

My Journey with Hope

Dr. Jayne Cunningham describes her experience with a desperate 12-year old boy whose HIV-positive condition and reluctance to take his antiretroviral medicine made for an apparently hopeless case. Dr Cunningham is the Paediatrics Medical Officer at the Alexandra Clinic's Phatsima Khanya HIV-treatment facility in Johannesburg's northern suburbs. Phatsima Khanya is treating more than 250 children with antiretroviral therapy. D. Cunningham is employed by Right to Care, a non-profit USAID-supported organisation dedicated to combating HIV and associated diseases, with funding from the President's Emergency Plan for AIDS Relief (PEPFAR).

Hope*, aged 12, came to Phatsima Khanya in 2007 after he had lost his mother to AIDS. He was virtually an orphan, since his father was completely uninvolved in his son's life.

When I first saw him, he had already been diagnosed as HIV-positive. My earliest memory of him was the day he arrived at the clinic with Shingles, a typical symptom of HIV. His face was swollen with sores and blisters that had become septic (infected) and he covered these with a scarf.

With Hope, we were losing the battle against HIV. He had little adult supervision, teenage ideas of independence, and no fear of death, so he neglected taking his antiretroviral (ARV) medicines.

While testing Hope's HIV condition, I accidentally pricked myself with the needle I had used to take his blood. At first, I didn't fully comprehend what had occurred. I just stood for a while holding my finger in running water. My mind went blank, but eventually cleared enough to seek my supervisor and report what had happened. She ran immediately to our clinic pharmacy and got the required post-exposure tablets for me. I do remember her saying that the most important issue after being exposed to HIV/AIDS is to take the tablets as soon as possible after the incident.

What followed seemed like a blur of different ARVs; 28 days of feeling desperately ill; two or

three calls a day to an HIV specialist; uncertainty about what resistance testing would show on Hope's blood sample, and fear of what the results would mean for me.

I had a terrible time with the medicines and an unusually strong reaction to them. I vomited every time I took them. I eventually got to the point at which--despite the risk (small that it was) to me and my family--I did not want to continue another day on ARVs.

I survived the ordeal, thanks to the HIV specialist's support and by switching to a simpler, newer ARV regime.

I had to consider that this child may have had a potentially resistant strain of HIV, especially since we had been unable to treat him successfully (as he was non-compliant). My biggest fear, however, was of that I had lost my nerve to continue in this sub-speciality field of medicine. Although I felt medicine was still the right career for me and what I should be doing, HIV/AIDS medicine might be putting my husband and children under increased stress.

When I returned to the clinic, I was not keen to see Hope again. He symbolised the patient who was difficult to treat. He acted sullen and ungrateful. Worse, he was not taking his medicines. I suppose I was also a little resentful.

After a month or two, I was feeling much better. I noticed that Hope's file often seemed to end up on my desk, although files were theoretically allocated randomly to the doctors. We were still losing the battle with him. He was good at coming to the clinic (catching two taxis), but he arrived alone, without a caregiver. On the other hand, despite numerous warnings, threats, pill charts, and long sessions with counsellors, nothing motivated him to take his medicines.

After two more months of this frustrating dilemma, I threw my arms up in desperation during yet another depressing visit and demanded, "Well what is it you want in life?" He responded, "I have always wanted a new bicycle with a bell." I told him that, if he could prove that he could take his medication and get to an undetectable viral load, I would somehow get him a bicycle.

Three months of intense positive counselling followed with one of our paediatric counsellors,

Lebo Molubi, who encouraged Hope with the vision of a new bicycle for Christmas, a recovering CD4 count, a decreasing viral load, and monthly check-ups at the clinic.

I thought a lot about the inspirational effect of positive reinforcement in those few months and of how I would obtain a new bicycle with a bell!

Everybody loves to be part of a good story, so it was not difficult to get my two children and our friends to forgo exchanging Christmas presents in favour of contributing towards Hope's bicycle. That step netted us around R1500--about half of what we needed. When I approached the owner of Linden Cycles, Jeanine Faul, she immediately offered to help and provided a new bicycle with gears, and a helmet, at a markedly reduced price. So, we had the bike. Our part of the deal was in place and it remained for Hope to play his part.

Hope's file appeared on my desk in December with the thrilling news that his CD4 count had gone from a critically low 12 up to a healthy 268. And his viral load was undetectable! Hope had kept his part of the deal.

With great excitement, Lebo and my family organized delivering the bike to Hope. Lebo arranged to meet him on the main road outside of his township. Hope was so excited; he arrived early. We regrettably arrived late and he waited for two hours at a signpost in the hot sun.

Hope's relatives and friends were there to watch. When I saw him leap onto his new bicycle fitted with a bell, all my negative memories of his name, file number, and my needle-stick injury disappeared. My children saw the benefit of sacrificing some of their Christmas presents for such a worthwhile cause!

Sceptics might say that Hope will stop taking his ARVs now that he has a bike. I would like to rather think that his name is symbolic. Many people at Patsima Clinic and Linden Cycles believe in him.

The first time he was due back for a check-up after receiving the bike, Hope did not arrive. Our hearts sank. But, he came promptly the next week, explaining that he had missed the due date

because it was the day school started. Hope said to me, "I really want to show you that I can do it." It seems that because we have put our trust in him, he wants to show us he can be trusted. Now, six months down the line he has a CD4 count of over 600 and a persistently undetectable viral load.

I have learnt invaluable lessons from this experience. No child is so non-compliant that it is not worth trying to save him or her. It also came home to me the extent to which others are willing to help when given a specific reason.

* Name changed for the sake of confidentiality. Hope's real name is similar in meaning and connotation.