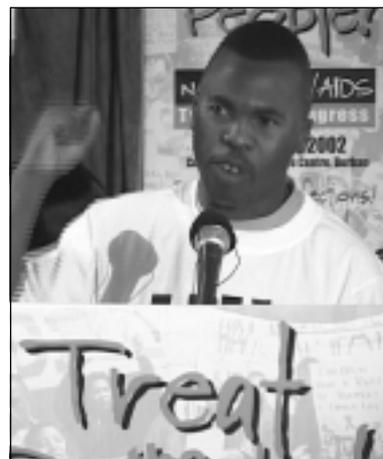


“I have been living with HIV for many years. I choose to live openly, because I have a right to exist in society like any other person. I do not have to apologise to anyone for being HIV positive. As people living with HIV, we have to lead the struggle for a Treatment Plan, the struggle against HIV associated stigma, the struggle for a better life for ourselves and others. We have to organise ourselves in support groups”.

Thabo Cele, TAC provincial organiser in Kwa-Zulu Natal and NAPWA provincial executive member.



What is a support group?

In a support group people with the same problem find ways to cope with and defeat the problem. For example, people with cancer form support groups to help each other cope. People who have survived traumatic experiences like rape or other forms of abuse come together to discuss their problems and find coping strategies. With HIV, support groups have to go beyond psychological support and have to also focus on improving services. We also have to ensure our rights are respected.

Why HIV support groups?

In South Africa, an estimated 4.7 million people are living with HIV. Of those, only 10% have tested and know their status. Support groups need to encourage awareness and openness about HIV. They need to fight against discrimination. They need to enlighten people that HIV is not a death sentence. Support groups need to counter the generalization that people with HIV brought it onto themselves by promiscuous behavior. Support groups need to help overcome fear of rejection by spouses, family and friends.

Disclosure is difficult, support groups can help

Disclosure, especially to one's family, can be difficult. Talking to other people who have been through this experience can help. Support groups should help us to disclose to our partners. You can have special days where everybody invites a partner, or parent to do community education.



Support groups can fight discrimination

Many people with HIV experience discrimination from strangers, our families, friends, lovers, healthcare workers and government. Discrimination is a result of ignorance. Members of a support group should support each other and should speak to families who discriminate against support group members. Many people do not know how HIV is transmitted. They do not know that many illnesses associated with HIV can be treated, or that HIV can be turned into a manageable chronic illness through antiretroviral treatment.



Lack of knowledge leads to fear about HIV. As people living with HIV, we have to be experts in HIV treatments. We have to know the constitution and our rights. The more information we have, the better we can counter discrimination.

Support groups should take charge of health

We have a right to medical care – we can insist on being treated. We must seek medical help as soon as we feel sick. We have to take charge of our health by learning how to prevent and treat opportunistic infections. We must know the medications for illnesses such as cryptococcal meningitis, thrush and PCP so that we can demand these treatments. We should educate health care workers who tell us nothing can be done for us. In this way we will help ensure appropriate treatment for HIV.

How to form a support group?

Many support groups are formed through clinics and hospitals. When one of the support group members is sick, s/he can easily get medical help. Referrals of people who are newly diagnosed are also easier. However, support groups can be formed at schools, workplaces, churches, youth clubs, and at people's houses.

Support groups must be practical and empowering

Support group meetings must help us solve our problems. We can strengthen our group by linking to other organizations with expertise. If, for instance, one of our members has a problem with an abusive partner, we can contact Network of Violence Against Women to find help. We must also make sure that nurses and counsellors do not treat us as if we were his/her children. We are people with the ability to fight to change things for the better.



Gender issues

When men and women mix in a support group, men will sometimes dominate and women will feel disempowered. This defeats the purpose of the support group. Also, some men feel they will not be able to talk about “male specific issues” in front of women. So, sometimes men and women prefer to be in separate support groups. There is nothing wrong with this as long as exclusivity is not based on discrimination against other people, for instance, a belief that women are inferior to men.

Where do we find HIV/AIDS information

Start by asking at your local clinic or hospital. Developing a relationship with a nurse/doctor at your local clinic or hospital can help a great deal.

Organizations that can help with HIV information are:

- AIDS consortium: 011-403 0265
- Aids Law Project (ALP): 011-717 8600
- National Association of People living with HIV/AIDS (NAPWA): 011-872 0975
- Treatment Action Campaign (TAC):
Cape Town: 021-364 5489 or 788 3507
JHB: 011-403 2293
KZN: 031-304 3673
Eastern Cape: 043-760 0050



**PHOT OF BUSI
HERE**

“As people living with HIV, we cannot continue waiting for other people to fight for us. We have to lead the fight ourselves and this means learning about issues and talking about our experiences until people hear us. It means taking to the streets if one of us is being discriminated against. It means taking to the streets in protest until we all get proper treatment, social support and respect from society, healthcare workers and our government.”

Busisiwe Maqungo, TAC volunteer.



Join Treatment Action Campaign!



Dear Friend,
Have you just tested HIV positive? Are you feeling down?
You have a lot to live for!

Don't feel afraid and lonely. I feel for you and want to share my story with you in the hope that it helps. My name is Zoleka Lobi. I live in Khayelitsha. In 1999 I lost my brother to HIV. In May 2000 my cousin also died from AIDS. In October the same year, I lost a second brother to AIDS.

By the time my brothers died, I already knew that I was also living with HIV. My partner had come from Jo'burg with a company in 1997. We decided to get married. In 1999 I fell pregnant and went to St Monica's clinic. It is there that I found out that I was living with HIV. When I told my partner I had tested positive for HIV, he said I should not have done the test. He said had done a test in Jo'burg and had tested HIV positive. When I asked him why he did not tell me, he said he thought I would not want him if he had HIV. He reminded me that when we met he did not want to sleep with me. He asked me to marry him because he knew he loved me and wanted to be with me.

We fought for weeks and I decided to move out and live on my own. I felt lonely I thought about my brothers that had died. I was angry with myself for not learning. I thought that if I was faithful and was married I was safe. My husband was not sick, he was a handsome man and was good to me so it never occurred that he could be HIV positive. I felt that I had failed my family because they would have to bury another one of their children. After some time I went back to my husband, I was angry but I still loved him. I would rather be with him than go back to be a burden to my family. Besides, I could not raise a child on my own.

After my maternity was over, I went back to work, my baby was 3 months by now. I was not happy at work, I was always scared that someone would find out and that I would be kicked out of my job anyway. My fear became so bad I decided to leave my job even though I was not fired.

I decided to go to a clinic to find out if there were social workers that could help me. It is then that I learned more about HIV. I was counseled on how to live with HIV and they explained to me that having HIV was not the end of my life.

I went back home and told my husband about the information I had received at the clinic and encouraged him to also go. He told me I was curious and asked what I went to a clinic for because I



was not sick. I told him I would go back because even if I was not sick I needed to get information and help to accept my status. When I went back to the clinic, they told me about a support group.

Meeting people who speak openly about living with HIV helped me!

It was at the support group that I met people from Treatment Action Campaign. I was surprised to meet people who are so open and who know so much about HIV. The HIV positive T-shirts they wore just changed the way I thought about HIV. Many of them were healthy and did not feel sorry for themselves. They told me about a branch meeting coming on Saturday in Khayelitsha and I went. The meeting was big. Many people from the community came. Then this young woman stood up in her HIV positive T-shirt and started talking about treatments as if she was a nurse and she told us she was living with HIV. She told us about the constitution, that is the law of this country and that communities must treat HIV positive people as equals and not discriminate against them. That encouraged me to go to many workshops. Now I can talk in front of a group of people about my HIV status and about treatments.

Educating the community

In TAC there are mainly volunteers. We are encouraged to use the information we get to help other people. I also go home to the Eastern Cape to do education. I work in the Khayelitsha branch and we do workshops on Saturdays to train new people and to educate the community.

I joined TAC's Project Ulwazi as a volunteer educator. We go to clinics and support groups to talk about the importance of testing and that there are treatments that can help if someone is sick with HIV. We also educate pregnant women about the MTCT program that can protect their baby and encourage mothers to test for HIV. Other volunteers go to schools and workplaces to do education there. We also do talks for Radio. This is very good to give me confidence.

Fighting discrimination

I have had some problems in my community. Towards the end of 2001, my neighbours started insulting me about my status when they got drunk. One time, it got so bad that we fought and they wanted to burn my house. One of them wanted to stab me but I defended myself. The police were called and instead of arresting the people for insulting me in public, I was jailed for defending myself. I spent a weekend in jail. On Monday, TAC people came and asked the police why they did not arrest the neighbours. The police did not take the issue seriously and told them I would be released. The TAC people explained to the station manager that the law says no person can insult another person for having HIV and demanded that they do something about it.

After some meetings with the police and with the people who insulted me, the people were arrested. They came out the next day and started insulting me again. TAC

people came to educate them about the law and about HIV. It took some time to sort this out. TAC worked with the Khayelitsha Development Forum and organized a demonstration to hand over a memorandum to the police saying that they must treat cases of discrimination with seriousness to send the message to the community that it is not acceptable. From the police station we went through the streets handing out pamphlets and carried our banner.

Now there are so many people in Khayelitsha who were their HIV positive T-shirts all the time and no one insults you. This helped my neighbours to see that I am strong and that I am not alone and they cannot victimize me anymore. We are now good friends with my neighbours and some of them have also joined TAC and educate about stigma and discrimination.

TAC challenges the government

Many people say TAC fights the government. TAC challenges the government if its policies are not catering for our needs, people living with HIV. This does not mean we fight government. In the same way we fight pharmaceutical companies for denying people the right to treatment by asking high prices for medicines, TAC will challenge policies of government that do not fulfill people's rights. TAC took the government to court when it did not want to provide medicines that can protect babies against HIV. After a lot of community mobilization TAC won this issue. Now the government is obliged by the constitution, the highest law of the country, to provide this service at clinics and hospitals in all provinces. This will help protect at least 35 000 babies from getting HIV a year.

Now TAC is asking the government to implement an HIV Treatment and Prevention Plan. Many other organizations, like Cosatu, the South African Council of Churches, Women's organizations and many more, support this Treatment Plan. This Plan requires government and business to provide more nurses and doctors, medicines for all people living with HIV and antiretrovirals for those of us who need them. With antiretrovirals, people living with HIV can lead a long and healthier life.

The Health Minister must push for this plan to be accepted by all of government. If she fails, the 600 AIDS deaths that occur in South Africa every day become her responsibility. Although everyone must be involved, she has to give the leadership. A Treatment and Prevention Plan will help save many of these people's and reduce the number of people getting infected with the virus. Fighting for people's rights is not fighting a government. Even if we elected the government, it does not mean we must allow it to disregard our needs.

TAC is prepared to help the government

A big part of TAC's work is to make sure that medicines are affordable. For this, TAC has campaigned against companies that produce medicines and sell them expensively. This has helped to make medicines cheaper. One company called Pfizer

was even forced to give its medicine Fluconazole (also called Diflucan) to government for free. In this way our government can treat us better and spend less money.

In 2001, TAC helped the government to win a case against the Pharmaceutical companies. Government wanted to make a law that would make it easy for people to get cheaper medicines, for all illnesses and the companies wanted to prevent this to guard their unjust profits. Government won this case and it has helped many African countries gain confidence to not let the drug companies bully them. This law must still be passed in parliament.

The education we do helps with the services at the government clinics. We also regularly hold clean-up campaigns at clinics. This shows our willingness to help government to make our health service better for all.

TAC volunteers save lives

It does not affect me if people talk badly about TAC because I know how TAC has changed my life. TAC is changing the lives of many people. Many TAC volunteers visit people at home and educate families about that many illnesses people living with HIV get can be treated. Many people I know would be dead if it wasn't for TAC volunteers who went to their homes and took them to a clinic to get treatment. Many people still do not know HIV can be treated. TAC helps these people.

Antiretrovirals keep me healthy and alive

I have been luckier than my brothers. I live a healthy life. I have been on antiretroviral treatments funded by MSF at Khayelitsha clinic. It helped to be in TAC because by the time I started with my treatment I was already educated about how the drugs work. I knew about side effects and how they can be managed and I have not had any since I started. I am sad when I think about my brothers and wish they could have lived a few more years so that they could also get treatments like me. But the fact that I am on treatment has helped my family to have hope. It has taken away the fear that I will die soon.

Sometimes they forget I have HIV. At first they have been very scared by President Mbeki saying ARVs are toxic and my mother did not want me to take them. Now she is the one who reminds me first to take my medication.

You can see how my life has returned to normal even though I am living with HIV. I invite you to join TAC. If you cannot join TAC immediately, please join a support group and learn about treatments. It is a good way to learn to deal with HIV. In TAC you learn a lot about being a leader, taking responsibility. It also enriches your life if you are doing something for the community.

If there is no TAC office in your province, call any TAC office to ask how you can build a branch or to ask for information.

How to contact TAC

NATIONAL OFFICE 34 main road Muizenberg, Cape Town tel: (021) 788 3507/
Fax: 021 788 3726 Email: info@tac.org.za Website:
www.tac.org.za

WESTERN CAPE: Town 1 properties, Sulami drive, Site b, Khayelitsha. Tel:
364 5489/3649514

GAUTENG: 185 Smith str, Oakland house, corner smith and Biccard str,
Braamfontein. Tel: 011 403 7021

EASTERN CAPE: 5-6 Madyaka Str, Highway, Mdantsane, East London. Tel:
043 7600050/043 760 3235

KWAZULUNATAL: Unit a, 3rd floor, Doone house, 379 smith street, Durban 4001.
Tel: 031-304 3673/ 304 9007

