

2 Just a virus, just a disease

AIDS is a disease. It is an infection, a syndrome, an illness, a disorder, a condition threatening to human life. It is an epidemic – a social crisis, an economic catastrophe, a political challenge, a human disaster. AIDS is known. It has been analysed assessed assayed tested measured surveyed considered reflected documented depicted exhaustively described. Its virus is primal particular sub-cellular mutant enveloped nitrogenous. Our knowledge of it is clear and precise. But the disease is also unknown. It is guessed estimated projected approximated sketched debated disputed controverted hidden obscured. Still, it is mere fact: an event, a circumstance, a happening, a reality as present as the ocean or the moon.

AIDS is mouth and tongue and scar and nerve and eye and brain and skin and tum and gut. AIDS is smell and feel – of sweat and grime and snot and breath and bowel and secretion, discharge, pus, putrescence, disintegration, excrement, waste. Human waste. AIDS is feeling – painful sharp tingling burning heavy dull weakening wasting enervating diminishing destroying bereaving. AIDS is fear. It is breathless and nameless.

AIDS is stigma disgrace discrimination hatred hardship abandonment isolation exclusion prohibition persecution poverty privation.

AIDS is metaphor. It is a threat a tragedy a blight a blot a scar a stain a plague a scourge a pestilence, a demon killer rampant rampaging murderer. It is made moral. It is condemnation deterrence retribution punishment, a sin a lesson a curse rebuke judgment. It is a disease.

AIDS is a disease triggered and sustained by a virus. The virus is the most researched and best understood in the history of humankind. Scientists know precisely how it is genetically constructed and how it is chemically made up. We know how HIV replicates, how it is transmitted, and how it works to destroy the body's defence mechanisms, causing the catastrophic breakdown of immunity that is AIDS. We know a great deal about how HIV moves through populations and what social factors hasten its spread. We also know what living conditions and social circumstances speed up the onset of AIDS after someone has been infected with HIV. AIDS is the most scrutinised and studied and analysed disease in the history of medicine.

Even so, there is much that is unknown. Some continuing puzzles concern its epidemiology (the study of the spread of disease). We don't know exactly how many people are infected with HIV, or the precise number of those who have died of AIDS. For some areas, like North America and Australia, the figures are almost exact and very reliable. In other regions, those that AIDS most heavily burdens, the figures are estimates – for the most part, very rough estimates. These are based on well-established methods of inference and models of disease projection. But their application and the results derived from them are rightly the subject of a good deal of controversy.

Other puzzles are concerned with how the virus itself operates and how the human body responds to it. Some individuals, a tiny fraction, remain uninfected despite extensive exposure to HIV. We don't know why. Others, also a miniscule number, remain free of illness despite long infection with HIV. We are not sure why. Some populations have escaped the mass infection patterns that signal an epidemic. Others, in central and southern Africa, have not. The reasons are not clear. Anyone who pretends to know exactly why is pretending.

AIDS is the worst microbe-borne epidemic since the great plague, probably carried by rats and passed on from their fleas to humans, killed at least 25 million people – one third of Europe's population – in the mid-1300s. At least the same number of people have already died from AIDS. The United Nations special agency dealing with the epidemic, UNAIDS, estimates that by the end of 2002, after the epidemic's first two decades, cumulatively 25 million people had died from AIDS. In 2002 alone, as many as three million people died. The same agency estimates that there are currently more than 42 million people worldwide living with HIV or AIDS.

AIDS was first diagnosed in North America. But most of those whom AIDS now threatens with death live in Africa. Africa is the world's poorest continent. In the last five hundred years it has suffered the ravages of slavery, colonialism and exploitation. It continues to be crippled by debt and by the exclusionary policies of the world trade system, enforced by wealthy countries, which exclude its products from many profitable markets while undercutting the prices its farmers can obtain for their produce. Currently perhaps as many as thirty million Africans have HIV or AIDS.

The most signally important thing about AIDS is a hopeful fact – that it can now be medically managed. When the virus's replication within the human body is disabled, its effects become remediable. Drug treatment can now stop viral replication. AIDS is therefore a manageable condition. The drugs that disable viral replication exist, in ample number and manifold combinations. They are capable of being produced cheaply. What prevents their inexpensive production and ready distribution is in the first instance laws, national and international, that protect the exclusive rights of the corporations that have intellectual property title (patent rights) to them.

Where the drugs are available and accessible, and are administered under proper medical management, AIDS illnesses and deaths have been reduced by as much as 90 per cent. This has happened in affluent areas of the world. The epidemic therefore confronts business and political leaders with a pressing moral question. The means to prevent death from AIDS exist. Are they willing to take the measures needed to ensure that adequately supervised treatment reaches thirty million Africans and other people in the resource-poor world – or will they let them die because they are poor?

This question is pressing because without access to the new drug treatments, most of the 42 million people in the world living with HIV and AIDS will die of AIDS over the next ten years. Death from AIDS is lingering, painful, and (particularly in resource-poor settings) very short of dignity. And because AIDS is a syndrome of disparate diseases – because unlike cancer or ailments of the circulatory system or heart it does not strike efficiently at a single vital organ, but allows wasting disorders gradually to wrack the body as a whole – and because most of those with AIDS are young adults whose bodies are otherwise still relatively strong, death from AIDS is almost invariably a ghastly, drawn-out event.

Perhaps worse than many of its other features, more puzzling, less tractable, and besides complicating everything else, AIDS is also shame.

Shame – the humiliation or distress that arises from self-knowledge of dishonour or offence or impropriety or indecency.

An apparently insignificant incident kept me thinking for a long time. On an early spring afternoon in March 1993, while I was visiting London on a government-sponsored information tour, my foreign office hosts set up a meeting with a British

writer and AIDS activist whose work I particularly admired. I arrived at the National Gallery before our appointed time to catch a glimpse of some of my best-remembered images – the shadowy elusions of Leonardo's drawing of the Virgin and Child with St Anne and St John the Baptist, the wiry-haired alert little dog attending the betrothal of van Eyck's Arnolfini, the altogether more languid pooch enjoying the hot afternoon with Seurat's Bathers, and the twisted death's head soaring sombrely past the feet of Holbein's handsome Ambassadors.

Under the coffee shop's thickly barred windows overlooking Trafalgar Square, my companion and I seemed to establish a quick rapport. Although visiting as an 'anti-apartheid lawyer', I was familiar with his subtle but passionate criticisms of conventional responses to gay sexuality and to AIDS. He in turn expressed a sympathetic connection with the problems weighing on me – how to stem the disquieting rise in HIV infections at home while trying to lay the ground for wise AIDS policies by our soon-to-be-elected democratic government.

As our conversation ranged widely, I began to sense in my companion a personal passion about the issues that I not only admired but which seemed to resonate with my own. But this was suddenly abbreviated when he paused to say significantly: 'Of course commitment does not have to mean you are HIV positive yourself. For instance, I'm HIV negative.' I was instantly puzzled. The avowal seemed illogical, unconnected. It exuded cold breath over our conversation like a lump of dry ice on a stage. Naturally I accepted what he said at face value. But I felt dismay spreading from my throat. If he was HIV negative, why did he need to insist on it? Surely such a thoughtful and provocative activist should avoid divisive, self-exempting labelling? Our conversation foundered. He took the check and soon after we parted ways on the steps of the gallery in the chilly dusk of late winter.

When I returned to South Africa, I wrote to thank him. But I decided not to ignore his pointed self-labelling. So I added a question. Why had he declared himself HIV negative, I asked, when the struggle for justice surely required indifference within it between those who are positive and those who are negative? I never received a reply.

But a few months later I bumped into him at a meeting in Berlin. That may have been my answer. He looked shocking. He was haggard and drawn, severely stressed or very ill – or, I thought, both. Later a mutual friend told me he had fallen ill with AIDS. He was probably feeling the effects of his impending slide downwards when we met at the National Gallery. He survived for long enough to benefit from antiretroviral treatment. He continues to write, as sensitively and perceptively as before. That he knew he was HIV positive when we met at the National Gallery seems almost certain.

Why could he not tell me? More precisely, why did this nuanced, committed person feel that he needed to make an unsolicited claim that he was HIV negative? Perhaps he feared that I imputed a personal connection to AIDS. Perhaps the adopted reserve of the southern English made the conversation's intensity uncomfortable. Perhaps he envied the lawyerly detachment he imagined that I was bringing to the issues.

Or did he just feel scared and lonely, fearful that I would encase him in stereotype, one all too familiar in those years – the self-interested, angry, afflicted, imminently perishable AIDS activist?

Perhaps he was already ill. Perhaps he felt the crackling drag of death upon his will, his energy, his courage, his life, as mortality hovered. Perhaps like us all he thought that denial deferred death.

If he had been asked, my companion could perhaps have answered some of these questions. But they should more truly have been directed at myself. For what was equally telling about our meeting that afternoon was that I, too, did not speak about my own exposure to HIV. For at the time I, too, knew that I had HIV. For more than six years I had known, since a Friday afternoon in December 1986 when my doctor, a well-meaning family friend on the point of retiring from a much-loved practice in Pretoria, phoned me during a busy moment at the Wits University human rights centre to tell me, without precursor, planning, request or approval, that he had sent my blood for testing, and that it had come back positive for HIV.

I look now in my legal appointments diary for Friday 19 December 1986. Court was in recess. The day notes the address of a close friend who had recently relocated to Cape Town. It fixes a lunch date with a funder at a nearby health food bar at 12h15. And it lists an arrangement to take two friends to the airport at 16h00 for a family visit abroad. My doctor's call came just after three o'clock. It delayed me, so that I was late for my friends. Not because we spoke for long. We didn't.

My doctor seemed nonplussed – grave and somewhat lost for words. But after he put the phone down I felt too stunned to move, incapable of my own distress. Eventually I dragged myself up. My first duty in a new, irreversibly changed, world. My friends and I battled to reach the airport through a crashing Highveld thunderstorm that whipped the Friday afternoon traffic. Somehow they made their plane, and I made it home.

What the diary does not show is that later that night, in the state of acutely heightened awareness that sudden shock or bereavement can bring, I visited a busy bar in Hillbrow, Johannesburg's cosmopolitan flatland. Standing in the crowd I felt not dulled but sharpened, uselessly so, my awareness not stupefied but concentrated, futilely, as though something intensely violative had befallen me, a limb suddenly torn off, for which no previous experience had prepared me and about which nothing could now be done. Alone in my car on the way home I operated the controls as if for the first time, the steering wheel unfamiliar beneath my palms. The silence around me seemed intense. All the organs through which I was breathing had suddenly been fixed with an unspecified but surely imminent term date.

The shock was double. Apart from the blow of learning that I was infected, most immediately I felt as though I had experienced a stunning bereavement – the impending loss of my own life. I was thirty-three, building my career. In many ways – developmentally rather than chronologically – I was just starting life. AIDS was incurable. Its eventual effects were horrific – and untreatable. In South African law, when an assault or road accident survivor sues the perpetrator, a separate heading under which compensation can be recovered – apart from the victim's claim for expenses, pain and suffering and loss of amenities – is for 'loss of expectation of life'. It is a bereavement the cold categories of the law recognise.

For the first time I knew what it meant to experience a loss of expectation of living. I knew with certainty that I would fall ill soon. And then I would die. Death would assuredly overtake me within a year or two. Even discounting these dramatic presentiments, AIDS put a short, sudden and shocking limit on my life. In December 1986 it was for me what for tens of millions of Africans it still is today – an imminent term of death.

Over the next ten weeks, through a stint at Harvard law school's human rights programme, the bruising sense of shock and the enveloping silence travelled everywhere with me. The east coast newspapers and the bleakly pessimistic gay press of early 1987 fed my sense of horror on a daily basis. They proclaimed the rising

death toll, the horrific manifestations of AIDS, their certain culmination in death, the social revulsion the disease almost everywhere evoked. Again, this not unlike Africa today for those with AIDS – a sense of horror, mixed with fear not only of the disease's effects but of people's reactions to it: and above all absence of hope.

In my shock I experienced what I later gathered is not uncommon among those not fairly forewarned of an HIV diagnosis: a sudden onset of AIDS-like symptoms. As I left for Cambridge, Massachusetts, I had a severe chest infection, sore throat, swollen lymph nodes. These all presaged, albeit mildly, the illness's eventual onset more than ten years later: vivid proof of the conjuncture of mind and body.

From America, baffled by his conduct, I sent my doctor courteous notes, diffidently enclosing patient information pamphlets and medical journal articles. These enjoined doctors – for ethical, psychological, legal and practical reasons – to obtain a patient's fully informed consent before HIV testing. They emphasised that the patient needs help and support – counselling – to cope with the result, whether positive or negative. In no circumstances should the news be communicated by telephone. A support structure should be in place. Never, ever, should the patient be left to face the news alone.

In the more promising days of treatment access, these norms are swiftly changing, and rightly so. Where life-saving treatment is available to the patient, it may be the doctor's duty to push the patient gently to agree to be tested. In Botswana, South Africa's land-locked neighbour, President Festus Mogae's government in 2001 announced a far-seeing national plan to provide antiretroviral treatment through the public health service to everyone with AIDS. But, as the death toll from AIDS continued to climb, poor enlistment baffled government health planners. So from January 2004, the Botswana government announced that unless patients at public health facilities actively declined to be tested for HIV, the test would be routinely administered.

Some of my activist friends felt dubious about the change. I differed. Provided that treatment is available, with guarantees of confidentiality and against discrimination, I thought and still think that testing is more often than not necessary, and beneficial. It is better that health workers trying to be true to their calling of beneficence should nudge patients who may need treatment towards the HIV test than that they allow patients to return home, trapped by fear and stigma, untested, to add to the epidemic's already appalling toll of unnecessary deaths.

By contrast, where no treatment is available – as in the bleak 1980s, and as is still the case through most of Africa – testing may do little more than expose those who prove positive to stigma, ostracism and discrimination. And without proper support (including counselling) an unpresaged HIV positive test result is almost always damagingly counter-productive. So my doctor erred doubly. But looking back I have scoured my conscience to ask whether part of me in fact suspected that he might use my annual visit that year to test for HIV. Every year when I visited him in early December for a check-up, he sent blood for liver function tests and platelet counts and cholesterol – benign, incomprehensible checks that held no meaning for me and less fear. They always came back clear.

But AIDS in the mid-1980s was a burning issue for young gay men. Perhaps with all the current talk, with the previous year's Sunday headlines agog with news of the 'gay plague' that had reached South Africa, with my doctor's knowledge of my sexually active post-divorce life ... perhaps between thought and suspicion and expectation and hope it must have crossed my mind that he might also take it upon himself to test for HIV. But if I did conceive of such a decision at all, without his first

discussing it with me, without arranging for counselling or for support or follow-up afterwards, it was only because I hoped and believed that those results, too, would be benignly insignificant.

Perhaps my doctor did too. But the positive result was all too comprehensible. It meant death. And I had had no preparation for anything so instantly and brutally terminal. I had no doubt that he should have consulted me first, and that he should, on getting the positive result, have arranged matters very differently. Neither privately nor professionally have I ever met a person, young or old, employed or unemployed, numerate or innumerate, literate or illiterate, housed in stone or brick or corrugated iron or plastic sheeting, for whom the significance of such a result is any different. Your state of health – the term of your life – is a matter of deepest privacy, most integral to your conception of your life and being. It is part of what defines hope and expectation. It has been said that what distinguishes humans from other animals is our conscious apprehension of mortality. That sense – its translation into present knowledge – must always be approached, addressed, its imminence determined and imparted, with utmost veneration.

No person, professionally qualified or not, ill-intentioned or well-meaning, for instrumental or intrinsic purposes, has the right to grasp that knowledge without at least first consulting and preparing the person it most concerns. That is more especially the case when the result reveals a reviled disease exposing the patient to dread reactions; and when the medical diagnosis can offer no present hope and intervention to the patient diagnosed.

My frozen half-gestures to my doctor sought to communicate some of this. One emotional evening in early 1987, shortly after returning from Harvard, I managed to confide in my friend and Wits law associate Carole Lewis, now a colleague in the Supreme Court of Appeal. But apart from her, I made contact with almost no one. I confided, after a time, in the person with whom I fell in love the next year. To a wise and patient private counsellor, and to a Wits doctor doing brave early work in the field, Professor Ruben Sher, I spoke. But not to family or troops of friends. I feared their reaction with a ghastly, sickening, isolating loneliness. For more than three years I lived with it solitarily, not quite alone in a treeless tundra of my own involuntary creation.

Practising law at the human rights centre was gruelling but engrossing. In July 1985 and again in June 1986 the apartheid government plunged the country into a state of emergency, proclaiming punitive legal measures that banned meetings, publications, protests and political activity. Communities long-established on their land were still being ‘resettled’ – forced off it in pursuit of the grand design of racial separation and subordination. Ramshackle ‘nations’ were still being fabricated as part of the grand plan of separating black and white, and were being declared ‘independent’ of the rest of South Africa. Fighters for the exiled African National Congress infiltrated their homeland. They targeted, with extremely rare exceptions, non-civilians exclusively. When captured, they faced trial for treason and murder. Scores of young white men who refused to be conscripted into the army were imprisoned as conscientious and religious objectors.

But despite increasing depravities, for the most part the apartheid authorities still took the law and legal processes seriously. Court challenges often alleviated or obstructed the noxious and futile apparatus of racial subjugation. And it created spaces for trade unions to grow and flex their worker power. No day was dull. While

work was sometimes dispiriting and often overwhelming, more often it was exhilarating.

It was also a diversion, a justification, a comfort and a distraction.

But it was not merely awareness of radically truncated mortality that seemed to be freezing my responses from within. Nor was it only fear of others' reactions to my condition. More horrifying was the inner sense of contamination I experienced. Yes, I felt too fearful to speak with anyone. But I also felt too ashamed. I was tainted, soiled, polluted. My blood and body were fouled with the most conspicuously vile infection known to recent human history.

Widespread and much publicised revulsion to AIDS – and fear of those with HIV – didn't help to combat these feelings: the witch-hunts at American primary schools, the rash of criminal legislation targeting those with HIV, the seclusion camps in Sweden and Cuba. In South Africa, proposals were mooted but fortunately abandoned, to force doctors to report cases of HIV or AIDS to the public health authorities. In August 1986, the mine bosses' organisation, the Chamber of Mines, announced the results of a study on blood samples of 300 000 male mineworkers. These showed that about 800 mineworkers – 760 of whom were from central Africa, in particular Malawi – had HIV. The reaction was drastic. The workers with HIV were summarily deported. This was achieved through the deadly mechanism of simply not renewing their yearly contracts at the beginning of 1988. Regardless of their years of service, they were sent back to Malawi – with its pitifully inadequate health system – to meet their fate.

It was this issue, brought to me because I was a human rights lawyer doing trade union work, that drew me into AIDS policy and litigation. Not my own condition, but a condition outside, graphically linked to apartheid injustice. It was easy to throw myself into AIDS activism in this guise. A dualism began. Publicly, I was a human rights lawyer involved with trade unions, community organisations, ANC fighters, military resisters – and HIV issues. Privately, AIDS was hideously, almost unthinkably, close.

Reactions like those that led to the expulsion of the Malawian mineworkers were all fuelled by a sense that those with HIV or AIDS had only themselves to blame. From this were excluded only the small minority of 'innocent victims' – children and blood transfusees, who could not be fixed with blame for their condition.

There is no doubt that many people thought and still think of those with AIDS or HIV as contaminated with a vile, self-induced affliction. But all too many sufferers are painfully conditioned into also thinking that way about themselves. Looking back on the problem I experienced in not being able to talk with my human rights lawyer colleagues, I see all too clearly that it emanated partly from within me. At some inaccessible, impenetrable level – even while challenging injustice against people with AIDS in the courts and on committees and on public platforms – I was still struggling with an overwhelming inner sense of shame. In some indefinable sense that I grappled to surmount, I felt that my infection showed that I had acted shamefully, dishonourably, so as to bring not only death but disgrace upon myself.

My colleagues were all committed – of course – to justice and fairness and nondiscrimination. But I confided in none of them. I could take no risks. Nor could I permit myself the comfort of connection. In dealing with clients and plotting public interest litigation challenges we developed close camaraderie and even friendship. But I could no more tell them that I had HIV than seek solace by confiding that I had

molested one of their children or pets. That was how deep, how powerful, how repulsive my condition seemed to me.

Perhaps you think my reactions excessively subjective, or the comparisons overstated. But powerfully irrational responses to AIDS overshadow the epidemic even today. For stigma – a social brand that marks disgrace, humiliation and rejection – remains the most ineluctable, indefinable, intractable problem in the epidemic. Stigma is perhaps the greatest dread of those who live with AIDS and HIV – greater to many even than the fear of a disfiguring, agonising and protracted death.

Stigma manifests itself in hatred, discrimination, rejection, exclusion. Workers are sacked. Spouses are shut out. Friends are abandoned. Services, help and support are refused.

What is perhaps most poignant and most impenetrable about stigma is that some of its impact seems to originate from within. The external manifestations find an ally within the minds of many people with HIV or AIDS. Stigma's irrational force springs not only from the prejudiced, bigoted, fearful reactions others have to AIDS – it lies in the fears and self-loathing, the self-undermining and ultimately self-destroying inner sense of self-blame that all too many people with AIDS or HIV experience themselves. It is the combination of these two forces investing AIDS stigma that renders its effects so powerful and so destructive.

The external manifestations of stigma are horrific enough. At Christmastime 1998 a 36-year-old South African old woman, Gugu Dlamini, was stoned and stabbed to death. The horror of her death has never been fully investigated, because her murderers were never held to account. The prosecution brought charges, but dropped them for lack of evidence. What is clear is that shortly before her death Gugu told Zulu-language radio listeners that she was living with HIV. Three weeks later, members of her own neighbourhood rounded on her. Her attackers accused her of shaming her community by announcing her HIV status. She died in hospital – her body broken not by the HIV she faced with such conspicuous courage, but by the injuries her neighbours inflicted on her. She left a thirteen-year-old daughter.

Three months after Gugu died I decided to announce publicly that I was living with HIV. My decision was impelled partly by horror at her murder. Simon Nkoli, a brave activist, died at almost the same time. His courageous openness about being gay while he shared a prison cell with other ANC leaders during the 1980s helped to ensure that gay and lesbian equality was included as a cornerstone of nondiscrimination under the democratic constitution. When he later fell ill with AIDS, Simon took the logic of confrontation and truthfulness a step further. He spoke out about the fact that he had AIDS.

He died, comatose, exhausted and dispirited, on 30 November 1998 – four days after his 42nd birthday. The new drugs had failed him. We surrounded Simon's body where it lay in the comfortless, busy wards of the Johannesburg general hospital. He had survived a childhood under apartheid – in the very Vaal townships near Sharpeville where a year before I had started my own quest for wellness on antiretroviral therapy. He had survived also a pitted, often fractured quest for love and friendship, and trial for his life on the capital offences of murder and treason. He did not survive AIDS. A media statement from family and friends stated his cause of death. More than six years after his death such openness, throughout Africa, still remains a rarity.

Simon's memorial service was held at St Mary's Anglican Cathedral, a capacious structure in downtown Johannesburg. Its traditional hewn-stone textures and spaces would not be out of place in the Cotswolds. It is here that the young

Desmond Tutu, later Nobel Peace laureate, began his rise to prominence as a moral voice against apartheid's injustice. Over the unremitting decades of racial humiliation and subjugation, the cathedral served as the venue for many protests, many moving ceremonies.

Now Simon's coffin lay there. Somehow his obsequies seemed harder, bleaker, crueller. His life's struggle had helped create the South Africa to which Tutu aspired. Now he had succumbed to AIDS. On a rain-spattered, chilly Friday evening, despite the good turnout the cathedral felt skeletally empty. I joined the speakers who honoured Simon. I spoke about his dying from AIDS, about how signally important openness was in the struggle for acceptance and fairness. But still I could not speak about my own life with AIDS – a life sustained for more than a year now by the drugs that failed Simon – the drugs that continued to be denied to millions of South Africans and others who needed them.

Another brave anti-apartheid activist led the way for me. Three months before Simon died my friend Zackie Achmat broke his silence about living with HIV. In an emotional letter to his friends he spoke about his infection with HIV. Zackie is a man of immoderate intelligence, personal magnetism and courage. He combines these qualities with unequalled guile (the latter hard-learned on the streets and in prison as a teenage anti-apartheid activist) and a steely sense of strategy. Already he had energised gays and lesbians in our new democracy to unite in challenging discrimination under the new constitution. Now his openness seemed to inspire him with even deeper energies.

Soon after 'coming out' with his HIV, he launched the Treatment Action Campaign. Rapidly it became democratic South Africa's foremost activist organisation, shaming the international drug companies and challenging the government on many of its policies. It called on them to adopt comprehensive AIDS policies that would make the newly available drug treatments accessible to the millions of Africans who desperately needed them. Faced with years of collusive paralysis between international corporations and governments in Africa, the TAC confronted both with remorseless inventiveness – finely crafted legal challenges, superbly researched, principled arguments and uncompromising stands that often exposed Zackie and its other leaders to personal risk.

By the time Simon died at the end of 1998, it was clear that the drugs had saved my life. Twelve months after the onset of fully symptomatic AIDS, I should have been in a harrowing terminal decline, with repeated, increasingly severe infections winnowing the flesh from my bones and the energy from my body.

Instead, I was fit and well and energetic. I was still taking protease inhibitors – by far the most powerful of the new drugs. Though their neural side effects (the excruciating facial pain and dental sensitivity) and the nausea had long passed, the gastric effects they caused remained drastic. After every dose (six chilled capsules twice a day) my bowels twisted in spasm. But together with the other two drugs their effect remained unmistakably dramatic.

As I was experiencing the first heady upsurge from the drugs at the end of 1997, I was asked to chair the governing council of University of the Witwatersrand. It is a heavy but engrossing and deeply rewarding task. It has taught me some of the sorrow and complexity of trying to run a major educational institution. But it has also brought me the rewards of working with researchers and administrators and thinkers of extraordinary integrity and ability and dedication – including a close working relationship with Wits's first black vice-chancellor, a brilliant and engaging

mathematician named Loyiso Nongxa, who like me had gone to Oxford on a Rhodes Scholarship.

My new energies spurred me daily, when I awoke, as I did my court duties, as I went to chair sometimes arduous and exacting meetings at Wits University and for my other 'causes', and as I spent evenings with friends. My energy, my appetite, my wakefulness all crested bountifully upwards.

Perhaps the drugs failed Simon because of the way in which he had become exposed to them. Like others living in mortal fear of AIDS at the time, Simon took them as they became available – successively and singly. After his release on bail in 1988, well-intentioned friends from abroad started sending him parcels of zidovudine (AZT). He took it for a time. Then he stopped taking it, later perhaps starting again. As other antiretroviral drugs became available, he took them too – first one, then another, then a third. By the time he fell seriously ill with AIDS in the mid-1990s, his virus had learned to outwit each drug in turn, becoming resistant also to similar drugs in the same class. So when he started combination therapy the virus had mutated into complex enough forms to evade confinement. It raged through his body until it finally prevailed over his strength on 30 November 1998.

By contrast, I had never taken any antiretroviral before. Thanks to my homoeopath I had for more than six years not even taken a single antibiotic. My body was 'drug-naive'. So when I started the knockout combination a year before Simon's death, it worked as Dr David Ho and his colleagues had dreamed it would.

Simon's death underscored for me the particularity and the partiality of my minor physiological miracle. Above everything else, I was taking the drugs only because I could afford to pay for them – at their still excessively inflated 1999 prices.

Publicly, on platforms, in committees and in the media, I spoke about the imperative need to make the drugs more widely available. Their prices had to be reduced. The drug companies had to be less graspingly miserly in sharing the rights to produce them. They had to permit poor countries to import them cheaply from other manufacturers. African governments – particularly South Africa's – had to commit themselves to tackling the crisis with concerted energy and determination. But on each of these issues I spoke in only a partial capacity – as a lawyer, later as a judge, always as an AIDS policy buff. Of my own experience as someone who had survived severe illness with AIDS because I could afford the drugs that gave me life I still remained silent.

Surely if I started speaking as someone myself living with AIDS, I would do so with greater moral force, more unchecked energy, better clarity about what had to be done?

It would only be a matter of time. I knew this. My illness in late 1997 was relatively well disguised from Johannesburg's close-knit legal community, because when I fell ill I was out of town on the Vereeniging circuit. Only my assessors, who sat with me on the bench and shared my judge's chambers during adjournments, saw how ill I was. Word nevertheless did get about. Why should it not? One of my assessors in those first oxygen-depleted, antibiotic-laden weeks at Vereeniging was the father of my lovely godson, Sizwe Mpofo. He expressed concern to Sizwe's mother, Terry, about how ill I looked. When she called to find out how I was, my initial response was panic and fear.

And yet my friends and colleagues were concerned, and wanted to express their concern and support. Why should they not? It was I who was not yet ready to receive it. My internal feelings of fear and disgust and self-blame were still too strong. I disentitled myself from the help I was entitled to claim and to receive.

There was wider talk. A journalist from a Sunday paper made an appointment to see me in my chambers at the High Court. He had heard it said at a dinner party, he told me, that I was HIV positive. Would I not give my 'story' to him? 'Speak to me,' he urged. 'If you don't, other less sympathetic journalists are planning run with it.' This I doubted. I knew that without a firm factual source, or direct confirmation from me, newspapers were likely to defer to South Africa's stern privacy laws.

His tone of implicit menace offended me, and I frostily declined. Undaunted, he asked me directly if I was HIV positive. I paused for a moment while I looked him in the eye. I hesitated. I would not lie. But what was I to say? Then I told him the fable of the King of Denmark. He, it was said, publicly wore the yellow Star of David to signify solidarity with his Jewish subjects under Nazi rule – and saved them, alone amongst the occupied European communities, from obliteration. 'In that sense,' I told him, 'of course the only answer I can or am willing to give you is that I am HIV positive.' He published nothing.

The King of Denmark's tale was doubtless apt. But my response gaped incompleteness. And more important, from a personal point of view, it was utterly unsatisfactory. Gugu's death marked a terminus to this. It was a particularly poignant and sobering challenge. Bereft of the privileges of job and medical care, defencelessly exposed to a community that later turned on her, she nevertheless spoke out about her HIV.

By contrast, I was surrounded by protections and privileges. My job was constitutionally secure – unless two-thirds of Parliament voted to remove me, I could not be sacked. Behind my suburban wall I lived in relative comfort. Those of my friends and family and colleagues in whom I had confided offered me only love and support. And unlike Gugu I had the best medical care. I had life.

If Gugu could speak out, how could I not?

This question challenged me. It also unnerved me. But I accepted the only possible answer to it. The problem was – how? How to do it, where to do it, with whom. And above all how to minimise the risk of wrong-headed sensationalism? How could I speak truthfully about my own position while trying to place the focus on the millions who, unlike me, did not have the protections that might enable them to speak out?

This question I pondered with my activist friends. Earlier I had spoken to writer Mark Gevisser, with whom I had edited a book of essays on gay and lesbian lives in South Africa. Should I do it through a media statement, a news conference, an exclusive interview with a trusted journalist? Wisely, he gave his views on all these possibilities – but suggested that the circumstances would present themselves.

And indeed, this is what happened. A respected judge on the Constitutional Court, John Didcott, died after a long illness. The vacancy for his position was advertised. By the closing date for applications, I was the only candidate nominated. But the constitution required the commission dealing with the appointment of judges to place a shortlist of at least four names before President Mandela. So the closing date was extended, and more nominations were canvassed.

The commission would have to hold public hearings. They were scheduled for shortly after Easter. I faced a public interview – nothing exceptional, since I had appeared previously before the commission. But this one would prove to be different. On Easter Saturday the head of the Constitutional Court, Justice Arthur Chaskalson, suggested that I come for lunch at his home. In the 1980s he had spearheaded legal challenges to apartheid. Formidably intelligent and steely-principled, he was a mentor to many human rights lawyers. I trusted and admired him.

So when I was agonising over my HIV status on being nominated as a High Court judge in 1994, I confided in him. I went to see him in his chambers at the new Constitutional Court's temporary premises. His face registered shock and distress as I told him that I had HIV. But he quickly absorbed the implications – and concentrated on helping me with my dilemma: should I tell the judicial appointments commission? I was in good health. My immune system checks were at that time still looking good. I still believed and hoped that I might never fall ill, or at least that illness could be postponed for fifteen or twenty years.

We talked through the issue. He agreed that it was neither necessary nor appropriate to disclose my HIV status. With effect from 8 December 1994, President Mandela appointed me a judge of South Africa's High Court. A dream I thought would never be realised had been fulfilled.

So once before Justice Chaskalson and I had faced the issue of disclosure. I had also told him about the journalist's insinuating visit. And he had clearly given it thought. Almost casually in the course of our lunch he dropped the suggestion that I make a public statement about my HIV during my upcoming interview. As always, he approached the matter with strict rationality. 'There is nothing to be ashamed about,' he said. 'Many people have HIV. And the time has surely come for someone in public life to begin by speaking out. Why not simply do it at your interview in two weeks' time? The commission offers you an appropriate and dignified environment to do so.'

There could be no quibbling with his suggestion. What he'd said was logical and reasonable. And it was persuasive. It was clear that the time for which I had tried to prepare myself had arrived. But as we finished lunch and I left to drive home, I felt emotions heaving inside. What would friends and colleagues think? How would the press react? I would have to tell my 78-year-old mother, Sally. She had a vibrant circle of friends of her age. How would they respond? How would my sister and her family be affected? How would I feel on the street, amongst colleagues, walking into court, going into a bar or café? The inevitably sensational aspect of the event appalled and frightened me.

Overcome by apprehension, I stopped my car next to the roadside. For a while I leaned my head on the steering wheel and let grief overcome me. Afterwards I felt better. However awesome public disclosure seemed, Justice Chaskalson was right. What I proposed to disclose stood the test of truthfulness. It stood the test of usefulness. And looked at objectively there was no shame in it. Shame, in fact, my shame – other people's shame, our shame as people with HIV, the fear and inhibition that shame produces – was at the root of the problem.

My brother-in law Wim and his family stoutly supported the move. So I set about telling close friends and colleagues who did not know. And on the Sunday before the commission convened I joined my mother for lunch at her retirement centre in the quiet Pretoria suburb of Arcadia. The autumn day was blissfully warm and sunny. In the early afternoon she and I took a slow walk through the lovely terraced gardens of the Union Buildings – the splendid sandstone crescent Herbert Baker had conceived in 1910 as the hilltop administrative hub of a white South Africa. Now the magnificent edifice proudly housed the offices of President Mandela and Deputy President Mbeki. Amidst the richly coloured cannas and late roses we sat down on a bench overlooking Pretoria's city bowl. I had to tell her that not only was I living with HIV – but that very shortly I planned to go very public.

But my mother had long followed my career. Always she expressed support and admiration for my work in AIDS. In my worst moments I had thought I would not

survive her. Now I could truthfully emphasise how well I was feeling on the drugs. Our deaths, parent and child, would be in due order.

I brought the conversation around and spoke gently to her. When I had finished there was a quiet pause. She continued looking calmly, almost abstractedly, at the flowerbeds. After a moment she glanced at me, and quietly murmured: 'I thought as much, my boy.' Later that week, when Jeanie discussed the implications with her, she became distressed. But she started wearing the red, furled ribbon of AIDS solidarity. And her friends splendidly followed suit. She died two years later, ten months after we had celebrated her eightieth birthday. At her memorial service, I read out Zackie's evocation of her, 'always in your garden, always wearing her AIDS ribbon'.

The commission convened in Cape Town. I was the morning's first candidate. Zackie made sure that he was there, sitting just behind me. If he leaned forward he could touch me. That taught me something I had not quite experienced before about the tangibility, the felt proximity, the physiological closeness, that friendship and support can bring.

Justice Chaskalson introduced and welcomed me. He referred to my previous appearances before the commission – when I had been appointed to the High Court, to the labour appeal court, and a previous unsuccessful pitch for the Constitutional Court. The moment came. He invited me to read my statement 'about a personal issue you wish to entrust to the commission'. I began to read. My friends and I had carefully crafted it to deflect as much attention as possible away from the sensational angle some inevitably might take ('Judge has AIDS') to the material circumstances that made it possible for me to speak at all.

I emphasised that I had chosen to speak out even though legally and ethically I was entitled to remain silent. This choice was available to me 'for very particular reasons – because I have a job position that is secure, because I am surrounded by loved ones, friends and colleagues who support me, and because I have access to medical care and treatment that ensures that I remain strong, healthy and productive'.

Those three privileged conditions – a secure job in a nondiscriminatory environment, support of those closest around me, and life and health – were exactly what Gugu Dlamini deserved no more and no less than me, but was not privileged to have. We were particularly anxious that my statement should not expose others, unprotected as she had been, to unfair and premature pressure to be tested, or to reveal their HIV status.

'For millions of South Africans living with HIV or AIDS,' I went on, 'these conditions do not exist. They have no jobs, or their jobs would be at risk if they spoke about their HIV. They not only lack community support, but face grave personal danger if they do so. And, most importantly, they do not have access to proper medical care and treatment. For them, in a still hostile climate, the choices are strictly limited. Their right to invoke confidentiality remains of critical importance to them. It is only by creating conditions in which people can speak out without fear that we can begin to end the silence surrounding South Africans living with AIDS and HIV.'

I concluded by stressing 'my hope that my decision to speak today may contribute to a greater climate of openness and caring, and to the prospect of proper medical treatment, for all South Africans living with HIV or AIDS'.

For a few palpable moments the commission's judges, lawyers and politicians sat in stunned silence. I sensed that some of them had family – or feared they had family – who were closely affected. Perhaps their fears were closer still. Then the

silence was broken by one, more, many questions. They seemed to embrace me, respectfully, supportively, even ardently. I emphasised that I been able to chose to make my statement because 'I am not dying of AIDS. I am living with AIDS.' The phrase caught on.

Before, it had felt like the hardest, most self-exposing thing I had ever done. After, I knew that I had freed myself of a vast burden – that of unnecessary secrecy. I was able to unite myself with the truth, finally to disburden myself of responsibility for a secret that I had not wanted to keep. More deeply, I was relieving myself of responsibility for others' reactions to my illness. My silence was designed to forestall them from condemning, despising me. Now if they wished to condemn me, it was their decision. I no longer sought to control. After more than twelve years, it was an inexpressible relief.

And finally, the act of speaking addressed – for me at least – that unspoken shame at the core of so much AIDS discrimination. My silence entailed collusion between my inner sense of shame – however unjustified – and others' anticipated reactions of condemnation.

My act of speaking realised the simple truth in Justice Chaskalson's advice. There is nothing shameful about having HIV or AIDS. If we can talk about it, we normalise it. And the sooner AIDS becomes a normal disease, the sooner we will be able to deal with it unemotionally and effectively. Normally.

The commission lauded my statement. It recommended me for consideration by the president. In the end I was not appointed. The justice minister, Dullah Omar, a friend and colleague from cases and campaigns in the 1980s, telephoned me immediately after the cabinet meeting where the decision was made. He had been mandated, he told me, to emphasise to me how the cabinet had agonised over the choice. The post went to a highly respected High Court and labour appeal court colleague, Sandile Ngcobo. A tough-minded lawyer with wide experience and strong constitutional commitments, Justice Ngcobo had academic credentials in addition to practical experience. He had also trained in a Washington, DC law firm and in the chambers of United States circuit appeals judge Leon Higginbotham before returning to South Africa to work in public interest law.

He quickly established himself as a powerful force within the court. In a deserving twist of fate, he wrote the Constitutional Court's commanding opinion in the first AIDS case that came before it, *Hoffmann v South African Airways*. For me this suggested, as so often in my life, that events have their own timeliness, their own rightness, their own roundness.

The commission's favourable response to my declaration was a small foretaste of what was to come. Not only was the public and media response massively and generously positive, but journalists and editorial writers quickly developed further the notion that the silence about HIV could be broken only by creating the conditions of nondiscrimination in which people can feel free to speak out.

If positive reaction was not wholly universal, adverse reactions were extremely isolated. One parliamentarian in the largely white opposition party condemned me for bringing AIDS upon myself. His party resolved formally that he had to apologise – which he did, fulsomely, in a letter to me. A single newspaper commentator – coincidentally, also a white male – wrote sneeringly that it was hardly appropriate that I should seek to glory in my condition.

These were isolated voices. In both news columns and editorial comments, coverage otherwise was emphatically and expansively supportive. The welfare services minister, Zola Skweyiya, sent a huge flower arrangement with an affecting greeting signed from 'Zola and Thutha Skweyiya'. Only weeks before, they had suffered a terrible bereavement when their official chauffeur had accidentally killed their young son in a driveway collision at their home. Their words were heartfelt.

Another minister, Deputy Justice Minister Manto Tshabalala-Msimang, herself a medical doctor, wrote with particular warmth: 'My office wishes to add its voice amongst those,' she said, 'who have been deeply touched by your courage and selflessness in the disclosure of your HIV status. We believe this notable act will contribute towards greater awareness of the HIV/AIDS issue. We also believe that it will contribute towards greater acceptance and protection of the human rights of persons living with HIV/AIDS.' Neither writer nor recipient could know that within weeks she would be promoted to health minister in President Mbeki's new cabinet, but that her treatment of AIDS would be dogged by desperate controversy.

Many others, in the cabinet and elsewhere, followed suit. From all over Africa and the rest of the world I received hundreds of calls, letters, messages and emails.

My judicial colleagues also reacted well. The afternoon after my statement, I flew back to Johannesburg. In the evening, the news of my statement led with other stories on the main evening television and radio bulletins. As I drove to the court the next morning, posters lining the streets inevitably proclaimed 'JUDGE HAS AIDS'.

But when I opened the door of my chambers, flowers had arrived before me. An Afrikaans-speaking colleague, Pieter Schabort, whom I had always identified as conservative, was the first to come by. He popped his head around my door – 'Strength to you, my friend,' he said. 'We're proud of you.' In a sense the flowers still haven't stopped coming. Nor has the release of positive energy.

But stigma remains. It is intense and real and prevalent. When I made my statement, I was confident that within a very short time other African leaders would follow – cabinet ministers, entertainers, sports stars, Members of Parliament. This has not happened. In South Africa, President Mbeki's open scepticism about whether HIV causes AIDS froze many reactions. In a speech in Parliament in late October 1999, six months after he succeeded President Mandela, he began a three-year apparent association with AIDS denialism – the scientifically unfounded doctrine that attributes AIDS exclusively to social and behavioural factors, and not to the physiological (and medically treatable) effects of a virus.

Nowadays he rarely speaks about AIDS, leaving it to his deputy president and to the health minister, Dr Tshabalala-Msimang. Her statements unfortunately also appear to reflect scepticism that AIDS is virally caused and can be medically managed. President Mbeki has never publicly stated that he accepts that HIV causes AIDS, nor that AIDS can be treated with antiretroviral drugs, though in his state of the nation address to Parliament in May 2004 he gave welcome public endorsement to antiretroviral treatment options when he committed government to a target treatment figure by 2005.

But in the years following his October 1999 speech, the president's apparent scepticism about the viral aetiology of AIDS, and the resulting public controversy, brought a profound chill to the attempt to bring reason and calm to the debate about AIDS policy in South Africa. It certainly seemed to stifle initiatives to openness about HIV that others in public office may have contemplated.

Certainly within South Africa, stigma has remained stubbornly intransigent. It would be crass to blame political attitudes for this when, as became evident to me, the roots of stigma lie so deeply within our own profound thoughts and feelings.

Partly because of stigma's continuing intransigence, the United Nations agency for AIDS, UNAIDS, proclaimed stigma its campaign theme for World AIDS Day 2003. It was a rightful focus. Stories from Botswana – a prosperous and cohesive southern African democracy squashed shoulder to shoulder between South Africa and Namibia – tell a sobering tale about stigma. Until recently many people seemed willing to face suffering and even death rather than receive help.

About one third of Botswana's people have AIDS or HIV – perhaps two-fifths of all young adults between 15 and 49. The government with unstinting forthrightness accepts the extent of the problem. President Festus Mogae has warned that his nation faces what he bluntly calls 'extinction' unless the epidemic is properly handled. Government AIDS policies are well directed and clear. Officials are committed to their implementation.

These policies are not just the usual African mix of public awareness, counselling and prevention. They go dramatically further. In his national address in 2001 President Mogae made a breakthrough announcement. Together with international drug companies and the Bill and Melinda Gates Foundation, his government would offer treatment with life-saving drugs to every citizen with AIDS. It was a visionary and far-reaching commitment. It set a bold standard that other countries in Africa have now begun to follow (in May 2004, Malawi, one of Africa's poorest countries, announced its own \$196 million programme to distribute free antiretroviral treatment to all who need it).

The Botswana government's pioneering commitment was widely known throughout the country. Yet takers were initially perilously few. One survey suggests that to stay alive and well more than 100 000 people in Botswana need the drugs without delay. Yet by late 2003 only about 15 000 people – perhaps fewer – had come forward to accept the free medication.

Why? I asked my hosts this question in June 2003, when I joined Botswana judges and business, civic and government leaders at an AIDS awareness meeting in Gaborone. President Festus Mogae had originally agreed to come, but was called away to a United Nations meeting in New York. He sent a well-liked and senior cabinet minister instead. She read his letter of apology. It had the ring of personal authorship. Despite severe (and audible) flu, the minister herself braved the Kalahari winter cold to attend. 'That's how important this issue is to us in the government,' she told the audience to applause.

My Botswana hosts gave me a one-word answer to my question: stigma. People are too scared – too ashamed – to come forward and claim what their government is now affording them as their right: the right to treatment, the right to stay well, the right to stay alive. The main medical centre in the capital, Gaborone, is the Princess Marina Hospital. The AIDS clinic here dispenses the treatments. Plans to allow doctors and nurses at private clinics to give the drugs to AIDS patients are being discussed. But they have not yet been implemented. So for now, poor people who need government-supplied drugs in or near Gaborone must go to the clinic at Princess Marina. Many of them – most still, it would seem – are deeply reluctant to do so. This, my hosts told me, is because they fear they will be identified as having AIDS. So they postpone it for as long as possible. They fall sick first. Even then they delay. They eventually go and stand in the clinic's queues. But mostly they do so only when they are approaching the point of death.

This led the Botswana government to introduce a radical re-think of HIV testing policies: wisely, I thought and still think (though some activist friends differ), from 2004 doctors in public clinics would test patients for HIV unless they expressly refused.

This change of policy, against the background of the offer of real treatment options, helps patients too fearful to confront their own HIV to be given treatment. Unless prompted, as in my own case, they all too easily postpone, prevaricate, suppress, deny. In dwindling hope and growing fear, they rationalise the symptoms they experience, dreading the diagnosis they fear they will eventually get. In some horrifically constrained sense, they are ‘choosing’ to die, rather than face the stigma of AIDS and find treatment. Illness and the attendant risk of death feel less horrific to them than the stigma of having AIDS.

That sense is internally, and not only externally, fuelled by the shame that many people with AIDS or HIV feel about their own condition.

And not only poor people fear what will happen if others think they have AIDS. A revealing moment in the minister’s speech in Botswana in July 2003 showed her own fear. She told the audience how sick she had been all week. She wished us to know what an effort she had made, and how vital the issue was to her, her cabinet colleagues and to President Mogae. So sick had she been that she had cancelled all her other appointments – except this one.

Here she paused. She seemed to reconsider. Perhaps she realised that her story might cause her audience to wonder what exactly had kept her in bed all week. But she wouldn’t let them jump to the wrong conclusions. So she looked up and pointedly added: ‘I want to assure you all I only had the flu. That was all. It was only flu.’

The audience shifted uneasily. There was some laughter. But the chuckles seemed to stem less from amusement than from recognition of her anxiety, the laughter designed to allay it and to reassure her: we know why you are anxious ... we understand and share your anxiety that others should not suspect you of having AIDS ...

I winced. Some others I think did too. The incident in the National Gallery in London sprang to mind. Did she have to spell out that it wasn’t AIDS? She certainly thought she had to. But why? She would not lose her job. By every principle President Mogae had publicly and repeatedly emphasised, that was unthinkable.

Perhaps she feared something worse – that we would think less of her – would despise her, hold her in contempt, or ridicule, for having AIDS or HIV. Her disavowal seemed to play right into the perception that having AIDS was something unworthy, disgusting, unclean, improper. But it stemmed from a sense within her. A sense shared by all too many people with AIDS or HIV.

My Botswanan ministerial hostess’s attitude remains widespread. In the whole of Africa not a single elected official from any national parliament has stepped forward to say that he or she is living with HIV or AIDS. In a continent in which those with HIV or AIDS number in the many tens of millions, no cabinet minister or governmental leader has come forward to say: ‘Yes, I too am living with this condition.’

Shortly before Botswana, I travelled to Zambia for a workshop with judges and magistrates and lawyers. In his opening address, Chief Justice Ernest Sakala movingly expressed the extent of Zambia’s national tragedy. His personal backing and stature ensured that almost all his colleagues on the Supreme Court, together with most of the High Court judges, attended. He spoke plainly: ‘The devastating effects of HIV/AIDS have not spared the Bench,’ he said. ‘The saying that if you are not

infected with HIV/AIDS you have at least been affected is true for all of us. None of us seated here can deny the fact that in our families we have each lost a loved one because of HIV/AIDS.'

Seated beside him, I looked up from my notes. 'In our families we have each lost'. His own family? His cousin? A niece, nephew perhaps? Aunt or uncle? Or a mother, brother, father, sister, wife? Perhaps a son or daughter? This was getting close. Uncompromisingly close. And the same applied to the families of every one of the dozen or more judges present?

Even though I had myself lost friends, close ones, seen people die, I felt moved by the candour and urgency of Chief Justice Sakala's statement. When at the end of the long day I took a wintry evening walk through the streets of Lusaka, a gentle, friendly, desperately poor city, strangers met my eye, greeting me with the courteous engagement that seems endemic to African culture. I knew that according to national prevalence rates perhaps one out of every five of the young adults I saw on the street had AIDS or HIV.

By simple average calculation, that made it likely that apart from me at least one other judge in the workshop also had HIV. After my talk, animated discussion followed. Some of the judges spoke of how essential it was to create a climate in which their colleagues with HIV could, like me, speak openly. Yet no one did.

Why? To say that it is because of the enormous stigma still attaching to AIDS is to restate the problem. Why is there such stigma? Stigma often accompanies those diseases that are seen as incurable, deadly, transmissible and disfiguring. But it seems to mark most severely those conditions where the affected person is seen as responsible for getting the disease.

AIDS fits all these categories. As the new drugs become increasingly available, the stigma from incurability will surely wane. (That is why I think the Botswana government initiative on testing is so wise.) As more and more people are diagnosed and speak out, the stigma from silence will also wane.

But there remains something even harder to grapple with. The most inaccessible, the most intractable element of stigma is the disfiguring sense of shame that emanates from the internal world of some with HIV or AIDS. This sense colludes with external stigma, overcoming efforts to deal with the disease rationally, keeping those with AIDS or HIV in involuntarily self-imposed isolation, casting a pall of contamination and silence over the disease.

What causes this shame? I don't know. Without special expertise in behaviourism, psychology or the human soul, I can only cast within myself for some inkling of the truth. And my conjecture, neither novel nor dramatically revealing, is that it is to do with HIV and sex. HIV is a sexually transmitted infection. Perhaps other sexually transmitted infections leave similar feelings. I do not know, since (perhaps ironically) the only one I have ever had is HIV. That has been my fortune, where life's forces have taken me.

Why does sex leave shame? Perhaps it lies in the embarrassment that arises from exposure of what one thought was utterly private and intimate. Perhaps to admit to having a sexually transmitted infection is to be caught out in an act of sexual intimacy, with all its attendant embarrassment – and shame. Pregnancy, too, is a sexually transmitted condition. Women made to wear the scarlet letter in the darker days of sexual oppression might have experienced a comparable sense of shame. But pregnancy is a condition, not an infection. A pregnancy, even one unwanted, even one deemed illicit, holds life and hope and the possibility of growth and fullness. Infection with HIV offers none.

Certainly for me some of the internal shame seemed to come from the fact that my HIV came from a sexual act. In my case it was male to male penetrative sex. When my doctor told me that I had HIV that Friday afternoon in 1986, I was a gay man recently come out. Though always, in my practice and social and political life, I expressed myself as resolutely open and proudly gay, perhaps my sense of shame derived from the fact that my virus was homosexually transmitted. Or so I thought.

But this was wrong. As the African epidemic took hold and spread, it became clear that I was not alone. For millions of heterosexual Africans with AIDS or HIV it is no different. Their shame about HIV is as intense. Even women who say that they married as virgins and remained celibate within their marriages express shame at their condition, and experience the difficulty of speaking out about having HIV.

Perhaps therefore the internal stigma is connected with the merely sexual – not homo- or heterosexual. Perhaps in our deepest selves we feel that a sexually transmitted infection shows others that we have been ‘caught out’. The infection leaves a mark, a stain, a print, linking us back to an act so private, so intimate, so sacrosanct, so emotionally and spiritually unguarded – the moment of sexual coupling – that its external manifestation in an illness, its exposure to the world, is deeply embarrassing and therefore shameful.

Perhaps we still regard ourselves as guilty of some sort of sin of sexual contamination, as marked by moral inferiority, by an uncleanness or exposure of body, and hence a sense of moral inferiority. Some religious moralists inflame all this. They forget that AIDS is a disease. We all do.

These speculations remain painful. And they remain close to me. They must to any South African living in this fearsome, fearful epidemic. In my own household I experienced the telling force of stigma and shame. My garden was tended twice a week by a gentle, smiling man in his mid-thirties. ‘Gladwell’ (as I shall call him) loved its beds and corners and the two kitties and two ducks who share it with us who live there. My housekeeper’s young daughters, Diana and Paulina Kekana, who share the property with me, would follow Gladwell around as he weeded and planted and mowed on Mondays and Thursdays. Over the eight years he worked for me I thought I came to know him well.

At the end of 2000 I saw his health declining. Worried, I asked him about it. Had he seen a doctor? ‘Yes,’ he said, ‘I have been to the hospital. The doctor has given me pills.’ ‘But did he tell you what’s wrong with you?’ ‘Yes, he says it’s TB [tuberculosis].’ This was plausible. For a few months it was. Until it became clear that the ‘pills’ Gladwell said that he was taking were not working. Gladwell was looking tired, becoming thinner. I decided to broach HIV with him. It was long after my own public statement, and Gladwell knew – he had seen – that the drugs had saved my life. More than most people in the country, I enjoyed contacts and access that would ensure drugs for him, if he wanted them. This he also knew.

I took him aside one day.

‘I want to ask you: have you had an HIV test?’

‘Yes, I have.’

‘May I ask what the doctor said?’

‘It was clear.’

‘Are you sure?’

‘Yes.’

‘You know that I can help you, Gladwell.’

‘Yes, I do. It was clear.’

‘But you don’t seem to be getting better. Are you taking your TB pills?’

‘Yes I am.’

‘Why are they not working?’

‘The doctor says I must take them for another few months. Then I will be clear.’

I was sceptical. But how could I override what he told me? Zackie, who uses my home as a base when he is in Johannesburg, asked Gladwell the same questions. He offered to take Gladwell for an HIV test. He repeated the offer to get drugs. Gladwell refused. As he grew thinner, I had to relocate to Bloemfontein, where the Supreme Court of Appeal sits for almost half the year. When I returned at the end of May 2001, Sophie told me that Gladwell had returned to his family in Zimbabwe. At the end of June we received news that Gladwell would not return. He had died, five weeks after last tending my garden.

Did Gladwell die of AIDS? Probably. We cannot know. Gladwell did not want us to know. Yet, as I look back, I see things with greater clarity. I see that I failed Gladwell. My notions of autonomy and respect, so vital in principle, were misapplied in the lee of the jet fuel fires of fear and stigma and internal disempowerment that were consuming Gladwell’s life. Although I thought that I was offering him help, and thereby the choice of living, in Gladwell’s mind he had no choice. The stigma associated with AIDS left him no choice. Like those at the top of the World Trade Centre towers who ‘chose’ the horror of jumping one hundred stories to death, rather than the horror of being consumed by jet fuel flame, Gladwell ‘chose’ to refuse our offers of assistance. He ‘chose’ to return to Zimbabwe to die, rather than let us help him deal with AIDS.

Gladwell died of stigma and fear. Surrounded by fear and uncertainty, he made himself inaccessible to help. He was scared of stigma. But, more disastrously, I think he was also ashamed. Yet I could have done more to reach him. I should have done more to reach him. Looking back, I know now exactly what I should have done. Remorselessly, my conscience enacts it for me. I should have made an appointment with Dr Johnson – on a Monday or Thursday. I should have waited for Gladwell, and told him about the appointment. I should have told him that I was leaving for Dr Johnson in ten minutes. I should have told him he was free not to come. But I was going, and I wanted him to come – I wanted him in the passenger seat of my car. I should have opened the door and invited him to get in. I should have told him that my doctor would diagnose and if necessary treat him if it was AIDS. And that I would help him deal with his fears and loneliness if it was.

All these things I should have done. I did not. I failed Gladwell as much as stigma and the dislocation of his home country and southern Africa failed him. Gladwell is with me, in my thoughts, on my mind, in my reflections. He is with me more than comfort allows.

Looking back to the National Gallery, I can see a little more clearly why my companion and I parted in silence when we could have communed with each other about the fact that each of us had HIV. It was not the stigma of others that silenced us. It was our own. We had not yet accepted that AIDS is a disease. Perhaps we all still don’t.

NOTES

1. Websites with facts on AIDS include <http://www.aidsmap.com/>, <http://www.aegis.org/>, <http://www.cdc.gov/hiv/dhap.htm>, <http://www.avert.org/>, <http://www.thebody.com/index.shtml>.
2. Recent research on improvements in morbidity and mortality as a result of antiretroviral drug regimens from *The Lancet* vol. 362 Issue 9377 p.22.
3. Information on bubonic plague from <http://www.cdc.gov/ncidod/dvbid/plague/>.
4. Meanings of 'shame' and 'stigma' adapted from the Shorter Oxford English Dictionary.
5. Information on Botswana government's 'opt-out' approach to HIV testing, applied since January 2004, available from http://www.health-e.org.za/news/article_audio.php?uid=20031143
6. On apartheid law and resistance to it through law, a reference to Richard L Abel: *Politics by Other Means – Law in the Struggle against Apartheid 1980-1994* (Routledge, New York and London, 1995) is again appropriate.
7. The shameful history of the repatriation of nearly 1 000 Malawian mineworkers in 1987/1988 is fully documented in E Cameron & E Swanson 'Restrictions on Migrant Workers, Immigrants and Travellers with HIV or AIDS: South Africa's Step Forward' (1992) 13, *South African Industrial Law Journal* 496-500.
8. A helpful discussion of stigma is by Jeanine Cogan and Gregory Herek in the *Encyclopedia of AIDS*, <http://www.thebody.com/encyclo/stigma.html>, accessed 15 October 2003. Prof Herek has written widely on the subject: <http://psychology.ucdavis.edu/herek>.
9. The book of essays on gay and lesbian lives in South Africa is by Mark Gevisser and Edwin Cameron: *Defiant Desire – Gay and Lesbian Lives in South Africa* (published in South Africa by Ravan Press, 1994 and in the United States by Routledge, 29 West 35th St, New York, NY 10001).
10. *Hoffmann v South African Airways* is reported in 2001 (1) SA 1 (CC); 2000 (11) BCLR 1235 (CC) and can be accessed at http://www.concourt.gov.za/judgment.php?case_id=12079.
11. Mr Graham McIntosh, MP, of the opposition Democratic Party, wrote to the *Natal Mercury* on 30 April 1999, stating that 'Judge Edwin Cameron's HIV/AIDS

infection is a logical consequence of his self-proclaimed, public and enthusiastic support for and practice of a homosexual orientation'. A media statement dated 10 May 1999 by Mr Douglas Gibson MP, Democratic Party Federal Council Chairperson, recorded Mr McIntosh's public apology.

12. Information on Botswana from UNAIDS, Irin News

<http://www.irinnews.org/AIDSreport.asp?ReportID=2089&SelectRegion=Southern Africa&SelectCountry=BOTSWANA>, accessed on 15 October 2003, and Geoff Dyer '2 in 5' *Financial Times Magazine* October 11, 2003, issue no 25.

13. According to the IFPMA (International Federation of Pharmaceutical Manufacturers Associations) as of March 2004 more than 15 000 Botswanans (Batswana) were receiving medication and 25 000 were actually enrolled in the MASA program. At that time they expected 1 000 new patients to be enrolled each month in the program. See

www.ifpma.org/Health/hiv/health_achap_hiv.aspx, accessed on 5 August 2004.

14. Information on Zambia from UNAIDS and the Zambian AIDS Law Research and Advocacy Network - <http://www.zaran.org>.

15. The address by Chief Justice Sakala on Saturday 21 June 2003 is available at <http://www.zaran.org/judgesreport.html>.

16. Gladwell told me that he came from a Zulu-speaking part of northeast South Africa. My scepticism was aroused when the police repeatedly arrested him as an illegal immigrant. But arrest on trumped-up charges of immigrancy befalls many black South Africans. So when Gladwell produced what seemed to be an authentic identity document, I referred him to a colleague at the Wits law clinic. Sued for wrongful arrest, the police gave Gladwell a favourable settlement of several thousands.