

EQUAL

treatment

Magazine for the Treatment Action Campaign

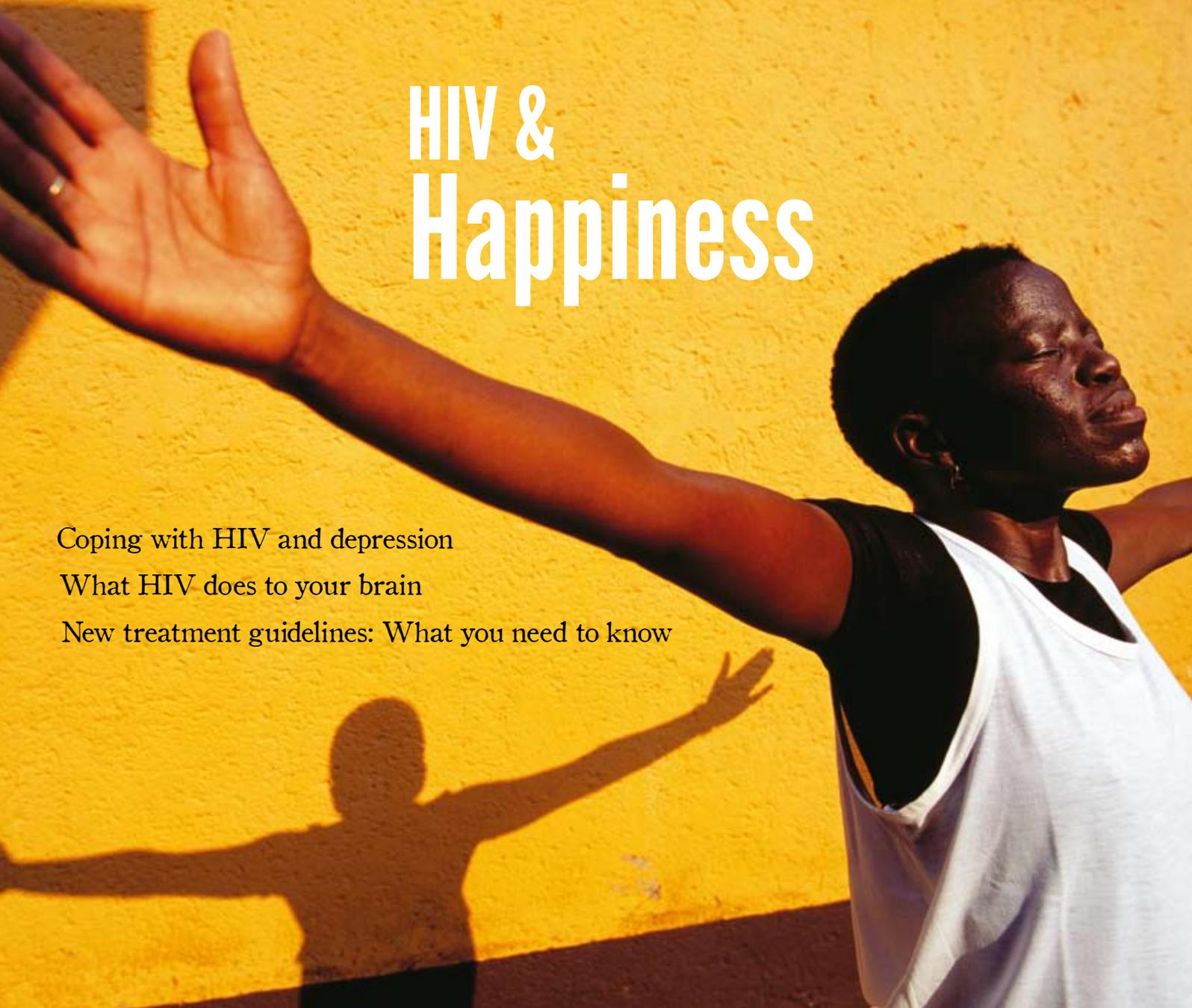
April 2010

HIV & Happiness

Coping with HIV and depression

What HIV does to your brain

New treatment guidelines: What you need to know



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Getting tested

Hearing that you are HIV-positive can feel like the end of the world. We bring you a short guide to coping with this difficult time and finding ways to move forward. Remember, HIV does not mean the end of happiness!

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HIV & the brain

HIV can take a heavy toll on our brains and lead to a number of serious conditions. Fortunately, antiretroviral treatment can help prevent and/or reverse many of these problems. We examine the brain risks related to HIV and delve into the mysterious workings of the body's control room.

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New treatment guidelines

In December President Zuma announced a number of important changes to when HIV-positive infants, HIV positive pregnant women and people co-infected with HIV and TB must be provided with treatment. We explain exactly what these changes are and outline the additional changes that TAC is campaigning for.



Editorial

I tested positive for HIV at the age of 22. For some time I was in denial, worried about the stigma associated with HIV infection and the risks attached to it. I did not disclose my status to friends, but instead began to isolate myself. I was scared they would see that I was HIV-positive.

Internalising the stigma of HIV in this way can lead to low morale, alienation and a sense of hopelessness. It can cause serious mental health conditions like clinical depression and substance abuse. Ultimately, it can cause some people lose their will to live. This battle with stigma is the main reason for suicide amongst HIV-positive people.

Together, HIV and mental illness can carry a double stigma. Many communities find it hard to accept people who have these diseases. The sufferers are therefore more vulnerable to social and health inequality, violence, poverty and unemployment. They are often in critical need of mental health care.

Access to mental health services is extremely limited for people with HIV. Very few primary health facilities have a dedicated psychologist. HIV counselling is only available when patients are tested for HIV, and is frequently provided by lay counsellors, who remain undervalued by the health care system. They often report working for months without pay. For patients there is no ongoing psychological support between getting tested and starting antiretroviral treatment.

Furthermore, this poor integration of mental health services in primary care facilities means that patients who default on treatment due to mental illness are often lost to follow-up.

The South African Depression and Anxiety Group (SADAG) has stated that the Department of Health in South Africa spends less than 1% of the national health budget on mental health services. Only 7% of the country's health facilities have specialised teams for mental health.

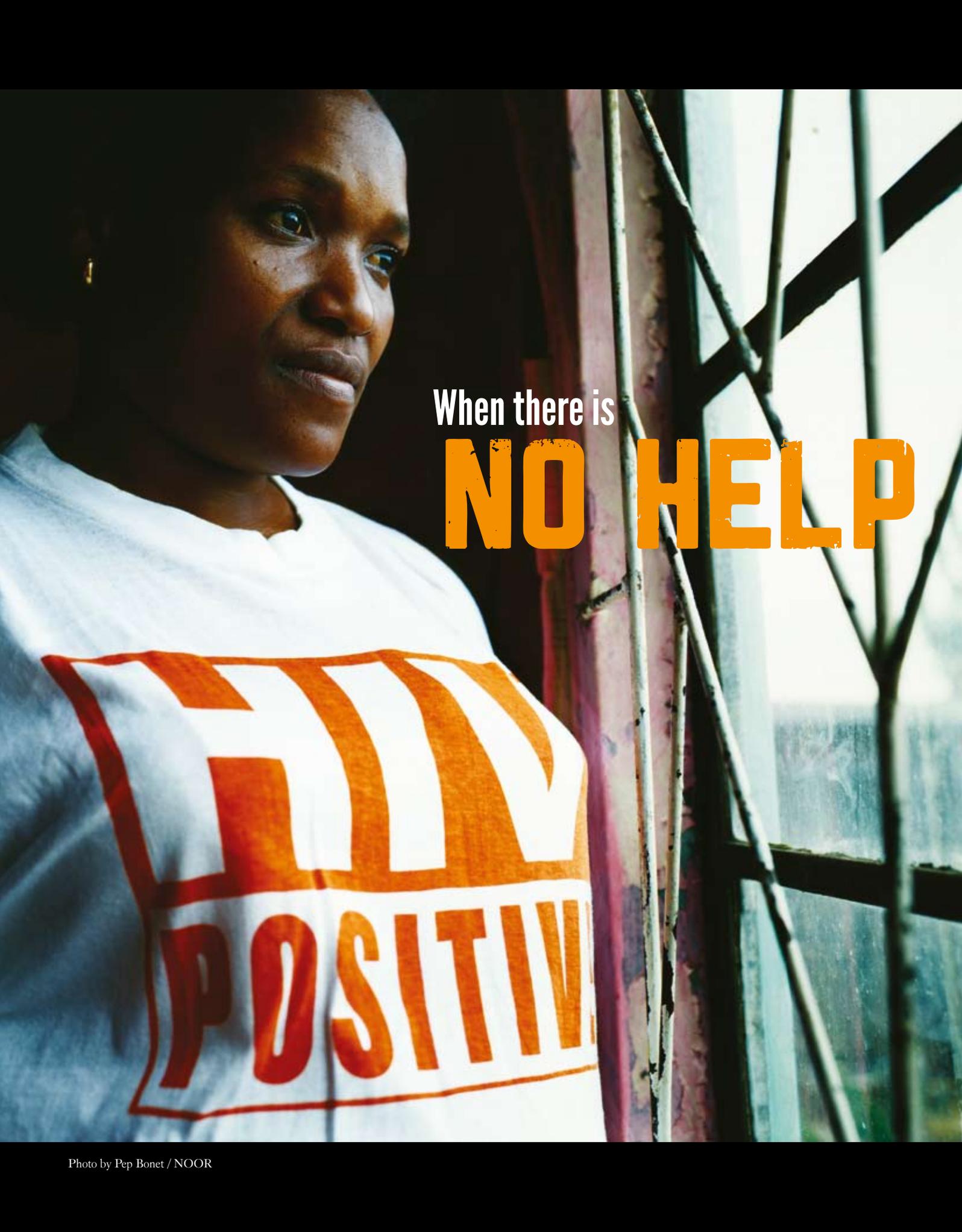
Like HIV/AIDS, mental health conditions are among the top three illnesses with the greatest disease burden for South Africa. These conditions are not only common here, but are also a global problem. An estimated 12% of the global burden of disease is due to mental illness – a figure that is predicted to reach 15% by 2020.

In 2005, the Human Sciences Research Council (HSRC) found that 42% of HIV-positive South Africans had mental health conditions, compared to 30% of those who were HIV-negative. Despite this, South Africa's mental health policy guidelines make no mention of the association between HIV and mental health. Only the South African HIV & AIDS and STI National Strategic Plan 2007–2011 (NSP) notes the connection. The NSP recognises the links between HIV and mental illness and specifically aims to improve the provision of psychological care.

We need to increase both human and financial resources to address these challenges and to transform the delivery of our health services. Health is a fundamental human right, not a luxury. The global community, especially donor countries and agencies, must realise that health is a global public good, and that we all share the responsibility of saving lives. Health solidarity is needed – now and always.

Vuyiseka Dubula, Treatment Action Campaign (TAC) General Secretary

Sources: Palitza K. "Mental Illness in HIV-Positive Patients Largely Ignored", 8 June 2009 (Inter Press Service); Department of Health, "HIV & AIDS and STI Strategic Plan for South Africa, 2007–2011" (2007).



When there is

NO HELP

In Gert Sibande, Mpumalanga, as many as four in ten people are HIV-positive. As in other rural areas, health care services are stretched to the limit. With so much demand for so few resources, the mental health needs of the people of Gert Sibande are often ignored.

By Malusi Mbatha

According to the South African Depression and Anxiety Group (SADAG), a leading mental health advocacy group, the most common HIV-related mental illness is depression. An estimated one in three HIV-positive people suffer from depression. In addition, a report by the Mental Health and Poverty Project (MHaPP) in the Department of Psychiatry at the University of Cape Town found higher rates of mental illness amongst people who live in poverty, are unemployed and on the margins of society. This double stress of poverty and HIV is a reality for many residents of Gert Sibande. However, mental health is not a priority in the treatment, care and support of HIV patients in the area.

The situation on the ground

- The lack of mental health services is mainly due to a shortage of staff. In some clinics only two lay counsellors are available, treating about 40 people per day. As a result, many patients are being turned away at testing stations.
- Another problem is the payment of lay counsellors. Some have gone four to five months without being paid. Services are often unavailable due to high rates of absenteeism.
- There are concerns about the quality of counselling that is available in the public sector. Most consultations are rushed because there are too many patients and too few counsellors. In addition, the quality of training provided to lay counsellors falls below required standards.
- Patients who have just discovered that they are HIV-positive lack ongoing counselling. As a result, many do not take – or even collect – their medicines. Others seek

The situation in Bethal

In Sead Clinic, in the small rural town of Bethal, mental health care has collapsed, according to reports from Nqobile Tshabalala, a Treatment Action Campaign (TAC) Prevention and Treatment Literacy Practitioner (PTLP) who is deployed there.

Lay counsellors at the clinic have not been paid for close to six months and have stopped coming to work. As a result many patients are being turned away. Nurses at the clinic, who chose to remain anonymous, expressed concern that they have to turn away many of the people who seek VCT (voluntary counselling and testing). The clinic services around 90 to 120 patients per day with only two overburdened nurses. This pressure has resulted in cases of negligence. Mental support is often completely ignored.

In addition, TB counselling is not available at the TB clinic or Bethal Hospital. After a patient is diagnosed with TB, he or she receives medication but no further support. This has reportedly led to poor treatment adherence in the area and a rise in the number of patients with multiple-drug resistant TB (MDRTB).

Mpumalanga only has one MDRTB hospital, located outside Gert Sibande in Witbank (Nkangala district).

alternative treatment and mental health support, for example the services of traditional healers.

- There are no psychologists in public hospitals in Gert Sibande. Patients experiencing active depression are usually referred to social workers, but more serious cases require a psychologist. This service is simply not available.

The effect of poor mental health services

Some research suggests that patients with HIV/AIDS are up to 36 times more likely than the general public to commit suicide. Since the risk of suicide is influenced by cultural factors and by the availability of psychological support, the actual risk may vary dramatically between communities. Even if it is not as high as 36 times the norm, the increased risk will nevertheless be high – especially where mental support is limited.

A review article in the African Journal of AIDS Research found that about half of HIV-positive adults sampled had some form of psychiatric disorder. Depression was the most common of these. They also tended to have more mental problems than people who were HIV-negative.

Some studies from the Human Sciences Research Council (HSRC) suggest that poor mental health often leads to drug and alcohol abuse, anxiety and mood disorders, psychotic illnesses, sleep disturbance, medication side effects and HIV infection itself.

According to Linda Mavuso, Gert Sibande PTL coordinator, patients are often in active denial about their HIV status. This not only increases the risk of spreading HIV but can also lead to reinfection. Reinfection occurs when an HIV-positive person is infected with a different strain of HIV from the one that first infected them. Reinfection contributes to drug resistance. Over time this creates a need for treatment with more expensive second-line drugs.

Getting involved

In a bid to overcome some of these problems, one Treatment Action Campaign (TAC) branch in Amsterdam, Mkhondo Municipality, began to serve as an adherence club and support group at the local clinic. They worked closely with the sister in charge, Sister Max, to successfully trace and assist 30 patients who had disappeared or were experiencing adherence problems.



Nqobile Tshabalala, TAC district secretary in Gert Sibande, talks to branch members during a support group/adherence club meeting at Amsterdam branch. Photo by Malusi Mbatha.

During patient house visits, branch members often found medication that was no longer being taken. Patients frequently mentioned a lack of food as their reason for not taking antiretrovirals. Others said that their husbands would not allow them to take drugs. Some had resorted to traditional medicines due to the side effects of antiretrovirals – mostly hallucinations from efavirenz (see page 10 for more on these side effects). Other patients could not find an adherence 'buddy' amongst family and friends as they found it hard to disclose their status. Men in particular struggled to adhere to treatment due to alcohol abuse.

It became evident that the counselling and support offered by the local clinic was insufficient. The branch had to monitor and support each patient and help them with the difficult task of disclosing their HIV-positive status to family and friends. In most cases branch members would 'buddy' with the patient for their first three months back on treatment. Once the situation had stabilised they would trace other patients.

The Amsterdam branch achieved a 100% adherence rate with the first 30 patients they assisted. Five husbands also joined their wives in going for tests and taking treatment.

The branch continues to trace patients from the clinic. Today, due to the lack of other support groups in the area, all patients who test positive are referred to the TAC branch for ongoing assistance.

Phindile Mavuso is a 32-year-old woman who lives in Amsterdam. She is just one example of a patient who nearly died after stopping medication and consulting a traditional healer for medical and mental support. In an interview, Phindile mentioned how it all began when she was pregnant and had to take an HIV test. Her results came back positive. She was told by the nurse to take one dose of nevirapine per day, as well as during labour, to prevent her unborn child from becoming infected with HIV. There was no counselling or follow-up. After the baby was born Phindile continued with her normal life. She did not know that her illness could be managed, or that she could receive treatment at the public clinic. When she fell ill, Phindile consulted her family's traditional healer, who gave her a traditional medicine called 'imbiza'. The healer told her that her ill health was due to being 'bewitched'. Phindile was aware that she had previously tested positive for HIV, but the comfort and sympathy offered by her traditional healer caused her to be in denial about her condition.

After a while she realised that her illness was becoming worse. She could no longer walk, nor could she stomach 'imbiza'. Neighbours took her to the clinic. There she met TAC PTLP Mama Shongwe, who explained to her how she could be assisted. Mama Shongwe then checked Phindile's CD4 count, which was below 50, and started her on antiretroviral treatment immediately. The branch allocated her a 'buddy' and a support team. Since then, Phindile has been living a much happier life and she has enrolled in college. Her CD4 count is 1099 and her viral load undetectable.

A group of TAC branch members commented on why people still consult traditional healers for mental support. They noted that most people are not properly counselled. As a result, when patients experience side effects at the early stage of treatment they often think that their medication is not helping them. They are therefore more likely to visit traditional healers. In most cases the healers tell them that they are just 'bewitched'. They advise patients to have a cleansing ceremony or to use African medicine. After consulting a traditional healer,

most patients fall into denial about their illness. They neglect to take their antiretrovirals and their condition worsens.

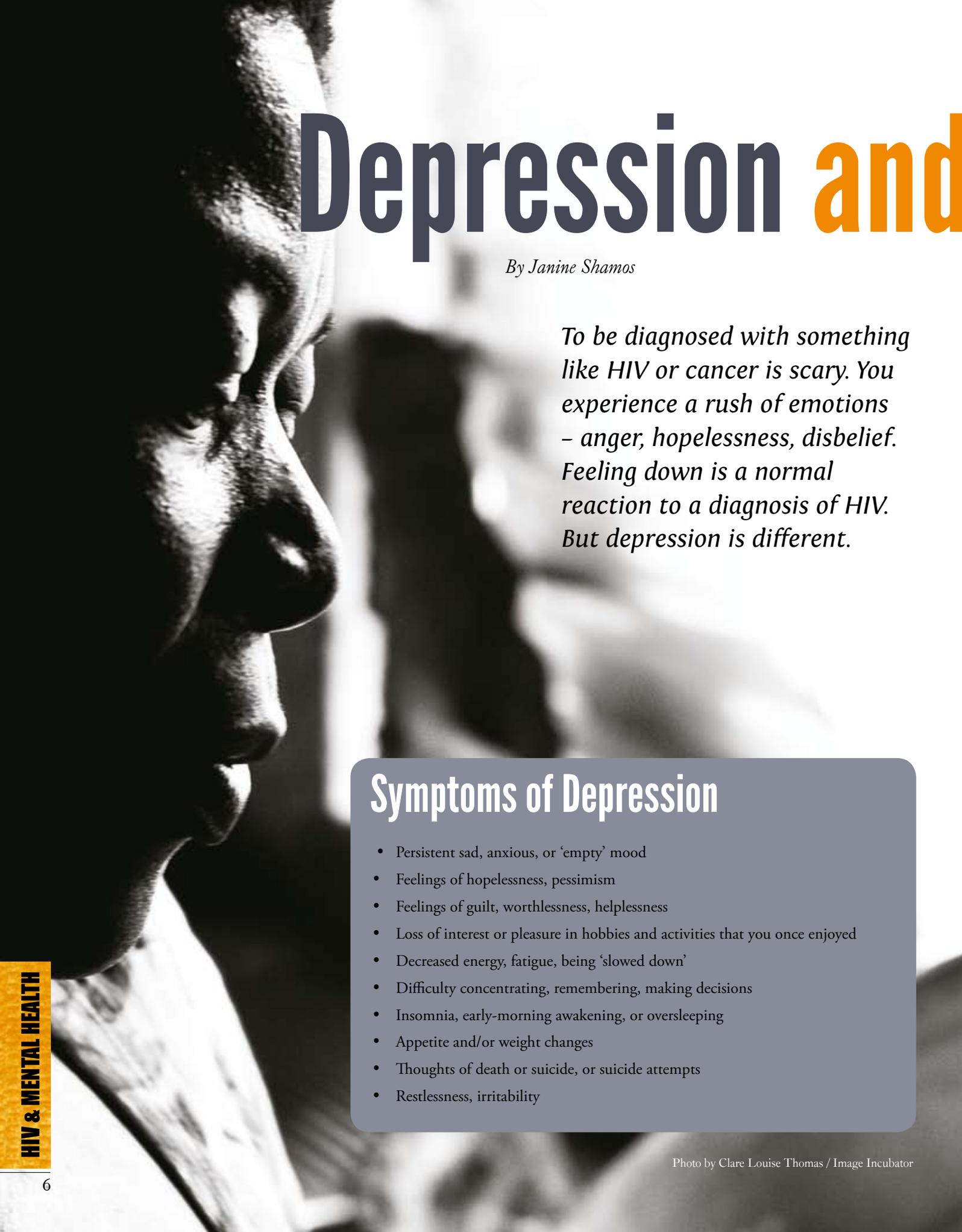
Towards a solution

Quality training for community health workers is paramount in these rural settings, where some of the greatest challenges include debunking mistaken beliefs about treatment. Task-shifting (enabling community health workers to take on some of the tasks that are normally performed by nurses) can be vital. It can make a huge difference in such under-resourced settings where service delivery – particularly for mental health – is either shelved or given little attention.

In areas such as Bethal, social mobilisation to encourage early HIV testing, access to antiretroviral treatment and PMTCT (prevention of mother-to-child transmission) is working well. However challenges arise when patients arrive at the public clinic and find that lay counsellors are either absent or do not offer quality support. A major concern when monitoring all ARV rollout sites in Gert Sibande was the complete lack of supervision, ongoing training, monitoring and therefore motivation among lay counsellors.



Photo by Malusi Mbatha



Depression and

By Janine Shamos

To be diagnosed with something like HIV or cancer is scary. You experience a rush of emotions – anger, hopelessness, disbelief. Feeling down is a normal reaction to a diagnosis of HIV. But depression is different.

Symptoms of Depression

- Persistent sad, anxious, or 'empty' mood
- Feelings of hopelessness, pessimism
- Feelings of guilt, worthlessness, helplessness
- Loss of interest or pleasure in hobbies and activities that you once enjoyed
- Decreased energy, fatigue, being 'slowed down'
- Difficulty concentrating, remembering, making decisions
- Insomnia, early-morning awakening, or oversleeping
- Appetite and/or weight changes
- Thoughts of death or suicide, or suicide attempts
- Restlessness, irritability

Photo by Clare Louise Thomas / Image Incubator

HIV

What is depression?

Depression is a medical condition that affects your thoughts, feelings, and ability to function in everyday

life. It influences the way you sleep and eat, the way you feel about yourself, and the way you think about the world. Depression is more common than the flu. It can limit the energy you need to focus on staying healthy, and it makes daily events like work, social activities, and taking care of yourself or a child extremely difficult – even impossible.

Depression is a disease that can strike anyone and is NOT a sign of personal weakness, nor is it a condition that can be willed away. Men, women, black, white, young or old; anyone can get depression.

The disease affects how a person relates to those around them, and it can cause relationships to weaken. Some people respond to depression by becoming angry and abusive to the people who care about them, or to children who depend on them. Many people try to treat their depression themselves with alcohol or street drugs. Others turn to herbal remedies that have no proven efficacy.

People with serious illnesses like cancer, heart disease, diabetes or HIV are at greater risk of becoming clinically depressed. Most people with HIV are able to lead full, productive lives, but as many as one in three may suffer from depression.

Depression is not a natural addition to HIV, yet many people – even some doctors – mistakenly believe that it is. As a result, depression is often undiagnosed and untreated. Treatment can ease symptoms in over 80% of sufferers, helping them to manage both illnesses and enhance their quality of life. Despite this, nearly two-thirds of them do not get the help they need. Some researchers have found an association between depression and an increased risk of illness and death in HIV-positive people. It can also increase the risk of suicide.

How is depression diagnosed?

Some of the symptoms of depression could be related to HIV, to specific HIV-related disorders, or to the side effects of medication. Or they could just be a normal part of life. If you have five or more symptoms every day for at least two weeks and if they interfere with your routine activities, it is important that you see your doctor to find out if you have depression.

Treatment

Remember that depression is a separate illness from HIV that can and should be treated, even when a person is undergoing treatment for HIV or AIDS. Your doctor will ask about your symptoms, how you feel emotionally, how long you have felt like that, and if you are feeling better or worse. Once they have diagnosed depression, they will suggest appropriate treatment.

There are many different treatments, but they must be carefully chosen by a trained professional. Prescription anti-depressant medications are safe for people with HIV, but they must be monitored by your doctor. Counselling or 'talk' therapy can help depression, too. Being a member of a support group for HIV-positive people who suffer from depression can also be very helpful in making you feel less isolated.

If you think you may be depressed or know someone who is, don't lose hope. Seek help for depression.

Self-help

It takes more than just good medical care for people with HIV to stay healthy. They need a positive outlook, determination, and discipline to cope with the stresses of an HIV diagnosis – avoiding high-risk behaviours, sticking to medication routines, finding time and money for doctor visits, and often grieving over the death of loved ones. Depression *can* be treated no matter what other illnesses people may have, including HIV.

Self help for depression can be difficult, so do not be afraid to ask for help if you need it. Once you have beaten it, you can help others.

Sources: Ickovics et al. Mortality, CD4 Cell Count Decline, and Depressive Symptoms Among HIV-Seropositive Women: Longitudinal Analysis From the HIV Epidemiology Research Study. JAMA. March 21, 2001, 285 (11): 1466.



Tips for dealing with depression:

- 1. Get a good understanding of what depression is.** Treatment is much more effective once you know what you are dealing with.
- 2. Regulate your sleep patterns.** Get up no later than 8am and go to bed no later than 11.30pm, even if you can't sleep. If you have problems getting up in the morning, get someone else to wake you, or have a friend call.
- 3. Eat three meals a day,** whether you are hungry or not, at the right times.
- 4. Do things to occupy your mind.** If you have nothing to do all day, you will sit and think about your problems.
- 5. Set realistic goals and assume responsibilities.** Break large tasks into small ones, set priorities, and do what you can as you can.
- 6. Try to be with other people and to confide in someone;** it is usually better than being alone and secretive.
- 7. Start a 'depression diary'.** In this diary rate each day from 1 to 10, where 1 is the worst kind of day, and 10 the best. You will notice that even though it doesn't feel like it, your mood does improve.
- 8. Take part in activities that may make you feel better.** Going to a movie, a soccer match, or participating in a religious or social activity may help.
- 9. Get as much exercise as you can.** Make yourself walk briskly every day, at least. Be sure to speak to your doctor before beginning an exercise programme.
- 10. Get some kind of relaxation during the day.** It will help reduce the physical effects of the depression.
- 11. Challenge your way of thinking about things.** If you find yourself thinking in a depressive way, deliberately think in a new way. A good way to do this is to write down the original thought, then try to think of alternatives. Ask a friend to help you.
- 12. Let your family and friends help you.**

Photos by Clare Louise Thomas

Helping a loved one

Sadly, depression remains very stigmatised, and people with HIV and depression must overcome the stigma associated with both illnesses. It really helps to have the people you love to support you.

- 1. Help your friend to get a diagnosis and treatment:** Go with your loved one to a professional for diagnosis, or treatment.
- 2. Support groups:** Find out if there are any support groups in your area. Sharing frustrations, difficulties and thoughts with others in a similar position helps.
- 3. Be prepared:** Since depression is a disease, you will need to learn much about the disease, and more about your loved one who is suffering from it. You will need to offer care and to create a supportive environment for the sufferer. This involves understanding, patience and attention.
- 4. Supportive relationships are important:** Relationships with family members and friends are a vital part of the sufferer's fight against depression. Make it a habit to express care and appreciation for family members and loved ones. Feel free to pay compliments and to notice the good in loved ones.
- 5. Involve the person in your life and activities:** Invite your loved one for walks, outings, trips to the movies and other activities you would normally do. Encourage them to join in pleasurable activities and hobbies – both new activities and those that they enjoyed before the onset of depression.
- 6. Avoid pressurising the person to cheer up:** Depressed people are suffering from real problems, not just low moods. Do not expect them to be able to 'snap out of' the condition, and don't treat it as a faked illness or sign of laziness.
- 7. Be sensitive – listen:** An attentive listener is what most depressed people look for. Be there to listen and comfort, but respect the person's needs and abilities. Do not exclude them from family matters in the belief that it would be less stressful if they were not involved. Treat the person as normally as possible.
- 8. Encourage:** Encouragement is vital – remind the sufferer that seeking treatment is a sign of strength. Tell them that treatment for this illness is always available and has proven to be very successful. Reassure the depressed person that the condition is only temporary and that they will recover in time.
- 9. Avoid patronising or babying your loved one:** Appreciate the fact that the depressed person is not at their best. Try to help out where necessary. You should not seek to do everything for them – while this may seem the best thing to do in light of the sufferer being unable to do everything for themselves, it is actually helpful for them to accept some responsibility as this can improve their self-esteem.
- 10. Suicide:** If your loved one or friend mentions having thoughts of suicide, take it seriously. Seek professional help immediately. If a loved one makes an attempt at suicide, do not blame them – their actions and feelings are symptomatic of the illness.

Depression can sap the energy you need to focus on staying healthy, but it can be treated. No matter how advanced your HIV, you do not have to suffer from depression. Expect your mood to improve gradually, not immediately. Feeling better takes time. People rarely 'snap out of' a depression – but they can feel a little better day by day. If you or someone you know with HIV is depressed, seek help from a health care professional who is experienced in treating persons with both diseases. Don't lose hope.



Efavirenz and mental health

Efavirenz is one of the most effective antiretroviral drugs we have. It is widely used as a part of first-line HIV treatments in all countries. Unfortunately, for some people there are side effects associated with mental health. Efavirenz is not a drug for everyone, and if the side effects are difficult then switching to an alternative treatment should be easy.

These side effects are more common over the first few weeks and months of treatment. They can start after the first dose, or during the first few days. They generally become less severe over time and easier to tolerate.

Nearly everyone will get some of these side effects but for most people they will be mild and easy

to manage. This means that you may have some strange dreams, or find yourself daydreaming or becoming more worried, or you may get more upset than usual. For most people these symptoms will disappear over time.

About a quarter of people in the first efavirenz studies recorded side effects that included 'difficulty carrying out daily work'.

Be prepared. If you know about the side effects of efavirenz before you start taking it, it will be easier to manage them.

Severe side effects

A small percentage of people will experience these side effects much more intensely than others. If this happens to you, it is essential that you go to the clinic as soon as possible.

These side effects can lead to depression or make depression worse – sometimes triggering suicidal feelings and clinical paranoia. It is very important therefore that you are aware that such mood swings can be related to efavirenz and that you are not 'going mad'.

If you are feeling paranoid and worried about going outside, or have stopped seeing your friends as much as you would normally do, this may be related to efavirenz side effects.

If you have struggled with depression or other mental health problems before, it is important to tell the doctor about this when you start treatment. Efavirenz should not be prescribed if you have a history of depression or mental illness, even though this doesn't always predict who will get the worst side effects.

A small percentage of people who experience severe side effects have reported feelings of unexplained depression that are out of character, including suicidal thoughts. If this happens, you need to go to the clinic as soon as possible and tell the doctor about your symptoms.

This article was adapted by Marcus Low from a fact sheet produced by HIV i-Base. The adapted article was reviewed by Simon Collins of HIV i-Base.

Side effects of Efavirenz

- Impaired concentration, confusion and abnormal thought patterns.
- Mood swings including anxiety, agitation, depression, paranoia (feeling very anxious or nervous) and euphoria (feeling very happy).
- Sleep disturbance including insomnia, drowsiness, vivid dreams and nightmares.

Note: Most people experience these side effects in a mild form.

Reducing the side effects

Although you can take efavirenz with or without food, a high-fat meal can increase drug levels in your body by 60% and this can intensify side effects. It is therefore advisable to avoid fatty food two hours before taking efavirenz.

Taking efavirenz a couple of hours before you go to sleep, rather than at bedtime, makes it more likely that you will be asleep when the drug levels are at their highest – about four hours after taking efavirenz.

Efavirenz can be a difficult drug if you work shifts that switch between day and night on a frequent basis. You are also advised not to drive machinery or work other heavy equipment until you know how you are affected by the drug.

If you have difficult side effects with efavirenz and are not happy with how you feel, then tell your doctor. Ask to change it for another drug. You do not have to continue with efavirenz to prove anything to yourself or your doctor. If you know something is wrong, don't worry about asking to switch over to something else.

Sibongile's story

By Lefa Tlhame



TAC members in Ekurhuleni marching in July 2009 as part of TAC's 'Resources for Health' campaign. Photo courtesy of Sibongile Khumalo.

Before being diagnosed with HIV and TB, Sibongile Khumalo was sick constantly with coughs and flu-like illnesses. She was wrongly advised to drink untested treatments such as boiled dagga to combat flu, or vinegar mixed with fish oil to treat coughs.

Eventually, Sibongile consulted a medical doctor. He sent her for a chest x-ray, which confirmed that she had bacterial pneumonia (an inflammatory condition of the lung). Sibongile was also screened and diagnosed with TB.

"When I discovered I had pneumonia," she said, "I became very worried, because the doctor said it can be fatal if it is not quickly [...] treated. When I discovered that I had TB, [...] feelings of emptiness and despair took hold and wouldn't go away. The lows of depression made it tough to function and enjoy life like I once did. Hobbies and friends did not interest me any more and I was exhausted all the time. Just getting through the day was overwhelming."

After initially refusing an HIV test, Sibongile finally took one. As she underwent pre-test counselling, she asked that her results be released in her husband's presence. Sibongile tested positive for HIV and was advised to have CD4 count and viral load tests.

"When I discovered that I was HIV-positive, I was devastated," she revealed. "It was even worse than TB, because TB could be cured. I could not believe it was happening to me. I saw my marriage falling apart, wondering what [would] happen to my son and family, not to mention the stigma attached to the disease in my community. When my doctor said that my husband should test for HIV as well, he revealed that he was awaiting his second test results and that he had tested positive for HIV

at work a few months ago and was waiting for confirmation. I was shocked that he had not told me. I felt betrayed."

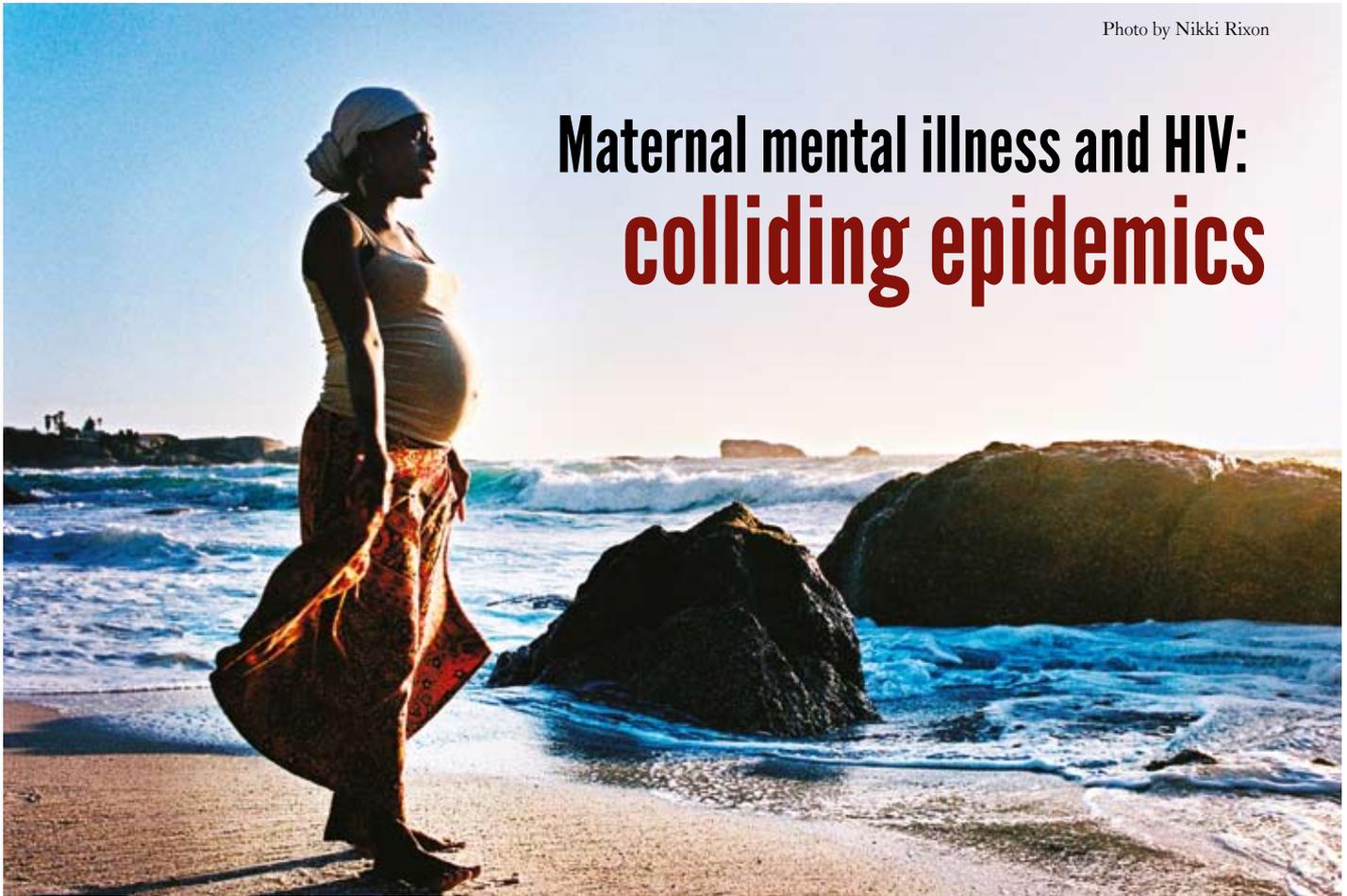
Living with HIV gave Sibongile a bleak outlook on life. She lost interest in hobbies, food, social activities and sex, and was easily agitated. At first she felt ashamed of her status, which her mum had disclosed to her family. Whilst her granny and younger brother were supportive, she felt neglected by her sister. Sibongile was unemployed and separated from her husband. She started drinking alcohol to deal with her depression and later stopped taking antiretrovirals (ARVs), choosing herbal remedies instead.

"I decided to go to church, [where I] eventually disclosed my status to the entire church," she said. "When I was telling my story, some church members began to leave, but later, others offered to help with whatever they could, such as food and transport to the clinic. I received a lot of support from the pastor, who was well-informed about HIV and AIDS."

As more people began to know about her HIV status, Sibongile's friends and neighbours offered support and suggested she apply for a disability grant. By participating in clinic HIV support groups and joining the Treatment Action Campaign (TAC), S'bongile was able to discuss treatment and related issues with people in a similar situation and she started taking her ARVs again.

Sibongile advises that if you have HIV and suffer from depression, you should take your ARVs as prescribed by your doctor. She recommends that you neither mix treatment with untested traditional medicines nor drink alcohol, but instead have a healthy diet. Also, participating in social activities or joining a support group can help you to feel better and more confident.

Sibongile tested positive for HIV in 2003. She is a member of the TAC Tsakane Branch and is a TAC Prevention Treatment Literacy Practitioner at Tsakane Main Clinic, where she gives talks on HIV, TB, STIs, ARVs and PMTCT. She is 32 years old and lives in Tsakane with her son. S'bongile's husband died of an AIDS-related condition in 2009.



Maternal mental illness and HIV: colliding epidemics

By Ingrid Meintjes, Simone Honikman & Bronwyn Evans of the Perinatal Mental Health Project

Zukiswa's story

"Since I found out I was pregnant, I haven't been able to get hold of my boyfriend. He won't take my calls. And his friends say he has gone to Jo'burg where the mother of his other two children is living. Worst of all, I found out two weeks ago that I am HIV-positive. I've been going through hell.

I am so worried about my baby. I am afraid the baby will get the virus. And what if I get sick? Who will support this child? I'm afraid to ask my mother because she never liked my boyfriend – said he was too old for me. I regret ever meeting him; with trusting him and not using condoms."

Meeting the counsellor

When Zukiswa registered at the maternity hospital, she was offered a questionnaire to fill in. This questionnaire asked Zukiswa about how she was feeling, not only about her pregnancy, but about events in her life and her relationships. She decided to fill it in. It was confidential and Zukiswa did not have to put her name on the form.

The nurse calculated her score on the questionnaire. The score showed that Zukiswa could be experiencing a mental illness. The nurse then explained that Zukiswa could see a counsellor, for free, to talk about some of her feelings. At first she thought it would be uncomfortable to talk about her problems and feelings with someone she didn't know. But she also thought that a stranger wouldn't judge her, and decided to see the counsellor.

Zukiswa met with the counsellor, and had follow-up appointments made for the same time as her next maternity visits. This meant that she didn't have to miss more time at work or find more transport money; all her appointments were at the same time.

After a few sessions, Zukiswa's mood started to change. She no longer felt as depressed or anxious. With the counsellor, she worked on solutions to her problems. She identified the resources she had around her, and thought of how to use these in the best way.

The counsellor also referred Zukiswa to the HIV counsellors at the clinic. Through the weeks of her pregnancy, Zukiswa learned about HIV, feeding options for her baby and how to protect her own and her baby's health. Eventually Zukiswa felt ready to disclose her HIV status to her mother. This helped her to get more support and understanding at home, which gave her the strength to cope with her HIV status, her pregnancy and her concerns about the future.

Depression during pregnancy: a hidden epidemic

Zukiswa is not alone.

In Khayelitsha, for example, a study has found that one in every three women suffer from postnatal depression (depression after the birth of their child). In Hlabisa, KwaZulu-Natal, a study found that 41% of women experienced depression during their pregnancy. This means that South African women experience depression around pregnancy three times more than women in developed countries. This is a 'hidden' epidemic.

In women living with HIV, what can cause mental illness during pregnancy?

Poverty is a very strong risk factor for mental illness: in South Africa, poor women are especially at risk, especially because of the impact of HIV/AIDS.

Pregnancy is often the first time that women find out about their HIV status.

- They have to come to terms with pregnancy and their HIV status at the same time.
- Many women experience severe stress when deciding whether to disclose their status.
- Women who are not already on antiretrovirals (ARVs) for their own health have to adapt to the medicine programme that prevents them passing HIV on to their baby (PMTCT – prevention of mother-to-child transmission)
- Before and after birth, there is anxiety about the status of the baby and possible feelings of guilt.
- Feeding choices may be very difficult, especially if bottle feeding may 'disclose' the mother's HIV status against her wishes.

All of this can have a significant impact on a woman's mental health. Mental illness has been proven to have a negative effect on a woman's HIV treatment and on her ability to get proper antenatal (before birth) care.

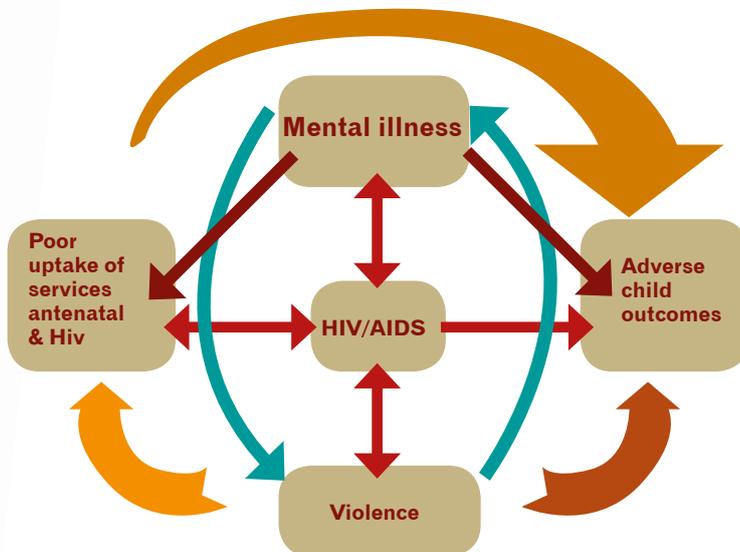
Pregnant women who are HIV-positive generally have poorer mental health than those who are HIV-negative. For some, mental illness may also lead to physical complications. Other factors that can cause women to experience high levels of mental illness are:

- Violence
- Lack of support
- Substance abuse
- Teenage pregnancy
- Physical illness

Consequences of mental illness during pregnancy

Women struggling with maternal mental illness are less able to care for their own needs or the needs of their children.

Mental illness & HIV/AIDS: colliding epidemics



Graphic: Ingrid Meintjes, PMHP

Mental illness in the mother can

- prevent her from accessing proper antenatal care
- interfere with the mother-baby bond
- cause her to default on PMTCT treatment
- prevent her from finishing her baby's immunisation
- lead to infant mortality
- lead to suicide or to conditions that increase the risk of the mother dying

Therefore, some of the most serious consequences of mental illness in the mother are increased vulnerability to

- HIV infection
- substance abuse
- the effects of poverty and other hardships
- violence
- self-harm
- loss of employment
- poor health
- complicated pregnancy due to decreased access to antenatal care

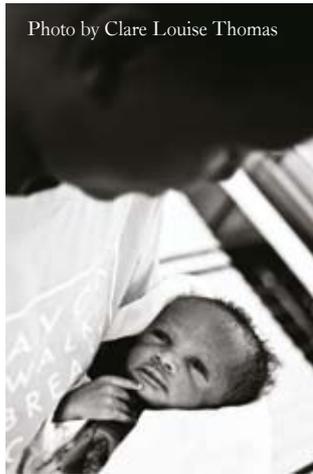
Mental illness in the mother can therefore affect her child's development – as a foetus in the womb, as an infant or as a child. Children may be affected physically, cognitively (in terms of brain development) and emotionally.

It is clear that addressing the mental health needs of the mother can improve the wellbeing of women, their children and families. In the long term, it is also good for the development of society. Caring for mothers is caring for the future.

The Mental Health Act (2002) states that mental health services should be part of general maternal care. However, public health services have not been able to adequately address this significant need.

Sources: Cooper, P. et al. "Post-partum depression and the mother-infant relationship in a South African peri-urban settlement" *British Journal of Psychiatry*, 175: 554–558 (1999); RoCHAT et al "Depression among Pregnant Rural South African Women undergoing HIV testing" *JAMA*, 295(12): 1376–1378 (2006); Stein DJ et al "Lifetime prevalence of psychiatric disorders in South Africa" *The British Journal of Psychiatry*, 192: 112–117 (2008); WHO "Mental health aspects of women's reproductive health: A global review of the literature" Switzerland: World Health Organization Press (2009).

Photo by Clare Louise Thomas



There are so many women who are dying inside from this thing [depression]. They don't know how to deal with it or how to cope. Everything in their lives is turning upside down. And they need someone who will understand and not judge them. I met with a counsellor as part of the Perinatal Mental Health Project. Finally I was able to get help. Meeting with this counsellor gave me the chance to finally speak out. Now I am doing just fine and coping very well with motherhood.

Ntombizodwa, PMHP service user

The Perinatal Mental Health Project (PMHP)

The PMHP aims for all women to have access to mental health care during and after pregnancy, as part of their ordinary maternity care. The Project has developed a model for providing screening, counselling and psychiatric services during pregnancy. Central to this model are partnering with maternity staff to offer screening for mental health risk, and an onsite, dedicated mental health officer.

In addition, the Project

- provides mental health training for health workers
- carries out research to promote development of relevant mental health services
- advocates for the roll-out of mental health services and policy development

The PMHP clinical service at Mowbray Maternity Hospital in Cape Town has been operating since 2002. The Project has screened more than 7,000 women, counselled over 1,100 and provided psychiatric services to over 100 – free of charge. Unfortunately, it is the only project of its kind in South Africa.

To find out more about the PMHP or maternal mental health, please visit www.pmhp.za.org.

WHAT TO DO IF THE TEST IS POSITIVE

By Ntombizonke Ndlovu and
Marcus Low

Finding out that you have HIV can be very traumatic. The news is likely to change your life forever. But it could also save your life, since once you know your status you can take steps to deal with it positively.

Many people are so afraid of learning their HIV status that they do not test at all. If these people have the virus, they are likely to get sick and die. They do not see that getting tested is a win-win decision: if you test negative, you can feel relieved and take precautions to remain negative. If you test positive, you can take steps to avoid the sickness and eventual death you will face if you do not get treatment.

WHAT TO DO WHEN THE TEST IS POSITIVE

1. TELL SOMEONE

Hearing that you are HIV-positive can make you feel scared, angry, helpless and sad. These feelings are normal, but you don't have to deal with them all by yourself. It is important to confide in someone you trust as soon as possible. This person can go with you to the clinic, help you learn about HIV, and remind you to take your medicines. Most importantly, they can be a shoulder to lean on when you feel down. You don't have to tell everyone right away, but try to tell at least one person.

2. LEARN ABOUT HIV

People often fear the things they do not know. This is why learning more about HIV will help you to cope. You will learn, for example, that testing HIV-positive is not a death sentence and that with the right treatments people with HIV can live long and happy lives. We are lucky to live at a time when HIV can be treated. Unfortunately you will also learn that the disease cannot be cured, and that you will have to live with HIV for the rest of your life.



Xolani's story

After testing positive I locked myself in the room for a whole week. I wanted answers. Why me? I felt like killing myself. I blamed my four previous partners and tried to figure out who could have infected me. On the day of my test result I disclosed it to all of them. I was angry and felt betrayed, but I also blamed myself.

I told my family, too, but that was maybe four years later, because I was scared of their reaction and the reaction of others in the community. At that time few understood about HIV.

Xolani lives in France location in Umgungundlovu.

3. FIND SUPPORT

Confiding in someone close to you is very important and if you are comfortable doing so you should tell your whole family. The more support you can get the better. Consider becoming part of an adherence club if there is one in your area – or starting one yourself. Also find out if there is a Treatment Action Campaign (TAC) branch in your area and get involved. The more you see other people with HIV living positively, the better you will do.



Zandile's story

With my first sister we didn't find out until after she died that she had been HIV-positive. Another sister started developing AIDS symptoms and I advised her to test for HIV. The result came back positive.

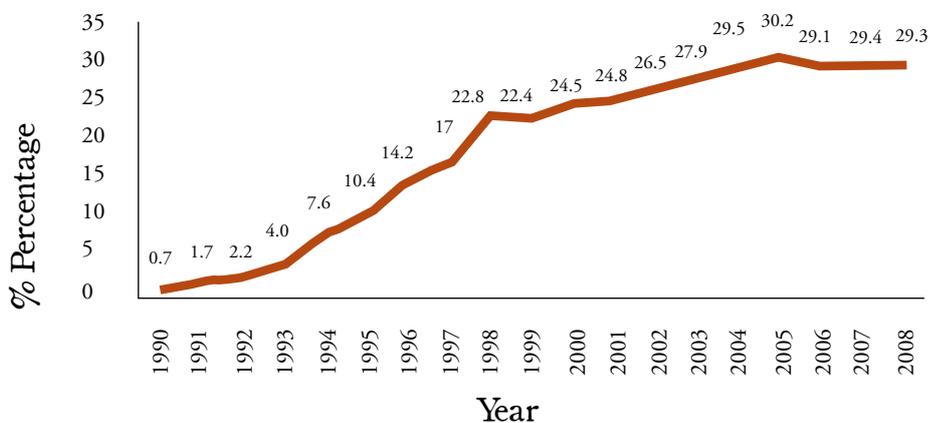
After my first sister died, I took it upon myself to get educated about HIV. I joined a support group linked to TAC and we started a TAC branch. So when my other sister told me that she was HIV-positive I tried to counsel her and help her deal with the stigma attached to the virus. I also educated my family and community about HIV so that they could support her. My first sister didn't get enough support, which I think was the main reason why her disease progressed so fast.

Our reaction plays a big role in the lives of our loved ones who are HIV-positive. If we don't support them they might not accept their status, which might cause them to default on treatment and to develop depression.

Zandile Zuma is from Elandskop and is a TAC member.

4. TAKE RESPONSIBILITY FOR YOUR HEALTH

If you look after your health, HIV is unlikely to turn your life upside down for too long. It is important to take your medicines as prescribed by your doctor. Do what you can to eat healthy food, get enough exercise, avoid alcohol and drug abuse, steer clear of smoking, practice safe sex and tell the doctor if you have any serious side effects or develop opportunistic infections. If you do these things, you are likely to stay healthy for many years.



HIV prevalence epidemic curve among antenatal women, South Africa, 1990 to 2008

WHAT IS PITC

PITC stands for Provider-initiated HIV Testing and Counselling

By Adam Malapa

Public health facilities in South Africa have been using a Voluntary Counselling and Testing (VCT) policy to test for HIV among the general population, as well as compulsory counselling for pregnant women.

Now, South Africa is moving towards Provider-initiated HIV Testing and Counselling (PITC). Unlike patient-initiated VCT, where a person voluntarily asks a health care worker to counsel and test them for HIV, any patient visiting a health facility will be offered HIV counselling. They will then have to decide whether or not to take a test.

Though we advise everyone to be tested for HIV regularly, you still have the right to refuse a test. No-one may force you to take an HIV test or deny you other health services because you refuse to take a test.

What are the benefits of PITC?

Universal access to testing and counselling is an essential part of HIV prevention, treatment, care and support. Where antiretroviral therapy (ART) is available, the biggest benefits come from diagnosing HIV at an early stage. Early diagnosis is also a chance to give people with HIV the

information they need to prevent HIV transmission to others. Even where ART is not available, treatments such as co-trimoxazole prophylaxis (medicine to prevent opportunistic infections) and prevention of mother-to-child transmission (PMTCT) offer vital health benefits.

How will PITC be implemented?

When you visit a health facility you will be offered counselling for HIV. After counselling, you may either give your consent to HIV testing or you may refuse to be tested.

Before and after testing you must always be given pre- and post-test counselling. You may opt out of pre-test counselling.

Counselling will be given to children if they are old enough to understand the benefits and implications of testing. If a child is too young, their parent or caregiver will attend the counselling before and after the child's test.

Counselling services must be appropriate and sensitive to your circumstances including your culture, language, sex, sexual orientation, age and developmental level.

HCT

HCT (HIV Counselling and Testing) is another name for the new PITC discussed in this article. This April government is rolling out a massive HCT campaign that aims to test 15 million people.

Pre- and post-counselling must cover the following:

- Information on **how HIV is acquired and transmitted**
- The **clinical benefits of early testing** for HIV and the **preventive benefits of knowing your HIV status**
- **Details of follow-up services** that will be available after testing
- Information about **the testing process**
- **Pre-test counselling** must explain the **legal protections against discrimination**
- Assurance for the patient that his or her **confidentiality** will be respected
- **Group and individual counselling options:** Pre-test counselling can occur either in a group or individually, depending on available resources. However under all circumstances patients have the right to ask questions in a private, confidential environment before testing. Patients must be explicitly, verbally notified of this right.

Your informed consent must be obtained before HIV counselling and testing services can begin. This means that you may not be tested without first being given all the relevant information and then agreeing to the test.

The Brain and HIV

By Nathan Geffen

People with HIV are at high risk of developing brain problems. However, antiretroviral (ARV) treatment helps to prevent most of these, especially if you start treatment before your CD4 count is very low.

The human brain is the most complex known thing. Our brains make us who we are. They make us conscious. Our memories, emotions and ideas are all caused by the activities of our brain. Without our brains we could not remember our own names. Neither could we love our friends nor read this article. Without a brain, we would not be people. When our brains die, we die; we no longer exist.

HIV damages the brain. But the extent of this damage and what can be done about it is not yet fully understood. Some of the evidence is contradictory. Scientists have increased research into HIV and the brain in the last decade. Over the next few years we

will develop a much better understanding of how HIV causes brain problems and what we can do to stop it. However, the evidence is clear that antiretroviral (ARV) treatment makes a big difference.

How the brain works

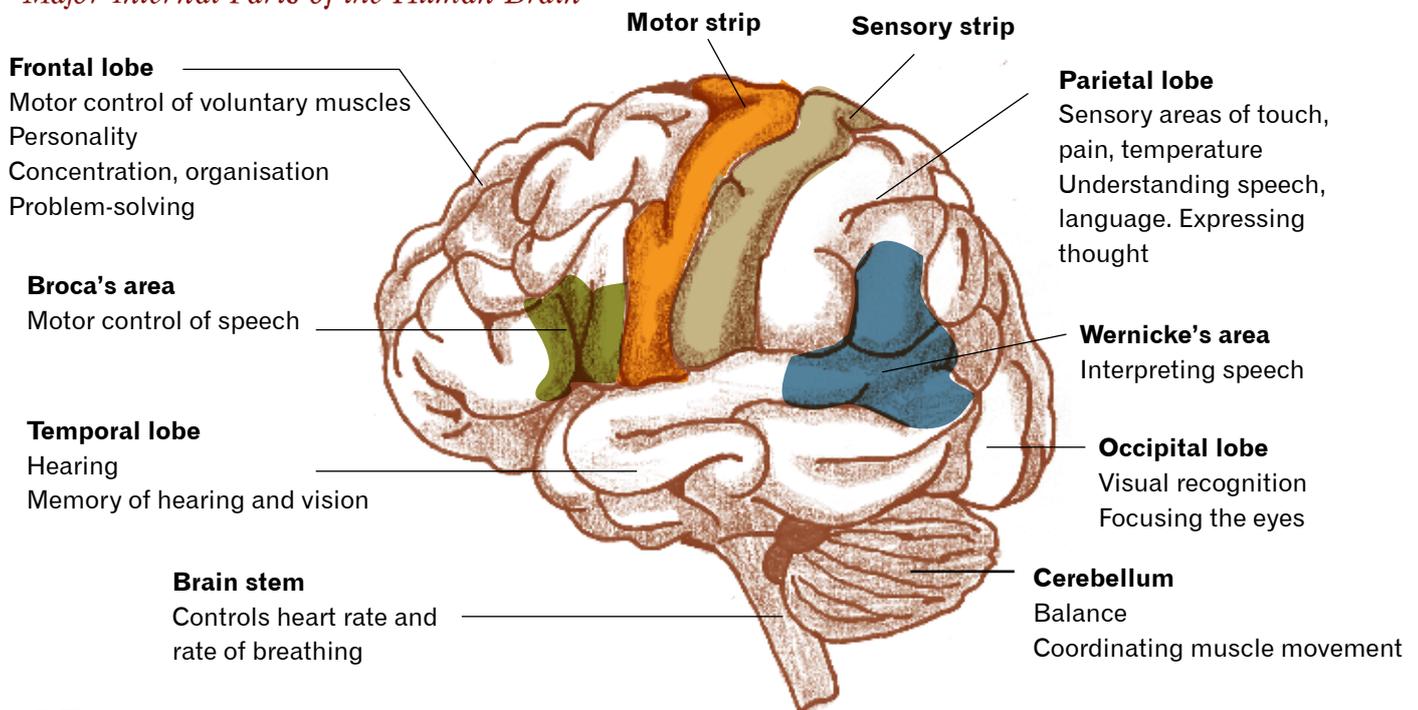
No one properly understands how the brain works. But scientists have learned a lot about how it functions.

A view of the brain

This map of the brain (Diagram 1) shows the parts responsible for some of the main human abilities.

Diagram 1

Major Internal Parts of the Human Brain



Facts about the brain

- An adult brain weighs about 1,5 kilograms (but this varies a lot between people).
- The basic units of the brain are nerve cells, known as neurons.
- The human brain has an estimated 50 to 100 billion neurons.
- The neurons are supported by trillions of other cells called glia. The glia have many tasks such as providing nutrition and insulation to the neurons as well as digesting dead neurons.



Parts of the brain

The hindbrain

This is the most primitive part of the brain and is found in most animals. It is responsible for the basic functions of life, such as the heartbeat and breathing.

Parts of the hindbrain:

- **Spinal Cord** – Controls the nerves throughout our bodies that are responsible for our movements.
- **Medulla Oblongata** – Responsible for respiration, digestion, heart rate.
- **Pons** – Involved in your levels of sleep, consciousness and arousal from sleep.
- **Cerebellum** – Helps us balance and co-ordinates our movements.

The limbic system

This is responsible for our emotions and is also involved in memory.

Parts of the limbic system:

- **Amygdala** – This stores our emotional memories.
- **Hippocampus** – Involved in storing our memories.
- **Hypothalamus** – Controls our appetite, thirst, sleep and waking cycle and much else.
- **Thalamus** – Relays information between parts of the brain.

Diagram 2

The hindbrain

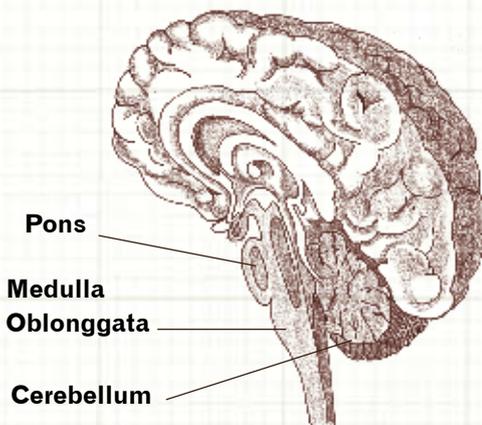
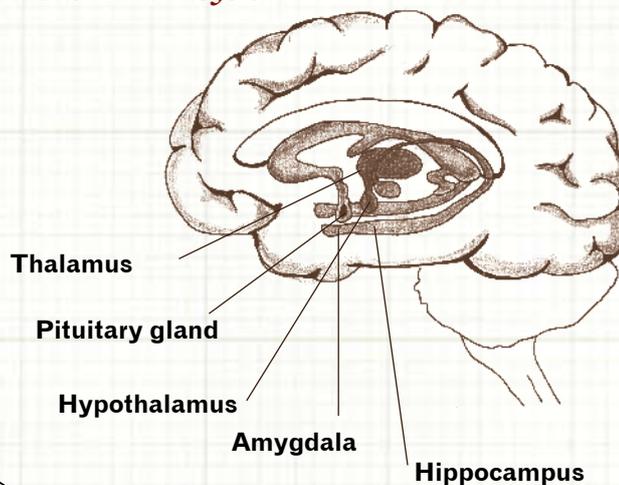


Diagram 3

The Limbic system



Neocortex

This is the biggest part of the human brain. It is responsible for our complex behaviour, for example thinking, language, mathematics, music.

Parts of the neocortex:

- **Frontal lobe** – Responsible for reasoning, problem solving, judgment, empathy and many other higher functions. This is the most recently evolved part of the human brain.
- **Parietal lobe** – Responsible for processing pain and touch, as well as calculating the speed of objects and where things are located. It is also responsible for movement, recognition, orientation and speech.
- **Temporal lobe** – This is where language recognition takes place. Also involved in hearing, emotion, memory and speech.
- **Occipital lobe** – Responsible for vision and image processing.
- **Broca's area** – Part of the brain primarily responsible for language.
- **Corpus Callosum** – The brain is divided into two hemispheres. The left hemisphere controls the right side of our body and the right hemisphere controls the left side of our body. This corpus callosum is the bridge between the two areas.

Diagram 4 *Neocortex*

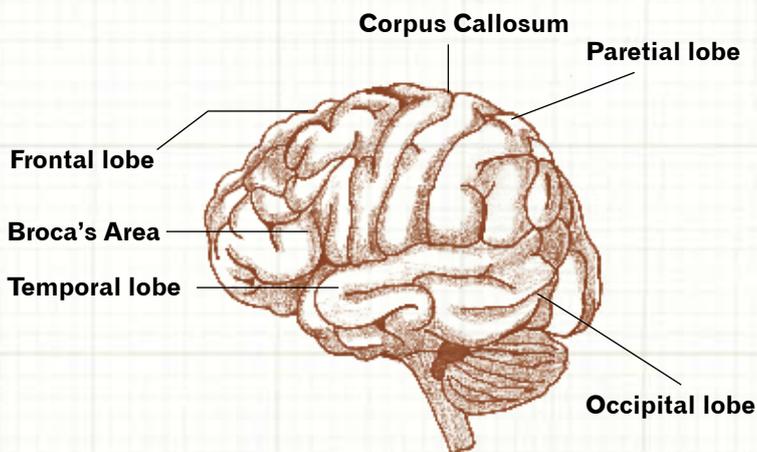
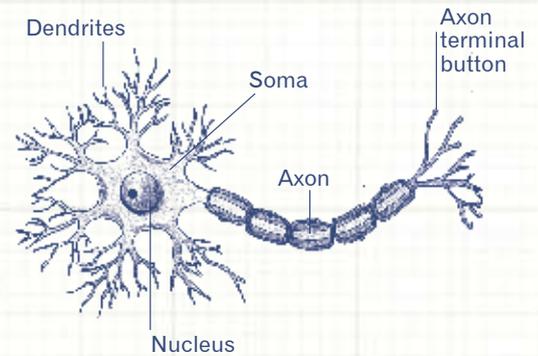


Diagram 5

Neuron



The neuron

The brain consists of billions of neurons. Neurons can be thought of as tiny machines, which send electrical signals to and from each other. They work together in weird and wonderful 'networks' inside the brain. Scientists have only the most basic understanding of these neural networks. Our personalities and what we do are a consequence of the interactions between these networks of neurons.

Brain functions

It is convenient to divide the functions of the brain into four categories:

- **Cognition:** These include memory, reasoning, language etc.
- **Emotional:** These include your moods, your capacity to love, hate, be angry, happy or sad.
- **Motor:** These include your ability to walk, run, catch, carry, reach, grasp, type etc.
- **Autonomous:** These are functions your brain controls without you even always being conscious of them, such as heart rate, digestion, control of urine, sexual arousal etc.



Brain illness in people with HIV

The most serious brain illnesses in people with HIV can be treated or avoided, especially if caught in their early stages.

AIDS dementia

Dementia is an extremely serious condition that often leads to death. People with dementia gradually lose their memory, their ability to think and to coordinate their movements. People with HIV dementia can lose their ability to work and function properly.

This disease is also known as HIV encephalopathy, HIVE, AIDS Dementia Complex and HIV-Associated Cognitive Motor Complex. It occurs in nearly two out of every ten people with HIV who develop AIDS, usually at a CD4 count of less than 200 cells/mm³.

There are four stages of AIDS dementia, ranging from mild (stage 1) to end stage (stage 4).

- In the mild stage patients can do all but the most demanding of their usual work and daily activities. If you think you are having mild symptoms, ask your clinic to refer you for tests. If you are diagnosed with mild dementia, insist on going onto ARV treatment because this condition can be stopped from getting worse and sometimes even reversed.
- In stage 2 (moderate) patients cannot work and need help with some of their usual daily activities. Again ARV treatment can be of great benefit to people who have progressed to stage 2.
- In stage 3 (severe) patients cannot do many intellectual activities we take for granted, like having a complex conversation or following the news. They cannot walk without assistance.

Photo 1 *Brain damage*



A brain that has been damaged by dementia. Source: Wikipedia.

- In the end stage patients cannot move properly or control their bowel movements or urine. They can hardly communicate.

Amazingly, with ARV treatment people with severe AIDS dementia can sometimes recover to the point where they can work and function properly. This is another reason why we need to make sure people start treatment before they have very low CD4 counts.

A recent study of children with HIV found that as more children had access to ARVs, the number of dementia cases dropped. This is evidence that if HIV-positive children take antiretrovirals it can prevent them getting AIDS dementia.





Symptoms of HIV Dementia

Cognition: Forgetfulness, difficulties concentrating, mental slowing.

Emotional: Loss of drive and initiative, withdrawal from social activities, failure to manage the financial and administrative aspects of life. Depressed mood, lack of emotion.

Motor: Slowing and impairment of fine movements (e.g. typing, buttoning up clothing), and changes in the way the person walks.

Autonomous: Unable to control urination, loss of sexual libido, erectile dysfunction.

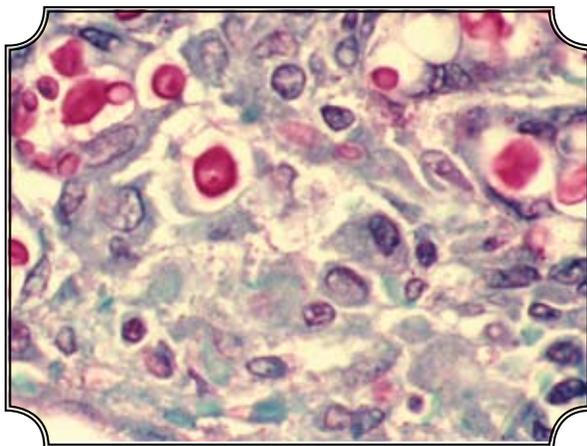
(Adapted from Eggers and Rosenkranz in HIV Medicine.)

Cryptococcal Meningitis

Meningitis is an inflammation of the brain and is extremely dangerous. People with AIDS are more likely to get meningitis. There are several causes, but a particularly common type in sub-Saharan Africa is cryptococcal meningitis.

This is caused by a fungus, called *Cryptococcus neoformans*. It usually only affects people with CD4 counts of less than 100 cells/mm³. People with symptoms of this

Photo 2 *Cryptococcus neoformans*



Cryptococcus neoformans, the fungus that causes cryptococcal meningitis.
Source: Wikipedia

illness will have a headache and a fever. Simple blood tests can detect if a person is infected with the fungus.

People with cryptococcal meningitis need to be hospitalised. They should be treated with amphotericin B (via an intravenous drip). They will also need to take fluconazole, sometimes for many years. They must start antiretroviral treatment (ART). Without treatment this disease is almost always fatal. With proper treatment, the death rate can be brought down to about 1 in 20 patients. In a study, four years after proper treatment, the majority of people who had cryptococcal meningitis and had been treated properly tested negative for the fungus. So this disease is curable.

The aging brain and HIV

If HIV-positive people receive ART before they develop AIDS, it is unlikely they will get cryptococcal meningitis or AIDS dementia.

Nevertheless, there is growing evidence that the brains of people with HIV are more prone to problems than HIV-negative people, even with treatment. Several studies show that as people with HIV grow older, they develop illnesses of the aging brain more frequently than HIV-negative people on average. These range from mild problems with cognitive and motor tasks that often go unnoticed to more serious problems like age-related dementia. People who reached low CD4 counts before starting treatment are more likely to experience these problems.

An example of a study showing brain problems in older people with HIV

In a French study of over 230 people over the age of 65 with HIV and stable on antiretroviral treatment, one in four had a mild cognitive problem. In the general French population (i.e. mainly HIV-negative people) of the same age, only one in 17 people have such disorders.



If you have HIV don't panic!

It is important to understand that the studies showing that people with HIV have more brain-related illnesses are based on averages. Many people with HIV who are on treatment will have no HIV-related brain problems throughout their whole lives. Even for people who do develop brain problems, the symptoms are often mild. They also usually occur at older ages. If you are HIV-positive and you have access to treatment, you are likely to live to an old age, be able to work and carry out your everyday tasks, just like everyone else.

HIV and children's brains

HIV-positive children are much more likely to have development problems. A recently-published study from the United States of HIV-positive children found that nearly half had learning disabilities. Those that had once had AIDS did worse on average on intelligence tests. Also, nearly half the group had been diagnosed with psychiatric problems. Again, this is evidence that putting children onto antiretroviral treatment before they develop AIDS can benefit their brains.

Antiretrovirals and the brain

The body has a 'blood-brain barrier' which makes it difficult for substances in the blood to penetrate the brain. This barrier is a bit like a sieve. To protect the brain, it only lets some substances through.

Antiretrovirals are divided into three groups according to their ability to penetrate the blood-brain barrier. It is possible that ARVs with higher penetration will reduce the risk of brain illnesses, but as yet there is no strong evidence to support this. However, there is evidence that higher penetrating ARVs reduce the viral load in the fluid in the brain called **cerebrospinal fluid**.

There is a large study being conducted in the United States called Charter. It has over 1,500 people enrolled. One of its objectives is to understand how we can use antiretrovirals to reduce brain problems in people with HIV.

Another study called START has begun. It is being conducted in many countries including South Africa. It is trying to answer the question of when we should start antiretroviral treatment. Part of the study will look at brain problems and try to determine if starting treatment earlier would reduce them.

How HIV damages the brain

This is not yet properly understood. Here is a very simplified explanation of what seems to be happening: HIV infects the cerebrospinal fluid, just as it does the blood. While HIV cannot infect neurons, it does infect some of the glia cells. The HIV in the cerebrospinal fluid and glia cells causes the immune system to react. But it seems the immune system overreacts and in so doing actually ends up destroying neurons.

Sources: Bartlett and Gallant. "Medical Management of HIV infection"; Bonnet et al. "High Prevalence of Mild Neurocognitive Disorders in HIV-infected Patients", ANRS CO3 Aquitaine Cohort, CROI, <http://www.retroconference.org/2009/Abstracts/34643.htm>; Brain Health and Puzzles, http://www.brainhealthandpuzzles.com/brain_parts_function.html; Clayden, "HIV, the brain and children", HTB, <http://www.i-base.info/htb/v10/htb10-11-12/HIV.html>; Collins, "HIV infection in the brain: a long-term limitation of HAART?", HTB, (<http://www.i-base.info/htb/v10/htb10-3-4/brain.html>); Eggers and Rosenkranz, "HIV-1 associated Encephalopathy and Myelopathy", HIV Medicine, <http://www.hivmedicine.com/pdf/hive.pdf>; Lobato et al. "HIV-encephalopathy in children: characteristics, risks, and survival", <http://gateway.nlm.nih.gov/MeetingAbstracts/ma?f=102214649.html>; Patel et al. "Impact of HAART and CNS-penetrating antiretroviral regimens on HIV encephalopathy among perinatally infected children and adolescents", AIDS, http://journals.lww.com/aidsonline/Fulltext/2009/09100/Impact_of_HAART_and_CNS_penetrating_antiretroviral.13.aspx; Singh et al. "HIV-1 Encephalopathy and AIDS Dementia Complex", Medscape, <http://emedicine.medscape.com/article/1166894-overview>. All website sources accessed February 2010.



NEW TREATMENT

Last year on World AIDS Day President Jacob Zuma announced a number of important changes to when certain groups of HIV-positive people in South Africa would be able to receive antiretroviral treatment (ART). The president also called for people to get tested and admitted publicly that he has gone for an HIV test himself.

By Marcus Low and Tandeka Vinjwa

The following treatment changes must be implemented from 1 April 2010. We must hold government accountable to its promises and make sure that these changes are in fact applied in our communities.



Photo by Clare Louise Thomas



Photo by Clare Louise Thomas

1 All HIV-positive infants under 12 months of age must be given ART.

If your baby is less than one year old and is HIV-positive, you can now insist that he or she is given ART. The CHER (Children with HIV Early Treatment) study showed that your baby will have a much better chance of surviving if given ART during the first year of his or her life. The Treatment Action Campaign (TAC) has been pushing for this change ever since the results of the CHER study were published.

2 All people co-infected with HIV and TB must be given ART at a CD4 count of 350.

If you are HIV-positive and have TB, you must now receive treatment as soon as your CD4 count is below 350. Getting treatment at this earlier stage will help your body to stay healthy and fight off opportunistic infections.

Apart from its commitment to provide treatment at an earlier stage, government also plans to integrate HIV and TB health services. This means that you will eventually be able to get your HIV and TB medicines at the same clinic.



GUIDELINES



Photo by Gallo Images

3 All HIV-positive pregnant women with CD4 counts above 350 must be given prevention of mother-to-child transmission (PMTCT) treatment from 14 weeks of pregnancy.

Two important changes affecting pregnant women will be implemented from 1 April 2010. Firstly, if you are pregnant and have a CD4 count below 350, you must be given treatment immediately. Secondly, if you are pregnant and your CD4 count is above 350, you must be given PMTCT treatment from the 14th week of pregnancy rather than only in the third trimester. Many women are turned away from antenatal clinics before they have reached 28 weeks – you must insist that you are seen and tested for HIV in order to access early treatment.

Whether your CD4 count is above or below 350, the new guidelines will significantly reduce the chances of your baby being born with HIV. We must make sure that government holds to their promise and that all pregnant women can benefit from these changes.

More changes must be made urgently

The changes announced on World AIDS Day were a big step forward, but they did not go far enough. TAC will continue to campaign for the following:

- The guidelines must be changed so that all HIV-positive people receive ART at CD4 counts of 350 – as recommended by the World Health Organization. It is a big step forward that pregnant women and people co-infected with HIV and TB will get treatment earlier, but that is not enough. TAC will continue to campaign for earlier treatment for all HIV-positive people.
- There is an urgent need to update the current first-line treatment regimen. TAC will continue to campaign for tenofovir-based three-in-one

once-daily pills to be introduced as part of the standard first-line regimen by July 2010. We urgently need to replace d4T with tenofovir because of the better side effect profile. This change is affordable and there are no licensing obstacles.



Photo by Samantha Reinders

Supporting each other

Fanelwa Gwashu runs an adherence club at Site B Clinic in Khayelitsha. Mary-Jane Matsolo visited the club to find out what it is all about.

What is an adherence club?

An adherence club is where HIV-positive people who are stable on treatment gather to support each other in taking their medication.

When was the club formed?

It started in November 2007 with about 200 members who were divided into three groups of approximately 60 people. Now we have 1000 members on treatment.

Who gets to be part of an adherence club?

Anyone who is HIV-positive, has been on treatment for over 18 months with an undetectable viral load and has no history of defaulting.

How important is it to know that you are not alone?

It's very important because it's not easy being on treatment. Being around other people who are in the same situation strengthens your focus on adherence. It helps you to realise that you can have a productive, healthy lifestyle like other club members.

What are some of the challenges you come across at the club?

Our biggest challenge is when people return to their rural areas and ask to be transferred to a nearby clinic. They find that club services aren't available there and they have to travel for days just to collect their treatment.

What happens at an adherence club meeting?

On Tuesdays and Thursdays we hold adults' adherence club meetings and on Wednesdays we meet with parents and children. Members arrive at 08:00 in the morning and place their medication cards in the tray. These are



An adherence club meeting in progress at the Ubuntu clinic in Khayelitsha. Photo by Mary-Jane Matsolo

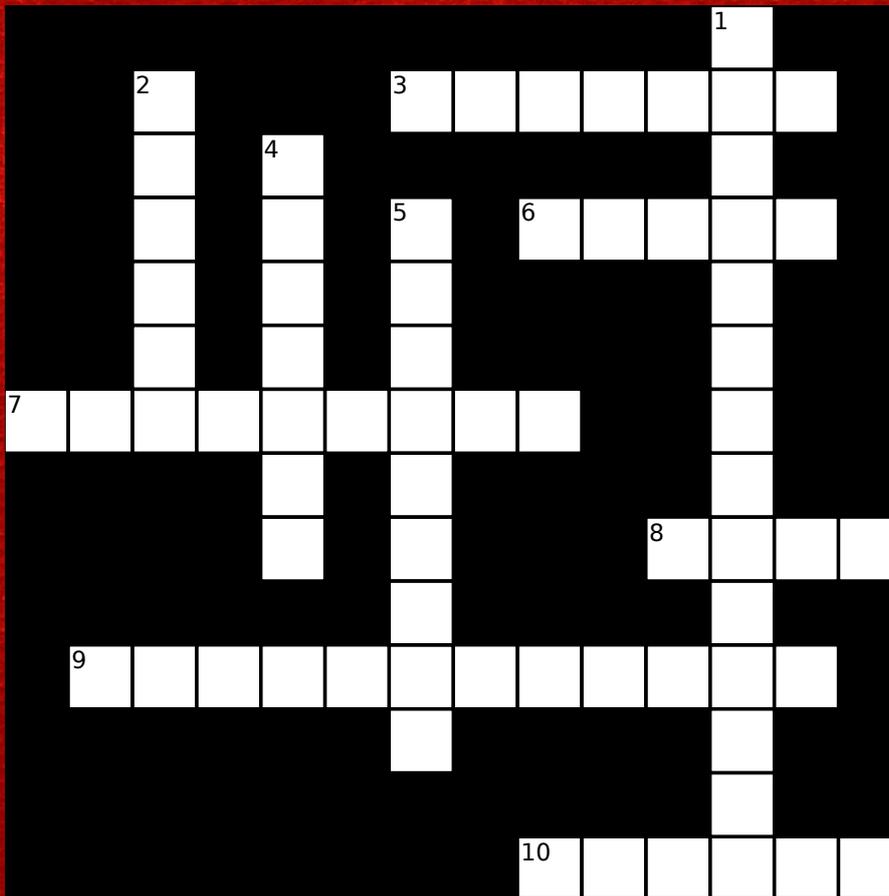
collected by two treatment supporters who take them to the pharmacy to collect the medication. The facilitators then start that month's discussion.

Have there been any significant changes since the club was formed?

Yes, there has been a huge change in the workload of nurses because people no longer wait in long queues for medication. It has also encouraged others to stick to their treatment and not to default as often as they did before. What's more, our members are all employed and don't get laid off from work because of being continuously late or absent. They are less likely to have their status revealed if they don't want that to happen.

Do you have any inspiring stories of how the adherence club has changed someone's life?

One story that inspires me is of a woman who is employed as a domestic worker. She has been on treatment for years and has managed to keep her job ever since she started at the club because she no longer has to wait long hours at the clinic. She just drops off her card in the morning and collects it after work. She doesn't have to ask for days off. We also have a truck driver who knows that he doesn't have to take a day off to collect treatment – he can simply call and arrange for us to collect his medication. Then he just drives by later to pick it up.



We will give a R200 Pick n Pay gift voucher for the first crossword drawn from a hat with all the correct answers. The answers can be found in this issue of *Equal Treatment*.

Last month's winner will be announced in a future issue.

Fax or post your completed crossword, with your name, address and contact number.

Address: Equal Treatment, PO Box 2069, Cape Town 8001
Fax: 021 422 1720

Crossword Puzzle

Across

- 3 The basic units of the brain are nerve cells known as ____
- 6 Meningitis is an inflammation of what part of the body? HIV and mental illness often carry a double ____.
- 7 What first-line antiretroviral medicine may sometimes lead to mental health problems?
- 8 AIDS dementia is divided into how many stages?
- 9 All people co-infected with HIV and ____ must be given antiretroviral treatment at a CD4 count of 350.
- 10 From April 1st, all HIV-positive infants under ____ months of age must be given antiretroviral treatment.

Down

- 1 ____ treatment helps to prevent most brain problems related to HIV.
- 2 HIV and mental illness often carry a double ____
- 4 PITC stands for provider-initiated ____ and counselling.
- 5 An ____ club is where HIV-positive people who are stable on treatment gather to support each other in taking their medication.

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