

'If I stop taking the pills I know I'll die'

By Christina Stucky

The medicines are kept in an old 5-litre ice cream container on the table in the backyard shack. One by one, Nhlanhla takes out the bottles and packets.

"This one, I take three pills at night. This one, I take one pill in the morning and one at night, and that one I take one only at night."

Holding up small bottles filled with liquid in each hand, he raises one at a time: "This one I take a cup in the morning and this one one time in the morning and one time at night."

He indicates the lace-covered table top where a small cup lies, marked with a sliver of red tape.

The 10-year-old boy knows he will be swallowing tablets for the rest of his life. If he stopped taking them, he says, he would die.

His grandmother Dimakatso shakes her head and smiles, marvelling at the boy's ability to remember the quantities of medicines he has to take.

"I can't remember them all," she says. But it is she who has to remind him to take them, every morning at 7.30 and again 12 hours later. If he comes home late for his second dose of the day, she gets cross with him. Since the death of her daughter last year, keeping her HIV-positive grandson alive is her responsibility.

"It's nice to play with my friends and I forget," he says, avoiding his grandmother's eyes.

"Nhlanhla needs to be back at seven o'clock for medicines," she interjects. "I need to take responsibility to make sure he is at home by that time."

Before he started anti-retroviral treatment, he was often sick. "I was so skinny that I would ask my brother to count my ribs. You could see my bones," he says, sticking a finger in his now fleshed-out rib cage. He was urinating blood and vomiting. He admits that it scares him "a bit" that death is only a handful of pills away.

When he began treatment he felt nauseous, sores developed on his head and his hair fell out. His stomach grew round and hard. He holds out his hands to show how far his stomach protruded.

"But after a while I became better and my stomach was normal." He speaks matter-of-factly while he bunches up the edge of the table cloth.

"I'm now better. I can concentrate at school."

He lets go of the table cloth and says with just a hint of defiance: "I can do everything like other children."

Nhlanhla has been living with HIV in more ways than one, since birth. His mother died of Aids-related causes in October last year. He doesn't think about his mother often, he says.

"It's because I like to play a lot and don't have time to think about her."

His fingers again gather up the edge of the cloth, concertina-style. But he misses the way she cooked pumpkin.

Dimakatso and Nhlanhla share a large bed that takes up a quarter of the space in a shack in her younger sister's back yard. The main house is a warren of rooms occupied by the sister, her three children and two grandchildren. No adult male lives in this household. Nhlanhla's father left when was two.

Nhlanhla's older half-brother Themba's father died before he was born. Themba sleeps at a relative's house nearby but spends most of his time in his grandmother's room watching TV or hanging out with his friends.

"Sometimes when we are busy playing we get cross and we fight with each other. He kicks me so bad, it hurts," Nhlanhla says. Themba has the studied coolness of a teenager-cum-rap star, but when his friends are not around, Nhlanhla knows his brother worries that he will die like their mother.

One evening the two brothers were watching TV together and a commercial for Bioslim, a diet product, flashed on the screen. Nhlanhla said he should buy some, thinking it would make him

look like the people in the "before" pictures. But Themba advised him against it. "He said it was for fat people and I'm too skinny."

Sometimes the brothers use their dead mother as leverage with their grandmother.

"I'm afraid to go to the shops because they'll want me to buy things," Dimakatso says. "They say: 'if Mommy were still alive she would buy these things for me'. But I don't have the money. That's what makes me very depressed."

The death of Themba's and Nhlanhla's mother was not the first time Dimakatso lost a child. One, a policeman, was shot in the line of duty and an infant was dead at 10 months. She never thought she would be raising her grandchildren, or be worried about outliving one of them.

"I didn't expect my daughter to die because she always looked healthy. I encouraged her to go and test but she kept saying she had nothing."

Nhlanhla's frequent illnesses and hospitalisation finally convinced the mother to allow the boy to be tested.

"He was eight when he was found to be HIV-positive. So I encouraged her to go too," Dimakatso recalls. When the results came back positive, Dimakatso accepted and supported her.

"I felt that anyone could catch the disease." Less than a year after the test, her daughter died in hospital.

Once a month Dimakatso and Nhlanhla rise early in the morning from their queen-sized bed. They set off before 7am to be among the first in the queue at the ARV clinic. The patients and their caretakers far outnumber the available chairs in the prefabricated structure that stands on a lawn on hospital grounds.

Adults lean against the postered walls while children mill about. There are no "cars for boys and dolls for girls" to distract the children, Nhlanhla says. If it isn't raining, he plays with other kids on the grass. It will be four hours before he and his grandmother see one of the two doctors who attend to between 50 and 60 children.

Holding his card, Dimakatso enters one of the numbered rooms with Nhlanhla. They sit down and the doctor asks Dimakatso if there is anything wrong with her grandson. The doctor uses "the thing they put in your ear", and sometimes he takes blood from Nhlanhla's neck.

It hurts but Nhlanhla never cries. Just before they leave, the doctor asks Nhlanhla if he wants some bubble gum. He always says yes. It's the only question the doctor asks him during the consultation. "I would like it if the doctor asks me about the treatment I am taking and how I am feeling with this treatment," Nhlanhla says.

"I would tell him that before it made me sick but now I'm alright."

Dimakatso then queues for another hour at the hospital pharmacy. Six hours after they arrive, they go home.

In Nhlanhla's support group all the children are HIV-positive and they talk about living with the virus that kills the "soldiers" that protect their bodies from illness. Knowing there are other kids like him helped him to "not be miserable". He feels "relaxed" now "because I am not sick".

Nhlanhla wants to run his own shop where he will sell radios and DVDs. He also wants to have a family and a wife who will cook for them. He wouldn't marry a lazy woman who can't cook. Dimakatso hopes her grandson will finish high school and perhaps even study. But she is not sure whether he will live beyond 16 or 17.

- Names have been changed and locations omitted to protect the identities of the persons interviewed

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