Prologue

1996, *Mashayabhuqe*

– AIDS kills everything

The round room is almost bare. Sizakele sits upright on a narrow bed, a sleeping child upon her lap. Her elderly mother is seated on a mat on the floor, her legs stretched out in the traditional manner. She is also cradling a baby in her arms, and two more toddlers drowse against her side. As Siza tells her story she gently slaps the hand of the sleeping child against her own, as if for emphasis.

'I started losing strength and energy,' she says, 'and I went to the hospital in town, but I was discharged. Then I came back home and attended another hospital. They gave me X-rays, but they said there was nothing wrong. Then they took my blood and they told me I have this disease.'

Her story is punctuated by a cough that tears through her spare frame. Despite her illness she is still quite beautiful. In the background, cows are lowing and birds call above the shouts of distant conversations. In the round room the children snore. Siza's mother sighs. 'It breaks my heart to see my daughter in this condition, and now there is nobody in this family who is working.'

It seems that Siza used to support all the children with her meagre wage. Although her sisters are doing 'piece work' in the towns they seldom send any money home. Now the family must rely on the kindness of neighbours for the occasional dish of food.

The grandmother looks down at the baby and wipes a hand across her face. She knows what is to come. Soon, very soon, she will be the sole carer of all these children.

It is by chance that I am here, in the early summer of 1996, in this hell of hidden death. I am working for a small television company that has been commissioned to make a film about AIDS. The film is to be used to forewarn non-governmental organisations (NGOs) about the coming epidemic and the impact it is likely to have on their beneficiaries, on communities, on civil society at large.

The visit to Siza has been one of our first, and the crew and I are sobered by it: people's lives are already too difficult, and now there is AIDS. It particularly affects our young assistant, who has grown up in the relative privilege of Soweto. Before we leave the homestead he empties his pockets into Siza's hands.

Here, in the rural hinterland of the post-apartheid state, tragedy is layered upon injustice. A century of labour migration has disrupted traditional patterns of life and notions of kith and kin. There are few men in evidence and even fewer young people of working age. Before, these migrants would send money from the factories, the mines and the suburban kitchens to the wives and elderly parents at the rural homestead. But now there is a steady stream of young people returning ill and in need of care themselves. Instead of cash, they bring orphans.

By 1996, this area of KwaZulu-Natal has the highest HIV prevalence in the country, with nearly one-fifth of adults infected. But the epidemic is yet young, and most are unaware of their status. Fewer still are visibly ill.

The country is yet to face the enormity of the coming crisis. So far there have been a few 'AIDS scares', and one major scandal in which the new democratic government was found to have spent a large chunk of the annual AIDS budget on a play with dubious educational messages. The mass media are unconcerned about the mounting epidemic. Indeed, recently *The Star*, one of the country's largest circulation broadsheets, had seen fit to dismiss the whole subject in an editorial concluding that the AIDS epidemic was not going to be as serious as we thought. Instead, it opined, we should direct our energy and resources at clear and present health dangers, like malaria and TB. At the time I had found this an interesting observation — for ten years now a small clique of AIDS experts had been warning that the plague was upon us, but so far it was nowhere to be seen. We had been told that AIDS would hit South Africa with such severity that the hospitals would be unable to cope, and a novel system of home-based care would have to be devised. This was the common talk of the day, and we braced ourselves for the crisis: the people huddled in blankets, dying on street corners. But so far, it had not happened.

My path to Siza's hut had been arduous, involving intensive research and painful soul-searching. One of the first people I had seen was Mary Crewe, the director of the Community AIDS Centre in inner-city Johannesburg. To her I had voiced my doubts about the real extent of the epidemic. In response Mary reached into a file and produced a chart of five years of antenatal HIV survey results. It was the first time I had heard of it. I could see that from the beginning of the survey in 1990, national HIV prevalence had soared from under 1 per cent to over 10 per cent. I was stunned.

'But where is the evidence, the dying people?' I asked.

Crewe responded by saying that the predictions had been based on uncertainty about how long Africans could live with HIV. It was now apparent, she said, that the average person, in Africa as in the north, had six to ten years of healthy life. It's the people infected in 1990 — the under 1 per cent — who are beginning to die at this time.

Turns out the good news is also the bad news. Ten healthy years also means ten years of being able to transmit the virus without realising it. Thus each year the numbers grow in an almost exponential curve.

In time our film team acquires a consultant. Peter Busse has been HIV-positive for eleven years, and open about his status for the last four years. Peter presides over our induction into this secret world with kindliness and patience. He emphasises the importance of distinguishing between HIV and AIDS. Young people who are diagnosed must not be allowed to think that HIV is a death sentence, when they have many healthy years ahead.

In a workshop Peter goes through all the basics, some of which, to my shame, I do not know. For example, when I hear that HIV is present in saliva I wince at the memory of an HIV-positive toddler chewing on my pen, and my mind wanders.

(What happened to that pen? Oh, but I must be OK. I had that HIV test when I bought my house, remember. I never did get the lab results, but I got the insurance, so I must be OK. Slight guilt at this memory … at the time, I knew the corollary was that HIV-positive people could not get insurance, could not buy houses; but I went along with it, without protest. I did, though, challenge the nurse to provide me with pre-test counselling, which was my right by law. She responded aggressively: what do you want that for? The test is routine for anyone buying a house. You haven't got it, you are a decent person, she said.)

In my mental meanderings I miss the next important bit of Peter's spiel where he explained that casual transmission, ie other than via direct exchange of body fluids, has not been proven to occur.

InPeter's workshop weallhavestoriestotell.Itturnsoutthat none of us are as innocent as we would like to have thought.

We may not know the statistics, but the epidemic has been hovering just outside our field of vision for so many years and we have turned our heads away. 'Close your eyes,' says Peter, 'think of the person you hold most dear. Can you see his face, can you hear her laugh? Now I want you to imagine that that person has HIV. How do you feel?'

As part of the film research, I make contact with a range of organisations and support groups for people living with HIV and AIDS in Johannesburg. They are not easy to find — no names advertising their presence in office blocks, no signs on the doors. It is like the underground world of the apartheid years — informal groups working for a common cause, virtually unfunded. And in secret.

At *Friends for Life*, which runs a buddy scheme for 60 HIV-positive people in the city, I learn why this is so. I hear stories of sick people thrown out of parental homes, women beaten by their husbands (who had infected them in the first place), people being made to eat off separate plates in separate rooms, mothers parted from their children. The immense stigma and vengeful discrimination has already set up a vicious circle of secrecy and ignorance that seems impossible to break.

The time of my appointment at *Friends* has been very carefully arranged so that I will not meet any of its members. Chris and Mark, the two men who run the project, tell me that every film they have ever seen about AIDS has insulted and offended them with images of wasting, dementia and open sores. That is not the reality of HIV and it is counterproductive, they say. People think: 'I am not like that, therefore I am not infected, and neither is anyone else I know.'

'I call HIV/AIDS "the other people's disease",' says Chris. 'It's time to tell the truth. HIV-positive people are just like everyone else.'

It's a hard one. I put it to them that a film that portrays people living positively with HIV is unlikely to shake us up. Why should we change our behaviour if being HIV-positive seems OK? This is so clearly not the right thing to say, but Mark and Chris tolerate my comments and we chew through this dialectic until it's time for me to go. The biggest problem with filming here is that few of the members are open about their HIV status. Confidentiality, in the context of film, means an absence of all evidence.

This was to be an ongoing problem for the film research. Across the country I meet dozens of people living with HIV, but the vast majority of them have very good reasons to keep their identities secret. Many had not even disclosed to their families, friends and employers out of fear of losing the love and support they would need to survive.

Back home I spend my spare time reading mounds of literature. It is the World Bank projections that make me cry. All our hard-won gains are to be washed away in this tidal wave of distress. When I broach the subject with friends and acquaintances in the NGO sector and government jobs I am rebuffed. They resent me for disturbing their peace of mind. They shock me with their determination not to hear the truth. Why are you always going on about AIDS, they ask? Why don't you talk about TB, or malnutrition, or any number of other diseases? We haven't managed to beat poverty yet, they say, and here you are presenting us with another intractable problem.

Most often they remind me that they are engaged in the reconstruction of the country, in righting apartheid's wrongs, in redressing inequality, in fighting racism, providing for basic needs. How can they be asked to dilute their energies with a hypothetical problem?

I take to carrying around the HIV prevalence graph for them to see what lies ahead, but they are not convinced. This whole period recalls the early 1970s when, as a young adult, I tried to talk to my mother's friends about apartheid. Like then, I feel as if I am in a parallel universe.

I am particularly disturbed by one comment from a friend that links 'this new obsession' of mine with my unhappy childhood. Yet, I have to concede that there is some truth in it. My father died a painful and protracted death in full view of the family, without the 'C word' being said aloud. Though I was only 11 years old at the time I have always felt implicated. Perhaps my whole political life has been one of infinite reparation.

In the end I resist what I feel is a reductionist view. Back in the 1970s my mother's friends, no doubt, felt the same about my abnormal concern for human rights. If it is only the damaged and the doubtful who can take these things to heart, then what hope for humanity?

Inevitably my research leads me to the battered office door of paediatrician Dr Neil McKerrow, at Edendale Hospital in KwaZulu-Natal province. I have been here before. While writing a story about adoption I had stumbled upon the amazing story of Pietermaritzburg's abandoned babies. The aftermath of the bloody civil war between the Inkatha Freedom Party and the African National Congress seemed somehow to have created great swathes of abandoned babies and children in the area. This was a new phenomenon, as in African culture the extended family has always cared for orphans. *Ubuntu*, the humanistic culture of Africa, tells us that to be human is to be part of a community. In this culture, all children are the children of all adults; and all adults are the parents of all children.

McKerrow and his colleagues had done their research and discovered that, far from this tradition breaking down, communities surrounding Pietermaritzburg were almost saturated with 'surplus' children. Nearly one-third of families were hosting children not their own — children of parents who had fled the hit squads, been killed in the fighting, or simply disappeared. When families and neighbours could absorb no more, the children found themselves on the street. At the time of my first visit to this hospital in 1995, there were at least a dozen children living permanently in the wards.

Though the root cause was the political conflict, a new problem was worming its way into this crisis. HIV.

One year on, the situation has deteriorated further. Not only are there increasing numbers of orphaned and abandoned babies, but McKerrow's wards are filling up with dying children for whom there is no cure. Their immature immune systems mean that they are the first in the family to show the symptoms of AIDS. One stick-thin girl of about seven years of age is stretched out motionless, tubes in her nose. McKerrow comments that they are just trying to stabilise her condition so that they can send her home to die.

It is clear that children are on the frontline of the epidemic, both in terms of the illness and its social consequences. McKerrow talks about a home he visits in the valley where a 12-year-old cares tenderly for his dying father, scratching his father's inflamed skin to ease the agonising itch. From McKerrow's perspective, as a paediatrician of long standing, the fact that AIDS targets adults of child-bearing age makes it the most serious illness that he has ever encountered.

Various organisations in the city are desperately trying to place children in homes in the local community, and when that fails, in white adoptive homes. Child Welfare is one of these. Social workers in their inner-city offices exude an air of burnout, hysteria even.

'I look out the window and I watch the women passing,' one social worker says. 'I know that one in five is infected with HIV, and if we can't even deal with the orphans today, how is it going to be in ten years' time?' He is still reeling from an earlier encounter with an HIV-positive mother who had come to see him, simply to ask: Will you look after my baby when I die?

His despair is common among those who work with young people for whom there is no hope. One counsellor I meet simply calls it 'the sadness'.

Though the child protection agencies in Pietermaritzburg are in turmoil, other NGOs are seemingly oblivious. Just across the road I visit an organisation providing educational support to out-of-school learners, whose staff will be part of the audience for this film. No, they haven't encountered HIV or AIDS. Nobody in their programme is affected. It is not a priority.

The squatter camps in the green rolling hills of the Midlands tell a more nuanced tale. Here ordinary people are slowly coming to acknowledge and understand this new threat.

'My husband comes in late every night,' says one plump, ageing wife. 'He is drunk and I know he has been round and about with many women. Then he wants to have sex with me. What can I do?'

This is countered by the men. We all know who the culprits are, they say — those women who drink and force us to have sex without a condom.

Everybody laughs. But one youth is not so amused. As the discussion about AIDS continues, he becomes increasingly agitated. 'You mean to tell me there are no signs of this virus? I could have this disease without knowing it?'

Everybody in the room knows somebody who has died. Though they may say it's from TB or pneumonia, it is young people who are dying and this is something new.

'It is going to kill us all,' says one old woman. Another nods. 'Like the death squads. We use the same name for this disease as we used for them — *mashayabhuqe*'.

Across the land, in this year of 1996, communities are in varying stages of adjustment to the new crisis. There is denial and anger; depression, despair and the grief of acceptance. The five stages of accommodation to dying, described by psychologist Elisabeth Kübler Ross, come readily to mind.

On the dusty road that leads away from Sizakele's house, our assistant realises we have left something behind, and so we return. Hearing our van pull up, Siza runs out of her hut, looking frantic. She is still clutching the crumpled notes he had given her. She thinks he's changed his mind, and wants the money back. It is less than R20.

We continue our journey through the Valley of a Thousand Hills to the village of Ndwedwe. Here we hope to meet a group of women that has been adopting Pietermaritzburg's abandoned babies. By now there are at least a dozen people in the van. Two women who live in Ndwedwe are in the front, directing — 'left', 'right', 'left', they point the way. There are no signs, and the crevassed, dirt road seems to wind impossibly around every single one of those thousand hills. The shadows are lengthening and there are voices in my head saying that this is all folly.

We are brought to a sudden halt on the brow of a steep hill. Way up top there is a row of mud houses, clinging precariously to the red earth. We extract ourselves from the van in time to be greeted by a line of ululating Zulu women dancing down the narrow path. They are momentarily dismayed when the guide explains our mission, but soon recover their pleasure in the occasion. It seems that, at first, they had thought we had brought a whole vanload of fresh babies for their care.

We meet three women from the Nzama family — all apparently married to the same man who is a migrant worker on the mines. Surprisingly, all three wives discovered in their youth that they were infertile. But now great joy has come into their lives in the form of these much-adored foundlings from the city.

'If I could show with my body how happy I am, I would be huge,' says Gertrude Nzama. 'My heart is filled with pure joy because of this child of mine.'

The women are motivated by compassion, as much as their own need. 'Even if you have a mother and you lose her, it is sad,' says Ntombizakhona Nzama. 'But it is too sad to be an orphan before you have even had a chance to say "ma".'

Only one of these children is HIV positive; though at her young age this may just be a measure of her birth mother's HIV status. This child has been allotted to the eldest wife. As Pendulike Nzama cradles her baby, she tells us: 'Women shouldn't be afraid to adopt a child with HIV, because there are so many diseases on earth. Any child may be born with a disease from the mother that may or may not be cured. So you shouldn't just take the child who is well and leave the sick one. You should take care of it.'

In the years that follow, during which I try to grapple with an understanding my country's crisis, I return again and again to the memory of the good women of Ndwedwe and their message of *ubuntu*. For, if there is any solution for this tragedy, it is they, and people like them, who will lead the way.