For Limakatso, it is her mum who provides the best love and support in her life. It took a week before Limakatso could pluck up the courage to tell her that she had taken an HIV test.

# HOPE SLOWLY



In one of the countries in the world that is most affected by AIDS, access to antiretroviral drugs is helping to loosen the disease's iron grip. The Wellness centre for healthcare staff has been a real refuge for nurse Limakatso. It means she doesn't have to queue in overcrowded waiting rooms with her own patients.

TEXT IRÉNE WANLAND PHOTOS TORBJÖRN SELANDER, IRÉNE WANLAND

meet Limakatso Lebelo in her childhood home in a suburb of Lesotho's capital, Maseru. The house is simple, but well-furnished. Limakatso has two siblings who are also studying to be nurses. Their mother Malimakatso is a teacher.

The nursing profession has a high status in Lesotho, and when Limakatso left high school with good grades, a career in nursing was her first choice. She received a student loan from the state, thanks to her good results. Qualifying to be a nurse requires a four-year university education, which includes midwife certification.

**WE SIT** and talk on the deep leather sofas in the family's living room. For a while the conversation revolves around what it's like to work as a newly-qualified nurse in Lesotho. Limakatso describes the same problems as her newly-qualified Swedish colleagues. It's not easy to settle into the reality of the healthcare system when you're fresh out of university, and full of new ideas. It's not easy in Sweden or in Lesotho. "But those of us who've just qualified often get together and support each other; we need it to keep our spirits up."

Every now and then, when Limakatso discusses her professional life, she talks about "the bad things that happened to me", and then her eyes become sad.



Eventually, I ask her how she came into contact with the Wellness Centre.

Staff from the centre paid a visit in connection with a workshop for healthcare staff, and talked about their work. But by then Limakatso was already aware of her HIV status.

HER SUSPICIONS were raised when she began hearing rumours about her former boyfriend. He was from Nigeria, was settled with a job in healthcare, and they had been seeing each other for three years. It was not until he returned to his homeland that people began to imply that Limakatso had not been his only girlfriend during his time in Lesotho. And maybe he was carrying that disease?

Limakatso was 24 when she decided to

## RETURNS

#### HOPE SLOWLY...



A deadly, incurable disease, connected to sex – it has lead to silence and expulsion in a society bound by tradition. Lesotho has received much praise in recent years for its efforts to combat the infection. "Know your status" is the name of the campaign that broke the silence and encouraged many to go and take an HIV test.

take an HIV test. It was positive.

Limakatso tried to keep it to herself for a week, but then she just had to tell her mother everything. When she recalls that moment the tears begin to flow; it was so recent, and the feelings are so raw.

Her whole body cries out "why me – when I'm so young and have my whole life ahead of me?"

Her mother understood everything, and Limakatso's expression is so gentle when she talks about how much her mother and siblings have been there for her and supported her. It is her mother who accompanies Limakatso to the It wasn't until 2006 that married women in Lesotho were awarded human rights by law.« Wellness Centre on each visit, and who is always ready to talk and be a shoulder to cry on.

"It's been a huge relief for me to be able to go to the centre," says Limakatso. The alternative would have been to queue in an overcrowded clinic and risk meeting her own patients.

**AT THE WELLNESS CENTRE** she got her next surprise: Limakatso's immune system was already so weakened that she was forced to start taking antiretroviral drugs.

She had to have three separate counselling sessions and a carer in order to get the drugs. Naturally, her mother was the carer.

Limakatso now goes for an examination every month. Her levels have already improved, and after six months she'll be able to come every other month to get her medicine and check her medical status.

The other great thing about the Wellness Centre is that there is someone outside the family to talk to. I ask Limakatso what the nurses at the centre say to her.

"That my life isn't over, that thanks to the drugs I still have a lot of opportunities," says Limakatso with a weak smile.

**oF course** it's difficult to take in the fact that you're only in your twenties and you'll be on medication for the rest of your life, and Limakatso feels so alone. She knows of only one other person in her circle of friends the same age that has taken the test. He was a colleague at the hospital, and he took the test following a syringe injury, but it was negative.

I ask Limakatso if she knows how common HIV is in Lesotho. She doesn't know. I am thinking of the figures that indicate that almost a third of all adults in the country are carrying the infection. Almost four out of ten young women like Limakatso are HIV-positive. Yet still she thinks she's the only one among her friends that is carrying the disease. "Nobody talks about their status."

**WHEN WE** meet, Limakatso is smartly dressed; she's about to go to work after a visit to the family. The hospital is 120 km away in Butha-Buthe. She's only been working there for a few weeks, following a transfer. When you sign a



Her whole body cries out: "Why me – when I'm so young and have my whole life ahead of me?"

contract to work within state healthcare, it means you accept the placement given to you by the employer. She feels even more alone in Butha-Buthe. Limakatso doesn't know anyone there, and she misses home terribly. She can only visit her family once a month.

THE NOTICE PERIOD is three months and Limakatso has already started thinking about her future. I understand that she has mixed emotions; her thoughts are still dominated by the HIV test result.

"At some point in the future I want to study to be a psychologist. It will mean studying abroad and I'll need to get grants, but I'm going to do it!"

#### **LESOTHO FACTS**

**COUNTRY:** Lesotho is a small, mountainous kingdom, entirely surrounded by South Africa. The kingdom was created in the 1830s, when the country's national hero, Chief Moshoesho, fled the Zulu wars of conquest, taking the Basotho people with him. Moshoesho proclaimed a kingdom and later sought support from the British against attacks from the Boers. The country became a British crown colony in 1884, and won independence in 1966. Lesotho has 1.8 million inhabitants. The country is very poor, and depends heavily on foreign aid.

**WOMEN:** It wasn't until 2006 that married women in Lesotho were awarded human rights by law. Previously they had the same rights as children. They were completely dependent on permission from their husbands if they wanted to, for example, seek medical treatment, use contraceptives, apply for loans or stand for political posts. Neither could they refuse sex within marriage, or demand that their husband use a condom. Abortions are not permitted. 58 percent of the adults infected with HIV are women. The majority are infected when they become sexually active, between the ages of 15 and 30. Twothirds of those taking antiretroviral drugs are women. They are more likely to seek help than men. Women take the lion's share of the responsibility for sick family members and orphaned relatives.

**CHILDREN:** An estimated 11,800 children are living with HIV in Lesotho. In 2007, 3,520 of them required antiretroviral drugs, and 25 percent had access to them. Some 108,700 children have lost at least one parent; the figure has risen by 22 percent in two years. There are 46,600 orphans.

**HEALTHCARE WORKERS:** The country has about 80 doctors and almost 800 nurses. According to Doctors Without Borders, the number of nurses in the country dropped by 15 percent between 1994 and 2004, due mainly to emigration to other countries and deaths from AIDS.



Sources: <sup>2</sup> Ungass Country report Lesotho 2008 <sup>3</sup> Doctors without borders <sup>3</sup> The Swedish institute of international affairs

> Mpho wants to offer hope and strength

#### **62 INFECTED EVERY DAY**

Every day, 62 people become infected with HIV, and 50 die as a result of the disease. The country has the world's third highest estimated number of people with HIV; 23.2 percent of the entire population. An estimated forty percent of 25-49 year-olds has the disease.

But international bodies are impressed with the country's focused efforts over the past few years to combat the AIDS epidemic, using campaigns to encourage people to get tested, free antiretroviral drugs and investments in healthcare. However, still only 25 percent of those who need antiretroviral drugs actually got them in 2007.

#### OBSTACLES TO PREVENT The spread of hiv

- ✓ Shortage of qualified healthcare staff.
- People's reluctance to get tested and take antiretroviral drugs.
- The subordination of women.
- Strong belief in natural remedies.

Taking samples and sorting out medication are major aspects of the work at the Wellness Centre, but conversations are also important, since they contribute to a deeper healing process.

### **»YOUR LIFE IS NOT OVER«**



No family is unaffected by the many deaths in recent years.

Mpho Mosito at the Wellness Centre in Lesotho receives HIV-positive healthcare staff. The Centre is a place of refuge, offering hope and strength to continue the fight. And they don't risk to bump into their own patients. TEXT IRÉNE WANLAND PHOTOS TORBJÖRN SELANDER

The Wellness Centre doesn't look like much from the outside; two metal barracks on a waterlogged site. But this is where HIV-positive healthcare staff get the support and energy they need in order to keep going. The Centre's two nurses, Mpho Mosito and Motselisi Sebapala, are young and extremely professional. They both describe the immense difference between the high quality of the training and the reality that hits them when they begin their careers in run-down, poorly-equipped hospitals, with far too many seriously ill people queuing up to be seen.

"My training qualifies me to work at highly-specialised hospitals in Europe, but in our healthcare system I spent most of my time running about with bedpans," says Mpho.

That's why she was so attracted to the idea of working at the Wellness Centre. The nurses have to call on all of their

#### HOPE SLOWLY...

I have to give our clients hope, and show them that antiretroviral drugs can enable them to live a fulfilling life.«

nursing skills when meeting HIV-positive healthcare staff. They are called Nurse Counsellors, and a major aspect of the work involves support through discussion to those who in turn have to treat other patients as part of their job.

**BOTH NURSES** are faced with the whole complicated spectrum of problems associated with HIV. Up until just a few years ago, there was not much available in terms of treating the HIV infection. There isn't a single family that hasn't in some way been affected by the illness and death of close relatives.

This insidious disease, together with ignorance, poverty, the subordination of women, and lack of healthcare resources, has resulted in a culture of silence. Few were prepared to mention the disease by name, and there was no sense in testing yourself. What's the use in finding out that you have a fatal, incurable disease? Far better to pretend that nothing's wrong and just hope for the best.

**BUT ACCESS** to antiretroviral drugs brought about a major change in attitude. Now there is hope, and the government's efforts with testing campaigns and free antiretroviral drugs have begun to bear fruit. People are more open about it, particularly in the cities, and a growing number are regaining their health. It's like the disease is gradually loosening its iron grip on the entire country.

Mpho and Motselisi don't just organise HIV testing and procedures around antiretroviral medication. The deeper healing process requires long discussions. The Centre has retreats for grief recovery ("many people never had time to grieve over the death of a relative, and they are reminded of their grief every time they meet a patient with HIV in their job"); courses in home care and palliative care ("we have clients who



The Wellness Centre's Manager, Madonna Thakholi, hopes that the clinic will become a permanent part of Lesotho's healthcare system in the future.

are carers to relatives and neighbours"). The Centre also organises courses in stress management and there are plans to get clients involved in discussions covering working environment issues.

Mpho sees her main task as being to convey a positive attitude. "I have to give our clients hope; show them that antiretroviral drugs can enable them to live a fulfilling life, and that their professional contribution is really needed in the healthcare system."

MADONNA THAKHOLI is Manager of the Centre, and one of her most important tasks is to spread knowledge about the Wellness Centre's existence. She makes regular trips out to the country-

#### WELLNESS CENTRE – A PROJECT

**CONCEPT:** To support healthcare staff in countries affected by AIDS in southern Africa, so that they can continue to work. Many leave their jobs due to their own illness, sick relatives and poor working conditions. A large proportion move abroad to get better salaries and work in more developed healthcare systems.

**COUNTRIES:** There is a Wellness Centre in Swaziland, and one in Lesotho. Wellness Centres will be started up in Uganda, Malawi and Zambia during the year.

**INITIATIVE:** ICN, the International Council of Nurses, runs the project, aided chiefly by the Swedish, Norwegian and Danish association. Vårdförbundet supports the project in Lesotho, where Lesotho's nurses' union is responsible for the Centre on site.

**FINANCING:** The project in Lesotho is largely financed by Sida, which provides around a million a year for two years. The money is provided via the LO-TCO Secretariat of International Trade Union Development Cooperation and Vårdförbundet, which also makes up some of the cost. Vårdförbundet's department in Östergötland acts as a supporting department.

**TREATMENT:** All healthcare staff and their families can come to the Centre for support, testing and treatment, mainly for tuberculosis and the HIV infection. When fully extended, the Centre in Lesotho will have room for contact with 4,000 clients.

**FUTURE:** The project has close contact with the governments in each country, and the long-term plan is for activities to be integrated into the healthcare system and act as a kind of occupational health service for healthcare staff.

#### HOPE SLOWLY...

side to inform healthcare staff about the Centre. There is a huge level of interest, and an increasing number are opting to be treated at the Centre. Some clients are sensitive about colleagues finding out. "We try to take that into consideration by not booking in clients from the same workplace straight after each other..."

VÅRDFÖRBUNDETS department in Östergötland acts as a supporting department for the Wellness Centre project, and Anneli Gåverud and Ann-Marie Kempe visit the project in Lesotho twice a year to meet the staff, representatives from Lesotho's nurses' union and the Ministry of Health.

Anneli and Ann-Marie have thought about the ethical aspect of the project; the fact that it creates a "VIP lane" for healthcare staff in a poor country with serious healthcare resource problems.

"We would prioritise the treatment of healthcare staff in Sweden as well, if we were to have a bird flu epidemic, for example. The epidemic here is more insidious, but if there are no healthcare staff left then the whole of society suffers."∠

irene.wanland@vardforbundet.se



Ann-Marie Kempe and Anneli Gåverud with the Centre's Manager, Madonna Thakholi.

#### Östergötland support department

Östergötland has been the support department for the Wellness Centre project in Lesotho for several years. The department has also been involved in producing material on HIV/AIDS:

- Schooling for orphaned girls
- Things you do och don't want to know about HIV/AIDS

You can download the material from: www.vardforbundet.se. Go to 'Kontakt, lokala avdelningar'. Choose: Information/material/Informationsprojekt.

#### CONTACT:

anneli.gaverud@vardforbundet.se / ann-marie.kempe@lio.se

### Likopo uses her own story

Likopo Letsabisa is a nurse and she is HIV positive. Unlike many others, she has chosen to talk openly about her infection.

ikopo Letsabisa is a nurse at a clinic in Lesotho's capital, Maseru, which specialises in contraceptive advice and the treatment of sexually transmitted diseases. She uses her own story to encourage her patients to start taking antiretroviral drugs.

The infection began to make its presence felt two years ago, with a stubborn cough and sudden weight loss. The diagnosis was tuberculosis; she was offered an HIV test, but declined. The tuberculosis medication helped, and after



believe in modern treatment methods, but prefer to take herbal medicines instead, says Likopo Letsabisa.

a few months Likopo plucked up the courage to take an HIV test. It was positive, and very soon after Likopo began to feel really ill; her legs couldn't hold her weight, she lost her memory and was extremely weak.

She doesn't think that these were AIDS symptoms, but rather caused by depression triggered by the test result.

The tears flow when Likopo talks about that time in her life. It's because of her nine-year-old daughter Kelello. The girl thought that her mother would die, just like her father did four years earlier. "I hope she gets her confidence back now that she can see that I'm feeling so much better."

The antiretroviral drugs have done wonders. Likopo has even started worrying about her weight. "You should have seen how thin I was before; now I'm so hungry all the time I'm piling on the kilos.«

HAVING SEEN a private doctor, Likopo was able to transfer to the Wellness Centre. She has been receiving support and treatment there for six months. It makes such a difference to be able to meet colleagues at the Centre; they speak the same language.

When Likopo's own patients complain of tiredness and their HIV tests are positive, she uses herself as an example: "Look at how healthy you can be by taking these drugs!" ∠

**IRÉNE WANLAND**