FULFILLING FATHERHOOD
EXPERIENCES FROM HIV POSITIVE FATHERS
Founded in 1952, the International Planned Parenthood Federation (IPPF) is an independent, non-profit umbrella organisation working to advance sexual and reproductive health and rights in 183 countries around the world.

IPPF’s 38,000 clinics, drop-in centres, outreach and peer education programmes reach over 32 million women, men and young people each year. We work to expand access to maternal health care; gynaecological care; HIV/AIDS information, prevention, treatment and counselling; diagnosis and treatment of sexually transmitted infections; and safe abortion services - particularly amongst poor and marginalized communities.

IPPF’s Strategic Framework outlines five strategic priority areas for the organization: access, abortion, advocacy, adolescents and HIV/AIDS. Our goal for HIV/AIDS is to reduce the global incidence of HIV/AIDS and to fully protect the rights of people infected and affected by HIV/AIDS.

The Global Network of People living with HIV/AIDS (GNP+) is a global network for and by people with HIV/AIDS. The mission of GNP+ is to work to improve the quality of life of people living with HIV/AIDS. GNP+ has a board of 12 members representing six international regions: Africa, Asia/Pacific, the Caribbean, Europe, Latin America, and North America.

GNP+ actively promotes global access to HIV care and treatment, ending stigma and discrimination against people living with HIV/AIDS, and the greater and more meaningful involvement of PLWHA in the decisions that affect their lives and the lives of their communities. GNP+ achieves its mission through advocacy, capacity building, and communications programmes that draw from strategies based on lobbying for inclusion, visibility, access and rights.

GNP+ focuses on the involvement and participation of people living with HIV/AIDS in influencing international public policy, in designing, implementing, and evaluating programmes aimed at HIV/AIDS prevention and treatment. GNP+ has taken on the role as a member of the Board of the Global Fund, and as one of the co-organizers in collaboration with the International AIDS Society, for the World AIDS Day 2006 in Toronto, Canada.

**International Planned Parenthood Federation**
4 Newhams Row
London SE1 3UZ
United Kingdom
Tel +44 20 7939 8200
Fax +44 20 7939 8300
Email info@ippf.org
www.ippf.org

**GNP+**
P.O. Box 11726
1001 GS Amsterdam
The Netherlands
Tel +31 20 423 4114
Fax +31 20 423 4224
Email infognp@gnpplus.net
www.gnpplus.net
The world has made a promise to tackle the spread and impact of HIV/AIDS: governments have made declarations through the United Nations, and civil society organizations have signed on to a code of good practice. Putting this promise into action requires strong commitment to leadership, prevention, care and support, treatment, reducing vulnerability and human rights. If we are to be successful, we must listen to, and act upon, the voices of people living with HIV/AIDS who are part of every community.

Acknowledging and responding to the sexual and reproductive health issues and desires of HIV positive men and fathers is vital: positive fathers are key agents of change in the HIV/AIDS epidemic, playing a pivotal role in shaping the lives of their children and families, and perhaps providing a model to better address stigma and discrimination. There needs to be a strong focus on ‘positive prevention’, an essential ingredient when linking efforts aimed at prevention and care. It helps people living with HIV/AIDS protect their health, avoid other sexually transmitted infections, delay HIV disease progression, and avoid passing HIV infection on to others.

Programmers and policy makers must address the prevention needs of HIV positive people which will, in turn, benefit everyone, particularly as widespread access to treatment is becoming a reality and many HIV positive people are living longer and healthier lives. Men living with HIV not only have specific sexual health concerns which are frequently neglected, but they often lack information of how best to live a healthy sexual life within the midst of an epidemic.

In response to this situation, the International Planned Parenthood Federation (IPPF) – the world’s largest non-governmental provider of sexual and reproductive health services and rights – has worked in collaboration with The Global Network of People living with HIV/AIDS (GNP+) – which advocates internationally on this issue – to give voice to HIV positive fathers from around the world.

Revealed for the first time in this booklet are thirteen honest, candid and highly personal stories which seek to highlight the lives of HIV positive fathers, and to serve as a catalyst for the greater involvement of men in sexual and reproductive health issues. These fatherhood role models, who have chosen to speak out and live openly with HIV in their communities, demonstrate the complexity of parenting within the context of HIV/AIDS.

The decision to become a parent is often an easy one for many people. However, choosing to become a father is a decision that many HIV positive men are now facing and it can be a challenging one. Similarly, disclosing their HIV status to their children has for many men proved to be a turning point, not only in how they view themselves, but also how they interact with their children.

One of the recurring messages expressed in these stories is the love and concern of fathers to provide for their children's future, both financially and as influential role models. Whether as a biological father, adoptive father or step-father; whether in zero-discordant or same sex relationships, men help their children find value in their own lives and those of other people.

This joint IPPF and GNP+ initiative is a small step towards addressing the current realities facing many men living with HIV/AIDS. Fulfilling the dream to become a father, and addressing the corresponding sexual and reproductive health implications, including the prevention needs of positive people, will mean the re-orientation of sexual and reproductive health services.

We are committed to this work as we continue to strengthen our global response to the epidemic and to seek new ways of ensuring that those most vulnerable to HIV infection remain at the forefront of our efforts. We must keep the promise the world has made to take action on HIV/AIDS.

“Positive fathers are key agents of change in the HIV/AIDS epidemic, playing a pivotal role in shaping the lives of their children and families.”
MOTHER-TO-CHILD TRANSMISSION (MTCT) CAUSES MORE THAN 90 PER CENT OF ALL HIV INFECTIONS IN CHILDREN UNDER 15 YEARS $^2$
Rose and his wife are planning for the future of their four-year-old daughter and trying to be an open positive couple living in Kathmandu, Nepal. Rose has been living with HIV since 1997.

Rose uses educational play moments with his young daughter to help her understand HIV/AIDS from an early age. He plays an important role in providing her with HIV/AIDS education by incorporating the red ribbon into her nursery rhymes that she sings and having HIV education materials around the house. Rose has also taught her about the risks of coming in contact if he has an open wound caused by an opportunistic infection, and not to touch his shaving blade. These are just some of the challenges he faces as a positive father, but his daughter seems to be taking it all in her stride. “She often draws the red ribbon whilst sketching and is interested in watching HIV/AIDS film documentaries.”

“My focus has turned towards providing a future for my daughter. She tested negative in 2004 and I wish to preserve a healthy, positive relationship with her. I frequently think about her future and prospects for a brighter life. My wish is that she remains HIV negative and that she will be able to have a good education to help her become an independent adult who is able to live with dignity.

My dream is to find a private sponsor for my daughter’s private education. In the short-term, I’m already struggling to provide funds for her education. My health is declining and I know that I already need to access antiretroviral treatment. Our short-term lack of financial security to deal with the reality of my family’s survival needs is very difficult. I wish to look after my family, to deal with the treatment of my opportunistic infections and to provide good nourishing food for my family so we can all live healthily. When I recently suffered a tuberculosis infection on my neck, it was a most difficult situation for my family, even my daughter was upset and cried.

My wife and I often talk about our mistakes. We both knew my HIV positive status and how HIV is transmitted. However, my wife became pregnant with a second child. We went to see a doctor for counselling but the doctor was unsupportive and made us feel guilty for my wife becoming pregnant. Despite there being medicine available to help prevent mother to child transmission, we decided to abort the child by clinical methods.

This is the first time that I’ve disclosed my HIV positive status publicly. I want to help fight against the stigma, discrimination and misconceptions in my conservative Nepalese society. I am hopeful that disclosing my status can influence other men who are in some form of leadership position in society to make them more accepting, and to reduce stigma and discrimination towards other people living with HIV. I know that if I don’t disclose and tell my story, I’m isolating myself and my family. And I also want other HIV positive fathers to realize our struggle so they too can act responsibly and to help provide a future for their children.”

“Now my focus has turned towards providing a future for my daughter.”
SUB-SAHARAN AFRICA HAS JUST OVER 10 PER CENT OF THE WORLD’S POPULATION, BUT ACCOUNTS FOR ALMOST TWO-THIRDS OF ALL HIV INFECTIONS WORLDWIDE.
Rev. Wycliffe was diagnosed with HIV in 1992. Now 27, he lives in Kisumu, Kenya with his wife and three children.

As an HIV positive religious leader, Rev. Wycliffe believes it is time for fathers and other men who know their status to speak up. By knowing their status they can plan for their families and help come up with strategies to help one another. “In my culture, men are the bull. Men are influential mobilizers. People listen. Men are the best people to inform others to change stigma so that other positive men can get support.”

Rev. Wycliffe’s family faces not only being ostracized, because both he and his wife are positive, but also danger. By being a visibly open person living with HIV, he could be killed or stoned on any given day. “Within the Luo tribe, to have HIV automatically makes you a sinner and not deserving to be part of the community. There was a lot of pointing of fingers and people saying ‘He has that thing’. The children are teased and not seen as part of the community. Despite these responses, Rev. Wycliffe’s children were quick to reassure him that they still loved him and would continue to support him. “It took time to tell the children about my status. I laid the ground work by giving them the facts about HIV. I think they didn’t react poorly because they were informed.

I built my father a home and now I am locked out of it. My father is not informed about HIV and my mother has no voice in our culture. I still love my father and we talk on the telephone, but there is a lot of community pressure for him not to let me in the house.

Stigma is the biggest problem. We need to fight stigma through education, awareness raising and advocacy. We need to let people know that HIV can be managed, but the stigma kills. We need to know that life continues. We need to be informed, responsible and visible so we can plan for the future, the families and for ourselves. We can deal with the rejection of stigma by being an example. We can make stigma end by creating a national group of positive fathers where they can belong, get support and feel safe. A strategy of living positively and being advocates is needed.

There are no positive images to support fathers. I have a right as a human being to have sex, but I must be careful not to re-infect my wife. I cannot bring down my health and so I use condoms.

Fathers need income generating activities, group therapies and a place to share challenges and support as positive fathers. They need to know we are standing behind them and we are praying for strength to build us.

It is important for me to keep motivating my children, and for my children to know that I’m still here and that life continues.”

“We can make stigma end by creating a national group of positive fathers where they can belong, get support and feel safe.”
ALMOST NINE OUT OF EVERY TEN PEOPLE WHO NEED ANTIRETROVIRAL (ARV) TREATMENT – THE MAJORITY OF THEM IN SUB-SAHARAN AFRICA – ARE NOT RECEIVING IT.
Rev. Christo was diagnosed with HIV in 1987. Now 41, he lives in Johannesburg, South Africa, with his wife and two daughters.

When Christo and his girlfriend, Liesel, discussed marriage and sex for the first time, there was much to consider as a discordant couple. The couple had chosen abstinence prior to marriage, and this would mean becoming sexually active and looking at preventing her from becoming infected. Christo’s father, also a minister, hesitated to marry the couple if Liesel’s parents were unaware of Christo’s status, but Liesel vowed to find someone else to marry them if he would not perform the ceremony. After seventeen years of marriage, Liesel remains negative, along with both of their daughters.

“Being a father was something I never held in my mind. Then we found out if my viral load became undetectable with the use of antiretroviral (ARV) medications, there would be a reduced risk of transmission to my wife. We started dreaming about the possibility of becoming parents. Some people are amazed that my wife and I are parents, while others think we were irresponsible. They don’t know all of the research and testing we did, and precautions we took to limit the risk to my wife, who is still negative. When I told my parents we were pregnant I said ‘I have good news, Liesel is pregnant and she is still negative’. My mother was in tears and my father had to take a walk to absorb it all. It was more than we dreamed could happen. The impossible had come true. Every time I look at these children I still have to pinch myself.

In 1992 when I disclosed my status it was terribly difficult. As a reverend with a congregation it was a fearsome thing to do. People had no negative reactions because they knew I became infected as a haemophiliac, and therefore in their minds I was ‘innocent’. Now I don’t tell people how I became infected because it’s not important. It is easier for me to be open about my status because I can look people in the eye. If they want to discriminate that is on them.

In the first ten years after my diagnosis it was impossible to dream about a future beyond next year, but thanks to ARVs all of that has changed. Now I dare to dream. I have always lived positively since I knew my status. I live life to the full, while appreciating each day and every relationship. But now I can also think about where I want to be in life. I can think beyond two years and where I will be in ten years. I found a Chinese proverb that has become my life motto: ‘If you have a vision for a year, plant wheat; if you have a vision for ten years, plant a tree; if you have a vision for life - have children.’ Thanks to medication and information I can do this.

I was abstinent before marriage, but since our wedding condoms are part of my life. The important thing is not just the right to have sex with condoms, but also the right to choose to abstain, and to know your status. If I had not abstained others may have been infected. I think I was infected in 1984 but didn’t find out my status until 1987.

This is the first project I have seen focused on positive fathers. That’s why I was so excited to be part of it. Men are often alienated or not seen as part of the solution. Men can be agents of change that show others how to live a positive life. They can share messages of responsibility, help their families and be role models for infected or discordant couples.

Christo has been travelling a lot for work, so he is concentrating on renewing friendships and spending as much time as possible with his beautiful girls.

“The impossible had come true. Everytime I look at these children I still have to pinch myself.”
AN ESTIMATED 70 PER CENT (5.9 MILLION) OF THOSE LIVING WITH HIV IN ASIA ARE MALE, AND WITH OVER HALF OF THE WORLD’S POPULATION, THIS REGION IS NOW HOME TO SOME OF THE FASTEST GROWING HIV RATES IN THE WORLD \(^5\)
Aruna is a 45 year old Sri Lankan father living in Udahamulla. Although separated from his wife, he still sees his seven year old son once a week.

In February of 1998 the test came back positive and he was the first person living with HIV that the hospital had ever seen. The only counselling that was received was the advice to his wife: "Your husband is a bad man. He has AIDS. Run for your life." His wife's family wanted to protect her negative status and encouraged her to leave with their son 'temporarily'. That was seven years ago.

"Being a positive father is not easy. I see my son for fifteen minutes once a week. I have only picked him up and hugged him maybe two or three times in seven years because his mother is afraid that he will become infected. She knows I am careful, but is afraid that if he pinched me or scratched me accidentally he could touch my blood. Her family tells my son not to touch me because of HIV. For me, knowing my status changed how I am with my son. I can't touch him or hug him like any ordinary father can anymore. I have to love him from a distance.

In Sri Lanka, HIV is linked to sex and people make moral judgments about you. When I was first diagnosed, there was no counselling and no treatment. For six years I shut myself in: I was in shock. We are a very closed society when it comes to sex, and we don't talk about sexuality, which just drives the problem underground. I only know one other person that is open and public about their status, and only in selected safe circles.

There are no images of positive fathers that I've seen in Sri Lanka. There are no images of Sri Lankan people that are promoted as 'positive images'. There need to be more media campaigns because people need to see images they can relate to. Men are usually stereotyped as 'naughty boys'. People living with HIV/AIDS have a diversity of skills, and we can make a huge difference if we are given the opportunity to do so.

Friends may disappear. You may be unemployed like I have been for seven years, but try to be there for your family even if they should continuously push you away. My family is now OK with it. My father knew first, but he may have preferred not to know because he felt that he couldn't help. It must have been really hard for him to know I was HIV positive and not being able to do anything other than provide emotional support. Now they smile when I am up and around again. They tell me: 'Live! Live! Live!', and I live every second now.

When I was very sick, it felt like fire going through my bones. The pain was unbearable most times. I wanted to kill myself and end the suffering but then my wife did something for me. She sent my son to see me after almost two years. He toddled in and crawled up into my bed. He was two then. It changed everything for me. I wanted to live for him. I am alive today not only because of antiretroviral treatment, but also because of my son.

I would say to other positive fathers: 'Be a good father.' No matter how hard it may seem sometimes, do not ever quit on your son or daughter. Educate yourself and then educate the others."

Aruna runs an organization providing care and support to HIV positive people in Sri Lanka. He makes hospital visits to see people living with AIDS, and offers emotional support and assistance with their current needs.

"[My son] toddled in and crawled up into my bed...I wanted to live for him."
IN WESTERN EUROPE, THOUSANDS OF NEW INFECTIONS ARE OCCURRING EVERY YEAR AND LARGE NUMBERS OF HIV INFECTED PERSONS ARE UNAWARE OF THEIR STATUS
Paul, 51, lives and works in London, United Kingdom. He and his two adult daughters have been aware of his status since 2003.

After working in a bank for thirty years, Paul’s life was about to change. He was expecting a diagnosis of cancer but when the doctors told him it was HIV he was a little relieved. While his employers thought it was cancer they were very supportive, but once they knew it was HIV, that changed. Paul took a year off then joined the staff of the UK Coalition of People Living with HIV/AIDS. More than Paul’s job was about to change over the next two years.

“My daughters and I have always had a relationship where they tell me everything and I tell them everything. It is never healthy to lie to your children. When I disclosed my status, both of my daughters were very upset. My oldest daughter didn’t speak to me for a long time because she didn’t know what to say. I wish I had waited to tell them until I knew more about HIV. They had so many questions that I just couldn’t answer. My older daughter still doesn’t speak to me very often and I don’t really know my granddaughter. Her husband doesn’t know my status but he decided he didn’t want contact when I came out about being gay. My younger daughter has been brilliant. She has done research on HIV and actually came to live with me for a short period of time. It was great. My experiences have also impacted her choices in behaviour as well.

My ex-wife is my best friend. After the marriage ended we had spent so much of our lives together we decided to maintain the friendship. She was very upset when she found out, but she was upset for both my partner and me. She is a close friend of my partner as well. My mother and siblings have been 100 per cent supportive. They said they loved me when I was straight, they loved me when I was gay, and now they love me with HIV. I have very supportive friends and family.

When you are a positive father, the places that you can go to for support are usually full of young gay men. There aren’t programmes for older men with children or men that have been married. It can be very intimidating for a straight man. All the publicity in this country is largely aimed at gay men (who are still disproportionately vulnerable to infection) when there are bisexual and straight people that have HIV too. Realistically, no matter what services are out there, you have to help yourself. People may perceive us as victims but we are not. Life changes, and for some people who are very ill, it can look dark and gloomy. When I found out I was HIV positive it changed my life. I could do what I wanted to do, not what I had to do. I changed what I valued. Social status and money meant nothing and I could finally do what I had wanted to do, which is help people. It sounds funny, but becoming positive was one of the best things that happened to me. I’m a happy person now.”

Paul will soon be returning to university to study Advocacy and Volunteer Management.
RESEARCH IN INDIA, INDONESIA, PHILIPPINES AND THAILAND FOUND A WIDE AND PERSISTENT RANGE OF DISCRIMINATION AGAINST PEOPLE LIVING WITH, OR PERCEIVED TO BE LIVING WITH, HIV.
Adul, 35, lives with his wife and son in Chiang Mai Province, Thailand. He has known about his status since 2003.

After experiencing rashes and fevers, Adul went to hospital where he was tested for HIV. When the test came out positive, his family took him to another hospital but the same result was found. His wife also tested positive and Adul worried his son would be infected as well. Adul wanted him to be tested but was afraid of knowing the truth.

“I felt so scared when I first learnt about my HIV status that I was in a stage of denial, extremely anxious, and afraid to tell people. I feared that other parents would discriminate and not let their children play with my son, and that my son would feel inferior and ashamed that he has positive parents. I thought of my family, our reputation, and discrimination by the community.

My role as a dad has changed dramatically since I found out I was positive. Before I knew I was positive, I took my family for granted. Now I have a better understanding and realize the value of my family more. I care for my son and am much calmer than before. Knowing my HIV status motivated me to take good care of myself to be as strong and healthy as possible so I can fulfill my dream: supporting my son’s education to undergraduate level, and helping my family to live happily and earn sufficient income.

Social and cultural norms had a significant influence on my decision to accept and expose my HIV status. I was afraid to come out because I feared I would be discriminated against by society and relatives, but the feedback was the opposite of what I expected. I have had moral support from relatives who always teach, warn, and advise me, and everyone treats me as they did before they learned about my HIV status.

My opinion about my sexual life has also changed. I am well aware of prevention of re-infection and use condoms every single time I have sexual intercourse to prevent re-infection. I’ve never thought of having more children because I’m not physically healthy and am afraid that the newborns will be infected with the virus. Positive fathers need to remember to take good care of their kids.

Positive fathers can be advocates and educators to other men and fathers, to guide them to take care of themselves appropriately after learning their HIV status, avoid eating unhealthy food, exercise, and relax. We can contribute to HIV/AIDS prevention by sharing our own experiences to promote awareness and understanding among the community and the public. More efforts should also be made to reach people infected with HIV to encourage them to come out and receive proper treatment and care. More can be done to promote a positive image of positive fathers.”

In addition to visiting people living with HIV/AIDS, Adul also attends training sessions provided by Oxfam on medications so he can further disseminate such information to other people living with HIV/AIDS.

“Positive fathers can be advocates and educators to other men and fathers, to guide them to take care of themselves appropriately after learning their HIV status...”
MORE THAN 1.7 MILLION PEOPLE ARE CURRENTLY LIVING WITH HIV IN LATIN AMERICA, OF WHICH OVER 1 MILLION ARE MEN.

Fulfilling Fatherhood: Experiences from HIV Positive Fathers
George is the only openly HIV positive man living in Paramaribo, Suriname. His wife recently passed away, and he is raising his four and five year old sons on his own. Now 47, George found out about his status in 2004.

George has lived for many years in the Maroon interior of Suriname, working as a singer in a band. About one year ago his wife became very ill. Upon instruction from their physician, his wife was tested for HIV. Her results came back as positive, and George soon had his own positive status confirmed as well. George’s response to his wife’s declining health and diagnosis was: “Don’t be afraid. We will go through this together. We’ve been through lots of things and we will go through more. I’m not going to leave.” George’s young children watched him care for his wife until she died several months ago in her own home.

After watching their mother become so sick, the children were a little sad when he told them about his status. “It wasn’t really too hard to tell them because everyone knew about their mother and were talking about it. It was just important to let them know that their father is alive and healthy. When they did the test, the doctor told me to look after my children. My family wanted to take the boys, and community agencies also offered to help care for the children, but I can still do it. I live for my children; not HIV. My brother and sisters are very supportive, but my sister-in-law was afraid I was going to die.”

Socially, George’s life has changed as well. He could no longer sing with his band, because his band-mates were afraid that by sharing the microphone they too would become infected. Through the support of his local AIDS service organization, George became a volunteer and peer counsellor. Although his wife’s family was angry that George became an HIV advocate and was public about the life he shared with his wife, George let them know: “I’m an adult. I will do HIV work until I die so people will know about it.”

As an educator and counselor, George promotes condoms use and tells people: “Sex without condoms is very dangerous for your life. You could lose your family. Stand up for your rights. Stand up for your lives and families. Be an example in the community. It is your own lives you save and others. There is still much misinformation in the interior of Suriname. We should be getting messages to everyone and we should talk to the decision makers and grassroots people to get it done. Separate support groups for positive fathers are needed, along with education.”

Although he loves his boys, he doesn’t think he would have any more children because it would be difficult to find a mother that would be as good a mother as his wife was. “My children are making a difference for me. I fight for them. For them, I live a healthy life.”

George has become a visible advocate for HIV by speaking on the radio, making a video and writing a song about HIV. He also enjoys playing basketball, music and soccer.

“My children are making a difference for me.”
IN SOME AREAS, OVER 70 PER CENT OF HIV INFECTIONS ARE ESTIMATED TO OCCUR THROUGH MEN HAVING SEX WITH MEN (MSM)\textsuperscript{9}
At age 40, Shaun has been living with HIV for 20 years in Durban, South Africa. He has an eight year old son. Upon reflection over his own relationship with his father, Shaun thought of new ways to improve the relationship with his own son. Although he doesn’t feel any different from a negative father, he does have different anxieties about watching his son grow up and graduate. Shaun also has to consider how his visibility will impact his children. He is always aware of the stigma attached to HIV and is mindful to be sensitive to the needs of his children.

“My son is only eight, but I feel it is important to disclose in ways they can understand. My son knows I have a dragon in my blood and soldiers in my body like he does, and the soldiers fight the dragon. My son knows the medication I take makes the dragon sleep. It has almost become a fantasy to him to a degree. He will ask if the dragon is asleep. He is curious, he will ask questions and I try to be as honest as possible. As he is getting older he is asking more questions, about the dragon and what it does inside.

Deciding to be a father when you know you are HIV positive takes more consideration. You think about, if you care for the child, whether you will be able to look after the child, or will you just be creating another orphan. I tend to treasure the special moments and treasure milestones more, because I appreciate them as borrowed time. I have been out about my status for about 15 years, and am not a ‘traditional’ father, as I am also a gay man. It does add pressure being a single parent, even more so being HIV positive. But the feeling of being a parent still evokes a lot of pride and joy.

Faith based groups should be the targets for advocacy messages to encourage a more open minded response to the idea and constructs of what a man is, and what qualities a father should have. The definition of a man and father can’t be conservative and narrowly identified as it sometimes is, and all healthcare organisations, including women’s organizations, need to be sensitized to the healthcare needs of men. They need to offer support to other men when they do require support, and acknowledge the courage it could take to accept that support.

There needs to be more attention to the emotional and spiritual needs of fathers, and also practical tools and suggestions of how to discuss disclosure to your children and in ways they will understand. Not enough attention is being paid to HIV positive fathers. There isn’t sufficient awareness or affirmation of the role of positive fathers; not just in the family but also their role in the epidemic. Fathers have an immediate responsibility within the family to ensure there is appropriate and respectable upbringing. Also, fathers have a responsibility to show their humanness and caring side more proactively and be acknowledged as care-givers within the response to the epidemic.”

“There isn’t sufficient awareness or affirmation of the role of fathers; not just in the family but also their role in the epidemic.”
THERE ARE CURRENTLY OVER 10 MILLION YOUNG PEOPLE AGED 15 – 24 LIVING WITH HIV/AIDS, AND HALF OF ALL NEW INFECTIONS NOW OCCUR AMONG THIS AGE GROUP.
Henry is a 25 year old Ugandan man who has been living with his status for the last 3 years. Henry’s home and work is in outside Kampala (Gayaza-Nangabo sub-county).

Although not yet a father, Henry and his positive partner have discussed it and feel it may be an option in a couple of years, so long as she is able to have medication. If his partner was negative, he’s not sure he would become a parent. “It is a human right to have a child despite status. It’s OK to have children, as long as the man knows his responsibilities as a father and supports the woman during the pregnancy and after childbirth. People need to be empowered to know their rights. They have a right to sex, employment and being active in government. For couples that want to have children, it is up to the doctors to let them know the advantages and challenges of having children, and to tell them it’s the couple’s decision. Counselling is a key role for decision making.”

With the loss of his father to AIDS in 1990, Henry grew up with a mother who had become an HIV counsellor to support other discordant couples, and help her entire community learn about HIV awareness. In 2001, Henry’s brother died from AIDS, and in February of 2002, Henry tested positive. He then decided to use his personal testimony to prevent others from becoming infected, and to raise awareness about HIV. He is open to some of his relatives and they have often seen him on television advocating for condom use.

“In Africa, talking about sex is taboo. Men are not so open to talking about sexuality. HIV is often seen as meaning that you are young and irresponsible, which prevents men from opening up. Men need to accept their diagnosis and advocate for prevention, treatment, funding, and resource mobilization. We need to make sure that funds are being monitored and that the resources are getting to the right people. Positive people should be speaking to leaders at all levels. Youth leaders, religious leaders, women’s leaders, donors and members of parliament. People living with HIV and AIDS need to be empowered economically and socially.

“There are not enough positive images of positive fathers. There are a lot for women and girls but men are not willing to come out. Now is the time to give HIV a human face. Counselling and testing for sexually transmitted infections needs to be man-friendly. It’s difficult trying to open up to a partner. There is discrimination on many levels. If you are not open, then there is self-stigma and you think others are looking at you and they know. Or if you are open there is external stigma from a partner, employer or other people.”

To other men living with HIV, Henry would encourage them to seek treatment, get effective counselling, be visible and share their status with partners.

“We have to combine our efforts [in addressing HIV/AIDS]. We cannot leave anyone out. Men and women should be working as a team to deal with [HIV]. There is a saying in my language, ‘If a snake comes into your house, don’t ask where it came from. Get a stick and hit it in the head. Ask questions about where it came from later’. It does no good to try to blame people for infection. Just deal with it in the family. We need to talk to our partners, women, children, young people, injecting drug users, sex workers, gay men, colleagues, fathers, people without children…everyone.”

Henry works in Kampala as a Volunteer with the AIDS Challenge Youth Club and is also part of the Uganda Young Positives and Positive Society. In 2003, he had the chance to interview Nelson Mandela for MTV which gave him the courage not to give up and helped him to go on.

“It is a human right to have a child despite status.”
ONLY ONE IN FIVE PEOPLE NEEDING HIV PREVENTION WORLDWIDE HAVE ACCESS TO BASIC PREVENTION SERVICES AND ONLY ONE IN TEN PEOPLE LIVING WITH HIV HAS BEEN TESTED FOR THE VIRUS.
Scott is a 54 year old father of a 27 year old son, living with his wife in Schenectady, New York in the USA. Scott found out he was positive in 1985.

When Scott first learned his status he had custody of his seven year old son, and he worried about seeing his son graduate from high school. He concealed his status initially, out of fear of repercussions. He did not want to tell the people in his son's life, such as teachers, babysitters, or baseball teammates. When Scott realized he would be a long-term survivor, the next issue was to decide when it was the right time to tell his son.

“Choosing the right time to disclose to him was one of the most difficult decisions I had to make as a single parent. By the time I did, my positive fiancé had already passed away and he and I were living on our own again. I was afraid he would tell his mom and that she would drag me back to court. I was afraid if he told his friends he would be ridiculed on a day to day basis. He had already gone through a divorce and the death of my fiancé, so I was worried that the knowledge of his dad living with HIV would create an unbelievable amount of additional stress and worry for him. Telling him I was positive has changed our lives forever. I felt my son distanced himself from me more and more after that, more from the fear of seeing me die than anything else. He eventually joined the navy and moved to San Diego where he has lived for over 3 years. Today, his attitude is that he doesn’t need to worry about it because I look well and am living a healthy life.

When I decided to get married in 1994 to a woman who was HIV positive, we discussed whether or not to have any more children. Our decision was not to, because we had no way of knowing how much longer we were going to live and because of our ages at the time. My wife was very sad over this, more so than I, because that meant she could never have children. When our first granddaughter was born, she was able to be in the delivery room. Since then, she has felt very attached to her, and this has provided her with as close to the experience of having a child as she can get.

The first obstacle to overcome in order to live a more positive life as a positive father was to learn how to cope with my grief and losses. That was truly the most difficult challenge for me, and I would be lying to you if I said I didn’t go through a self destructive period after their deaths. It wasn’t until a near serious accident, and a connection to a path of self help, that I was finally able to snap out of my depression and begin to live with my illness in a more positive way. I tried cleansing meditations, channelling, walking, and many hours of therapy to help me cope with my losses. I began to meet others living with the disease who were activists, which inspired me to begin getting involved. I developed an understanding that there was a good chance I was going to live a long life with HIV and my outlook on life became far more positive.

Getting there took a great deal of time, and I lost a lot of good years with my son. But I feel, by making myself whole again, that he now respects me and my opinions much more than he did during my dark period.

We should try to let our children know that HIV is a manageable disease, and show them through good nutrition and exercise that we can become long term survivors. We should talk openly about our life with HIV so that our children are aware of what issues they need to be concerned about and educate them about being safe in their own lives.”

While actively involved in HIV advocacy, Scott has also helped to raise over $400,000 for the St. Peter’s Hospital Amyotrophic Lateral Sclerosis (ALS or Lou Gehrig’s Disease) Regional Center, for families of those affected with ALS.

“Telling [my son] I was positive has changed our lives forever.”
HIV PREVALENCE AMONG INJECTING DRUG USERS (IDUs) IS AS HIGH AS 44 – 85 PER CENT IN CERTAIN PROVINCES IN CHINA. SIMILAR LEVELS CAN BE FOUND AMONG IDUs IN OTHER PARTS OF ASIA AND EASTERN EUROPE.
Xu lives happily with his wife, and works alongside her each day in Yongkang city, Zhejiang province. He spends his leisure time studying calligraphy and playing Chinese chess with his fellow villagers.

Although I have HIV, I never give up my responsibility as a father.

“Although I have HIV, I never give up my responsibility as a father. Providing for my family is one of the responsibilities that I take very seriously. Because of my HIV status this has become even more important for me. I never give up my hope for the future of my family. Now I depend on medicine to prolong my life along with my medical knowledge and my optimistic attitude. One effective method of maintaining my health is to take antiretroviral medicine continuously, and the other is to get rid of the mental burden. And part of that is the wonderful support I have received from my children. Just like I support them, sharing my HIV status with them has eased a lot of pressure for me. I have their love and understanding. My only approach is to fight against this disease to my last breath.

After I was open about my status, the greatest challenge was discrimination. Although my family members and some of my friends expressed understanding and sympathy towards my situation, most people look at me oddly. I know that it is discrimination. Although I live with HIV and am discriminated against by other people, I can endure the pressure and challenge in my positive life. I believe that I have enough capacity to meet any challenge, to earn my own living and to play the role of a father as before. If I want to fight against the disease, I must depend on myself.

I think one of the most useful ways to prevent the spread of HIV is through education to the public and it would also to reduce discrimination. The government and relevant departments should provide cheaper or free testing. This act could reduce our burden in many ways.”
CURRENTLY THERE ARE 39.4 MILLION PEOPLE IN THE WORLD LIVING WITH HIV – THE HIGHEST LEVEL EVER – OF WHICH JUST OVER HALF ARE MALE.
David, lives in Windhoek, Namibia, and has one 13 year old son and 24 year old stepdaughter. He has known his HIV status since 1990.

Although David’s son has grown up knowing his father’s status, David continues to discuss HIV with him as and when he needs and wants to know more. With maturity, the implications of HIV have started to sink in with his son, and what was just a fact of life before is now accompanied by the emotions attached to such a diagnosis. On occasions when David has fallen sick, his son has been there to help out by being protective and showing how very caring he is. This has helped bring the two closer together.

“Informing my stepdaughter was more difficult as she is 11 years older than my son, and didn’t grow up with me from birth. She was grateful that I had told her, but not unduly surprised. Perhaps that’s because she realized I had been HIV positive all the time that we had known each other, so she knew I wasn’t about to fall down dead! I didn’t see disclosing to the children as being a sign of weakness. Rather I considered it to be a show of strength. I determined when and how I would disclose, and I was prepared for, and in control of, the process.

I decided to have children several months after I was diagnosed. It was difficult to know how best to go about having a child in a way that minimized the risk of infecting my partner. As with many HIV positive people I have met since, one of my first reactions on being diagnosed was: ‘Oh my goodness, now I can’t have children’. Which made me all the more determined to find a way of becoming a father, one way or another. My partner at the time, who was HIV negative, also wanted to have a child with me, and we explored the options together.

Planning for the future is probably the main challenge to living a positive life. I have to accept that I might die when my children are still relatively young. I want to provide as much as I can for them now and after I die. I feel I have to compensate for time that might be lost in the future. However, I am disqualified from things like life insurance because of my HIV status, so I have to look at other ways of providing for their future. This has become a bit of an obsession for me, and it’s hard to concentrate enough on day-to-day matters. When I’m with the children, it feels like I have to make up for lost time. This creates a lot of pressure, a lot of anxiety, which isn’t healthy. It’s a vicious cycle. Sometimes I wish I could just chill and take things a day at a time.

Any group of positive fathers who have come to terms with their HIV status would promote a positive image of dads living with HIV. The trouble is, we are all but invisible, as so few HIV positive men, and even fewer positive fathers, are open about our status – certainly where I come from. The way men are portrayed as fuelling the epidemic has contributed to this. Simply blaming us for everything that has happened is not going to change anything. We are as much a part of the solution as we are part of the problem.

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“I decided to have children several months after I was diagnosed.”
MEN ACCOUNT FOR AROUND 70 PER CENT OF HIV INFECTIONS IN SOME PARTS OF NORTH AMERICA

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Gustavo is a 45 year old gay father of two young men (aged 17 and 21) living in Ottawa, Canada. He has been living with HIV since 1999.

Once Gustavo told his two sons that he was HIV positive, they became much more open, honest and close. Gustavo didn’t tell them right away because he needed to absorb the information and come to the conclusion that it was not a death sentence. Although they were sad, they were very loving in their response. He filled them with reassurance by letting them know that everything was under control and he knew how to take care of his health. He was going to live.

“After finding out my status I felt stressed out and guilty, like I had been irresponsible. But I realized that I had to be there for my children, because sometimes the illness takes over. At the time I found out I had just lost my sister, my job, and had been in Washington on September 11, 2001. I was really depressed and my medications were also affecting my depression. I have overcome that with time and now I live in a positive way.

As a father I was unsure for my own future as well as my family’s. I have chosen not to tell my parents about my status; I am Latino and you cannot be Latino and gay or Latino and HIV positive. It was a major thing to move forward with my culture, and I had to get over it to get help.

I worry about accidentally infecting my sons, and being real with them. I educate my children about sexuality because the current system does not cover enough. It’s not always easy to talk about it on a personal level. I am open about my status, but I need to protect my children from stigma, so maybe I won’t talk to the media when I take part in an AIDS Walk. My sons deserve their own lives, although they are a part of mine. I tell my sons to focus on the fact that life is good and beautiful. We can’t let HIV take over our lives, life is bigger than HIV.

Telling potential partners about my status is an issue. I don’t have as much sex any more because I’m thinking about why I’m with that person and what I’m doing. I have become more peaceful in the process. I’m not sure I would want an HIV negative partner because of the risk factor, and I’m not sure they would understand about all the doctors, being tired and the other body changes.

Some fathers can’t come out because of culture. AIDS service organizations need to address publicity messages to different ethno-cultural groups. There need to be outreach programmes because fathers are being lost; they need a neutral space to help them accept the situation, to socialize and speak to counsellors. They need to be told they can live. Life changes and brings new things every day, and we learn from the challenges.

We have a chronic illness that is treatable but we are still fathers that love our children. HIV is part of us, but only a part of us.”

“...we are still fathers that love our children. HIV is part of us, but only a part of us.”
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4 Newhams Row
London SE1 3UZ
United Kingdom
Tel +44 20 7939 8200
Fax +44 20 7939 8300
Email info@ippf.org
www.ippf.org
UK Registered Charity No. 229476

Designed by Spencer du Bois

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International Planned Parenthood Federation
4 Newhams Row, London, SE1 3UZ, United Kingdom

Tel +44 20 7939 8200
Fax +44 20 7939 8300
Email info@ippf.org
www.ippf.org

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