA

Other solutions

Although the use of a female condom is more in women's control, some men will still refuse to allow its use. In these cases women have been forced to find other solutions for safe sex. As well, in some places, female condoms are scarce and too expensive for everyday use. Women have been creative in this situation too.

'My partner won't wear a condom even though he knows I am HIV positive. Then I was talking to another woman the same as me, and she said she uses a diaphragm and puts some spermicide in her vagina. I thought maybe I could try that.'

HIV positive woman, Britain

SEE FACT SHEET NO 8

For information on
Sexually Transmitted Infections





Whose responsibility?

The majority of people in the world do not know their HIV status. Most just assume they are negative and don't take any precautions. But making decisions about safer sex is everyone's responsibility, not just ours.

'If women go home and say, "We were given condoms today", they'll be told to take them back where they got them. This is why we include men in our support groups: so they can be educated and then go and speak with other men. We don't want to be told it's a women's affair.'

Agnes, diagnosed 1990, Uganda

'I'd been brought up to think of the man as the boss. It's funny because I was a bit of a rebel and got into drugs but never challenged that thing about men. I have tried to talk to my husband about using condoms but he takes no notice. Now I tell myself it's not all down to me. It takes two to tango and I can't carry all the responsibility.'

HIV positive woman, Scotland

Some of us insist on using condoms by saying that we don't want to get pregnant or that we want to space our pregnancies. Whether or not this is true it is a way of getting a man to practise safer sex without telling him you are HIV positive. Other women persuade their partners to take part in safer sex practices like oral sex or mutual masturbation and avoid vaginal or anal penetrative sex.

'If I don't want to tell someone I have HIV, I just insist on condoms. If he can't handle it, well forget it!'

HIV positive woman

Condom panic

Very occasionally, condoms break or come off. Don't panic! It's unlikely that your partner will be infected by a one-off incident. The chance of infection is more likely if you have repeated unprotected sex.

'Once, while my husband and I were making love, the condom split. We were both very scared. A few weeks later he had yet another negative test result.'

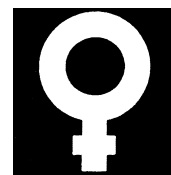
HIV positive woman

Natural balance

It has been shown in clinical trials that women who use douches and other substances in their vaginas are significantly more prone to sexually transmitted infections and HIV transmission. This is due to altering the natural balance in the vagina. You can help to restore the natural balance of the vagina by stopping douching. Some women find that putting live plain yoghurt in the vagina brings relief and helps to restore the chemical balance in the vagina.

Microbicides

We continue to hope that more research will focus on microbicides. These are anti-viral creams which create a film which destroys HIV. They are not very lubricating and therefore would be acceptable to people who practise 'dry sex'. Microbicides would be a wonderful safer sex alternative for all positive women who want to be able to control their own body.



Dry sex

In some places, men prefer their sexual partners to have a dry vagina. They believe it makes penetrative sex better for them. But because the vagina's moisture and secretions are normal and occur naturally in all women, to achieve dryness women have to use different methods, like drying the inside of the vagina with a cloth, or using herbs which promote dryness.

'If I don't use herbs to make me "tight and dry" my husband will go elsewhere.'

Mary, HIV positive, Zimbabwe

Drying the vagina may cause tiny abrasions (tiny little breaks in the skin of the vagina) even if you don't feel anything. Because of the dryness it is also far more likely that abrasions and tears will happen during unprotected penetrative vaginal sex. Dryness in the vagina may also cause condoms to split.

'It hurts, but then I'm not supposed to show pleasure anyway, or he'll think I'm experienced.'

Chipu, HIV positive, Zimbabwe

It may be difficult for women to persuade their partners that dry sex can be risky. You can try to explain to him that using condoms without lubricants can cause condoms to break. Perhaps he would be willing to try 'just a little' lubricant.

'One of the obstacles to HIV/AIDS prevention in Botswana is dry sex. The worst part is that women tell themselves that in order to get married they must agree to dry sex.'

Dipuo, HIV positive, Botswana

I'm afraid of violence

Some of us are already living with violent partners. Others fear what might happen if they made requests about safer sex. In these circumstances, it may be difficult or impossible to discuss safer sex. You may be able to get help from a local women's group or AIDS organisation. But if you are unable to find support, do not put yourself in danger in order to practise safer sex.

'Our law in Uganda is silent on issues like marital rape. It is presumed that once married you have fully consented to sex at all times.'

Beatrice Were, HIV positive, Uganda

It is important to believe that you are not responsible for your partner's violence. The violence is not your fault, no matter what he claims. You are important and your emotional and physical well being matter. Even in situations which seem impossible, changes may be possible.

'I've found it really difficult to love and care for myself, after living with violence for such a long time. I'm learning better ways now, but it is difficult. I owe myself all the understanding, patience and acceptance I can find.'

HIV positive woman

'What I've left behind is the violence, intimidation and abuse and I've found new strengths I never knew I had.'

HIV positive woman





Success stories

Communicating or talking about sex isn't always easy. Thinking about changes and dealing with HIV and the demands of safer sex can feel too difficult to contemplate. However, small changes may be made gradually and still make a big difference. Even if you feel overwhelmed today, perhaps tomorrow you will feel stronger.

'You can make changes. I didn't realise I could ask. I've started to say things like I love it when you touch me there.'

HIV positive woman

'In talks I give, listeners hear about my favourite letter sent after a presentation in which I disclosed how I became HIV infected. "Dear Jane Fowler", wrote a 12-year-old schoolgirl, "Gee, I sure never knew that anybody over fifty had sex."'

Jane Pecinovsky Fowler,
63 years old, HIV positive, USA



Lynde and Prudence

'Discovering how wonderful it was to make love with a woman - that was the best thing to happen in a long time.'

HIV positive woman, Australia

'I learned a lot by reading some books on women being more assertive. I believe in myself more now and I'm a bit more confident. I'm starting to learn how to be assertive and get my way. It's brilliant.'

HIV positive woman

'In my culture, talking about sex isn't really accepted. And I was afraid I would be rejected if I told my husband I was positive. It's taken a long time for me to tell him. We haven't really talked about sex yet, even though we use condoms now.'

HIV positive woman, Thailand

'Being diagnosed HIV positive makes me more ingenious. I prefer the games now - like flirting, kissing, touching.'

Ale, diagnosed 1998, Argentina





Grief and Loss

Losing someone you love or care about is painful. Being HIV positive also means we have all been brought face to face with our own mortality. All of us experience a variety of emotions, thoughts and behaviours when someone dies. There is no 'right' way to grieve - the process varies from person to person, from culture to culture and even from one community to another.

'There is no set way of grieving. It still overwhelms me and I think it always will. If anybody ever says it'll get better with time, I just tell them to get lost. Because it doesn't get better. It gets different. John will never come back.'

HIV positive woman, Australia



Remembering the women we have lost

'I'm scared of getting sick at the moment. Not fear so much of being dead – it's the process of dying. It's not looking good. At the moment I'm thinking I have to get a will together. I showered this morning and I was thinking, who will be the executor of my will? It's getting all the more serious, the fear of being sick and dying. I find it all so difficult, so huge.'

HIV positive woman

Making a Will

A will is a written document that makes clear what a person wishes to happen after their death. Making a will is easy. But many people do not make one because they think it is difficult or they believe it will make them die more quickly.

The following guidelines were developed in Tanzania in response to growing numbers of women and children left unprovided for. Sometimes there was no valid will and property, land, and money went to other family members.

A will must be made in accordance with local law, although the principles are similar everywhere. A will can:

- ensure that property, land and valuables are passed on to people that the person would like to receive them
- make clear who has custody of children, and if there is no partner, appoint guardians
- specify who will ensure the will is acted upon (trustees or executors)
- provide instructions about funeral arrangements

To be valid, a will must be:

- written in permanent ink or typed
- signed by the person and clearly dated
- witnessed by persons present at the same time as signing and dating. The number of witnesses required depends on the country. Those who will benefit from the will should not be witnesses
- written when the person is of sound mind and is not being forced to do so by someone else

Source: Writing a valid will, M.C. Mukoyogo. Published by AMREF, PO Box 2773, Dar-es-Salaam, Tanzania



Although death is an inevitable part of our lives, that doesn't lessen the pain when we lose the people closest to us. Most of us find it difficult to cope. When the people near to us die it also brings us face to face with the possibility of our own death. Will we have time to say our goodbyes? How will our loved ones cope?

Multiple loss

Some of us have already lost our parents, children, partners, siblings, children, friends and colleagues through HIV. We carry a heavy burden of sadness and grief. Losing other positive women we have joined with for support and to fight for our rights, brings another level of sadness to our lives.

Honouring those we have lost

'One may imagine that I would have become inured to death but this is not the case. Each death rose before me as a chimera of my own impending demise. Reinforced by the death of many of the brave women who had come together to form our group, this included my friend with whom I had started the group. I became increasingly aware of the importance of rituals and ceremonies that surround death. How important it was for me as a mourner to dedicate that time and involvement to remember the friend who died, to celebrate the life they had lived. To connect at least once more the networks of my friend's life and to share our grief with each other.'

Bev Greet, diagnosed 1984, Australia



Auxillia Chimusuro, Zimbabwe

I don't have the words to express the depth of my sadness that lovely Auxillia has died. We had been friends since 1992 and I loved her for her passion, her courage and her wonderful sense of humour. She taught me so much and with her very strong sense of justice she fought against the discrimination, stigma, ignorance and fear surrounding AIDS. She loved and cared for many people and in return she was loved by many. Auxillia, I love you and miss you.'

Jo Manchester, diagnosed 1986, Britain

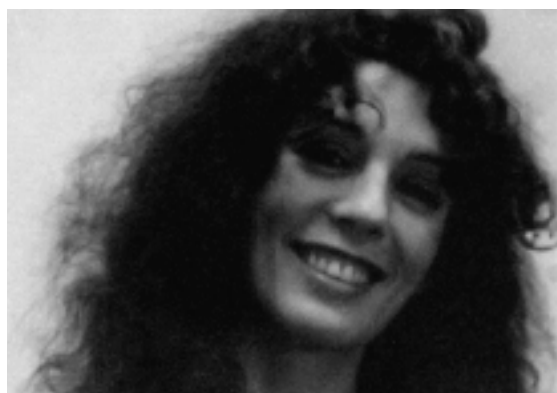
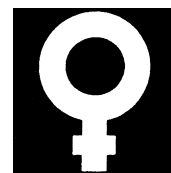


The late Auxillia Chimusuro and Winnie Chikafumbwa

Winnie Chikafumbwa

'The late Winnie Chikafumbwa was a trail blazer who was largely responsible for the formation of the National Association of People with HIV/AIDS in Malawi. Winnie was a gentle soul who forced herself to do battle and became a warrior and a victor on behalf of other people.'

Lynde Francis, HIV positive, Zimbabwe



Jeannine van Woerkum

Jeannine van Woerkum, The Netherlands

'All her work was tempered with a great sense of humour and love for others.'

Tanne de Goei, The Netherlands

Marife Tanate

'The brave, smart, and lovely Marife, was truly an inspiration for me. I will miss her. She taught me the ropes and was a role model for me. She fought for "the cause" until the very end.'

Colleen Perez, HIV positive, Guam



Petudzai's beloved little boy died in 1997

'August 1997 - the worst days of my life start. Taku turned two and I celebrated his birthday in hospital with him. It was his sixth admission. He died peacefully at home, 3 October 1997.'

Petudzai, HIV positive, Zimbabwe

But even in the most difficult times, we struggle to find ways to cope with the loss of loved ones and the possibility of our own death. Children and friends give us love and a reason to survive. We find support where we can. We draw on the amazing resources women find at the hardest moments in life.



Jennifer, Uganda

'In 1997, I started witnessing some new things happening in my body - feeling weak, tired, off and on headaches, fever, sleepiness. The symptoms knocked me down but I managed to come up. I fought as a fighter, as usual, living positively and contemplating dying with dignity.'

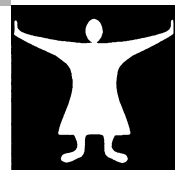
Jennifer, diagnosed 1988, Uganda

'Each year we held an AIDS memorial for our women who died. Gloria died from lymphoma, Christine, Ivy and Irene died from MAC. Christine died from an experimental drug that was given to her for her kidneys. Nancy and Barbara died from cancer while suffering from AIDS. The Sister-to-Sister Group definitely deserved a vacation from HIV/AIDS. We had lost 15 of our sisters.'

HIV positive
woman
USA



Sex work Selling sex



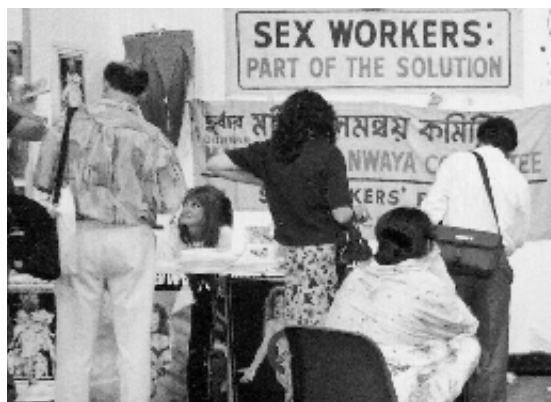
'I am a single mother and a lesbian who has been working as a prostitute in a massage parlour. I take the precaution of using a cervical cap and condoms on every single customer.'
HIV positive sex worker

'We can now insist on clients using condoms. I've found that the AIDS scare has cut down on the amount of penetrative sex I have had to do.'
HIV positive sex worker

'Usually customers are drunk, making it difficult for women to negotiate safe sex. If women insist on condom use, the men become violent.'
Mary, HIV positive, commercial sex worker, India

Some positive women have sex for money or in exchange for material goods like food. Some of us call ourselves sex workers and others don't. Sometimes the work is our choice. Sometimes it is the only way we can get money to feed our families or to avoid being homeless. Sometimes we are threatened with abuse and violence if we don't agree to sell our bodies for money.

There is little or no evidence that sex workers are responsible for the spread of HIV. Sex workers have generally taken responsibility for their health and well-being.



Indian sex workers: part of the solution

'We beg men to take precautions. We not only care about their lives, but of their wives as well. Still we are portrayed as villains.'

Selvi, HIV positive, commercial sex worker, India

Where condoms are available, many sex workers have insisted that clients use them. Even if a client offers more money to have unprotected sex, most sex workers still insist on condoms. Where condoms are not easily available many sex workers offer only safer sex activities like 'hand jobs' (masturbation) or 'blow jobs' (oral sex) and avoid penetrative vaginal or anal sex.

'When I first started work a client would occasionally talk about AIDS, saying he was worried. Some said they wouldn't go to the girls on the streets any more. Many still make a fuss over the condoms saying, "I'm clean, I only sleep with my girlfriend, I don't sleep with anyone else, trust me", or "I'm not paying money to do it with a rubber", or "It's because I like you so much - with the other girls it doesn't matter but with you I have to feel you!" But I have only lost one job because I refused to do it without.'

HIV positive sex worker

Those of us who are sex workers or sell sex for money often face discrimination, even within AIDS organisations and among other positive women. ICW welcomes all positive women and tries to emphasise our common bonds.

Social discrimination

'The sex worker lands on the street where she has no food, shelter or medical care. In Pune, every day there is a woman lying in the road in need of medical and social support. The society that is responsible for the suffering of sex workers, is not ready to look after them.'

Mary, HIV positive, commercial sex worker, India

Unfortunately, in some countries possessing condoms is used as evidence to arrest and convict women on charges of loitering and soliciting. This situation puts sex workers at risk, lowering their chances of protecting themselves and their clients from HIV by using condoms. ICW, along with other organisations is opposed to this situation and advocates for the ending of such practices through changes in the law.



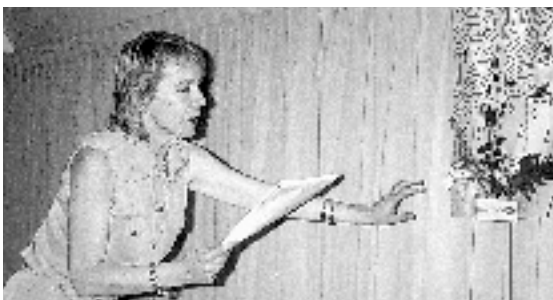
Women in Prison 11

For any woman being locked up in prison is a traumatic experience. For HIV positive women it can be especially difficult. Some of us were tested for HIV in prison and discovered that we were HIV positive there. Isolated and in fear of negative reactions from the staff and other prisoners, many women in this situation are unable to talk with anyone other than medical personnel. Others of us have been 'quarantined' or separated from other prisoners because of our HIV status.

'I was given the result in prison. I was told I was HIV positive but not to talk about it in case it caused mass hysteria. If anyone asked, I was to pretend I had hepatitis B. I was then put into isolation and my food was passed in through the hatch. I can't think of a worse place to hear news like that. I didn't know what to do. I was feeling sick from heroin withdrawal. I weighed only seven stone.'

Leigh, diagnosed 1987, Britain

Some women in prison haven't been able to write or talk to their family and friends about HIV because there is little or no privacy in prison. Letters get read and conversations listened in on. Prison staff tell other people and the news spreads quickly around a prison.



Leigh, Britain

In some countries like Argentina, Brazil, Britain, Thailand, Australia and the USA, positive women, both inside and outside prison, have been campaigning to ensure access to information and appropriate support for positive women who are incarcerated. These campaigns have to take account of the fact that even getting hold of information in prison can cause difficulties. For instance, if other women observe someone looking for information about HIV or asking for support, how will they treat her? Will she be further isolated and rejected?

'There has always been prejudice and stigma here at Albion. People here still whisper the word AIDS. It's sad, but real. We have a wonderful support group here every Thursday night. There is no set agenda. We share feelings, strengths, and hopes. We feel safe with each other because we all have something in common – both infected and affected'

Linda Suarez, HIV positive, Albion Correctional Facility, USA

It is clear that prison staff and all prisoners need education about AIDS in order to ease the isolation and abuse of positive women in prison. Outreach to women in prisons is slowly progressing in many countries. We still have a long way to go.

'Have things changed? Of course. But many HIV positive women still cope in secret because this illness touches on taboo subjects: death, sex, sexuality, drugs – all instill fear. HIV/AIDS still sets off discrimination among staff and inmates.'

Leigh, diagnosed 1987, Britain



ICW Statement on Young Women

World AIDS Day, 1 Dec 1998

Young women are the fastest growing population of people infected with HIV. ICW believes that people in the world from governments to communities and families, must acknowledge the special vulnerabilities that young women with HIV face - in all regions of the world. We must all seek out and listen to the experiences and voices of young women who are living with HIV/AIDS. We are all responsible for protecting young women from exploitation economically, sexually, and emotionally. Resources must be invested to empower, educate, and support HIV positive young women.



Marie-Joseph, Cameroun

Although there are similarities between the situation of older and younger women living with HIV, younger women often have far less personal power. They may be seen as immature and considered unworthy of the respect older women gain through marriage or having children. Some young women who have already embarked on relationships, are left isolated when AIDS hits them.

'For a young woman living with HIV/AIDS, life is never plain sailing. Society always looks at you with suspicion. You are perceived as a source of danger and death to the whole society.'

Beatrice Were, HIV positive, Uganda

'Today it is not surprising to find widows as young as eighteen in Uganda. Why are these young women expected to remain single for the rest of their lives while their male peers easily get community sympathy if they remarry? Is it because men are considered more human than women? Or is it their economic might which gives them power?'

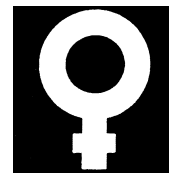
Beatrice Were, HIV positive, Uganda

Some of us discovered our HIV status while we were still in school. Our hopes and dreams about having exciting careers and independent lives, of falling in love, or eventually having our own families feel under threat.

'My mother also inquired if I was an HIV carrier. Then, again, she observed the glandular swelling on the upper hemisphere of my body and was all the more curious. She cautioned me: "If you know you are carrying AIDS, please let us know so we don't have to go on spending money on your education".'

Daisi, diagnosed 1992, Nigeria

If we tell our families and friends about our HIV status and get support from them, it may be accompanied with over protectiveness. We're grateful for the support but we want to become independent adults too. Even when we turn to support groups for positive women, we may experience similar over protective responses from older women in these groups.



I hear it from other young people - how low self-esteem and sense of self can play into the behaviours that puts us at risk for HIV in the first place. How they didn't have enough information about HIV to really know they were at risk to get it. How many times young women just want to be loved and told they are worthy of love and what they are willing to do to find this love. You know, young people don't grow up in a void. We all develop through the nurturing of family, friends, mentors, teachers and people giving services. What happens when any of this isn't available to us?

Antigone Hodgins, diagnosed 1990, USA

Like many young women growing up across the world we are also trying to work out our personal values and beliefs. We're beginning to think about relationships and now we have to grapple with what impact HIV has in our exploration of sexuality.

'By the time I gained university admission in 1994, I was already aware I was HIV positive. I was determined I would not relate in any intimate way with anybody and have sex. With that decision and being in a new environment, I felt very lonely, weak, and very uncomfortable and also so cheated when I saw other girls, fellow students, go out to parties, clubs, night shows, with their boyfriends.'

Daisi, diagnosed 1992, Nigeria

'Statistics show that the highest rising group of infections is basically the group from 18 - 24. That's the age where you go to nightclubs and you take risks and you're taking alcohol and you're taking drugs and you've got that attitude, stuff it, I'm invincible, I'm going to live forever.'

Cathy, 21, diagnosed 1995, Australia



Marie-Jo, Tita and Euphrasie, Cameroun

For many positive young women all of this happens in isolation. You think you're the only one in the world. Finding other young women and sharing our experiences of being HIV positive has made us feel less alone. Being able to talk to older women who have had similar experiences and are willing to act as mentors or guides has also been valuable.

One of the major problems for young women is that so much of the available information aimed at them is about preventing HIV infection. But we are positive already! In many places, young women are among the groups with the highest growing rates of HIV infection.

'If you say, "Oh, prevention, prevention", and you talk as if young people are not infected, and you don't talk about counselling and testing, then you're not really telling them they're at risk. People do it all the time and they don't realise it. That happened to me. No one ever said you should get tested. People even discouraged me from it. They said, you're young, you're a woman, you're fine.'

Antigone Hodgins, diagnosed 1990, USA

Listening and supporting young people as honestly and creatively as we can is important. We cannot be complacent about the work we all need to do with youth. Listening to the stories of young women is a necessary first step.

Oom, Thailand



Positive women Changing and Connecting



'Out of the torn threads that are left of our lives, we must try and make new clothes.'

Mercy
Makhalemele,
HIV positive,
South Africa

'I discriminated against myself for a long time. Now I'm starting to see the need for women's empowerment.'

Ruth, diagnosed
1991, Philippines

'Remember - United we stand, Divided we fall - Positive Sisters Unite!'

Linda Reed,
diagnosed
1988, Eire



Prudence, South Africa

HIV and AIDS have changed our lives forever. We continue to fight an uphill battle against ignorance, fear, indifference and hardships and heartbreak in our own personal lives. But we have learned much. We know that connections with positive women around the world help us all gain strength and confidence in our own lives.

'Out of fear created by the media, people with HIV are out of work, seen as worthless, and are left without hope and without a future. Yet we are not without hope and we are planning a future.'

Oom, HIV positive, Thailand

'So, if all goes according to plan, I will be very newly wed. I am so excited. This is something I thought would never happen once I got my diagnosis. Yet God has been good to me and it is going to happen.'

Sue Burton, diagnosed 1993, Netherlands Antilles

'We know from our own experience that positive women are very effective in creating awareness; people understand more after talking to them. But we need support if we are to support others.'

Dorothy, HIV positive, Kenya

'People were now free to talk about AIDS. They were more concerned and felt a need to help others. The problem was no longer the virus. We now wanted to define our needs and discover what was important for us.'

Agnes, diagnosed 1990, Uganda



Imani and Mercy

'Now I believe HIV is not the end of everything. It can be a beginning in which you take care of yourself.'

Diana, HIV positive, Malaysia

'I am of the opinion that all over the world a positive HIV test can evoke deep thoughts and fundamental changes in our lives.'

Jan, diagnosed 1995, Germany

'I am 32 years old, with four children and eight orphans of my late elder sister, who together with her husband died of AIDS. Shame, stress and discrimination here in Central Africa make communication about AIDS difficult. I talk to students, young school children, civil servants, traders, different churches, prostitutes, widows, Moslems, hospitals, HIV diagnosis centres, parents of HIV positive children. I have done a lot of work my dear friends. I have reached more than 2,600 positive women and there are many others.'

Collette Moussa, diagnosed 1991,
Central African Republic

'Ignorance breeds fear, fear breeds intolerance, intolerance breeds hate. If in some small way, my speaking out can help to break this terrible cycle then it is the least I can do.'

Doreen Millman, age 63, HIV positive, Canada



Human Rights and HIV

It is said we all have a right to life, health, and education. So where have these rights disappeared to?

Giovanna Torres, diagnosed 1995, Peru

'We must provide more information for women. But it's difficult when women have no rights, are taught they are inferior to men and are of little importance, while even little boys are told they have the right to dominate women.'

Martine Somda, HIV positive, Burkina Faso

All over the world women's human rights are violated every day. Many women cannot earn a living wage and cannot afford the basic necessities of life. On top of this, in many cultures women are not recognised, let alone treated, as the equals of men. These circumstances can make women more vulnerable to infection and illness. For these women, HIV is likely to be one of a number of factors which lead to oppression. Sadly, many of us also experience discrimination and stigmatisation simply because we are HIV positive.

Fifty years ago, The Universal Declaration of Human Rights was adopted by the General Assembly of the United Nations in 1948. All these years later we are still struggling for basic human rights. ICW believes all women living with HIV/AIDS deserve respect, basic rights, information, and support.

We hope that this Survival Kit helps in some small way.

'Now when I discuss my HIV status in front of people I know we can demand our rights. Now I am thinking I should support people who are afraid of being HIV positive and help them come forward with their demands for rights. They should not be suppressed by other people.'

Mary, 20 years old, HIV positive, India

'When I was diagnosed my first feelings were of anguish and disaster. But almost immediately I started going to a self-help group and slowly I got the courage to face the new situation in my life. Through this unique experience, I have matured and learned so much. I've met very special and powerful women who long for life and who hope to build a dignified and equal society.'

Marina, diagnosed 1996, Brazil

SEE FACT SHEET NO 9

for more information on
Human Rights and HIV



'I joined the Women and AIDS Support Network. Finally I was empowered and educated about my rights. I went to the courts and got my house back from my husband and his second wife.'
Anna, HIV positive,
Zimbabwe

Sources, Thanks and Acknowledgements

Sources

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- *AIDS Action - the international newsletter on AIDS prevention and care*, Healthlink Worldwide, Britain
- *AIDS Treatment Update*, NAM, Britain
- *Child Health Dialogue*, Special joint issue with AIDS Action, Britain
- *Fact Sheet 1.98, Breastfeeding and HIV Transmission*, SAFAIDS, PO Box A509, Avondale, Harare, Zimbabwe Fax: 263 4 336195 Tel: 263 4 3361/4 Email: info@safids.org.zw
- *HIV and AIDS What all women (and our partners) need to know*, North Manchester Health Promotion, Britain
- *ICW News - International Community of Women Living with HIV/AIDS newsletter*, Britain
- *Keep It Simple: K.I.S.S. Guide to Safe Sex*, Centre for the Study of Sexually Transmissible Diseases, La Trobe University, for the National Centre for Disease Control, Australia
- *Newsline - People with AIDS Coalition of New York, USA*
- *Positive Development: setting up self-help groups and advocating for change. A manual for people living with HIV*, GNP+ in collaboration with Healthlink Worldwide, Britain, 1998
- *Positive Women - A Newsletter by women living with HIV/AIDS in Uganda (NACWOLA)*
- *Positively Women - Living with AIDS*, edited by Kate Thomson and Sue O'Sullivan, Britain
- *Positive Women's Newsletter*, Victoria, Australia
- *A Positive Life: Portraits of Women Living with HIV*, River Huston and Mary Berridge, USA
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- *SAFAIDS NEWS - Southern Africa AIDS Information Dissemination Service Bulletin*, Zimbabwe
- *Sexual Healing - A Guide for Women with HIV*, published by The Terrence Higgins Trust for Positively Women, and written by Sue O'Sullivan, Britain
- *STOPAIDS News - A Trimester Publication of STOPAIDS Organisation*, Nigeria
- *WORLD - newsletter*, USA

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Your Notes

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