

# Review

## Side Effects

Lesley Lawson (Double Storey Books, Cape Town, 2008)

Reviewed by Karl von Holdt

You expect that reading history, especially recent history, will leave you with a new understanding of who we are, of how the present has been shaped by the past. Lesley Lawson's history of AIDS in South Africa, *Side Effects*, succeeds brilliantly in doing this.

Did you know that in the early 1990s the ANC and AIDS activists together drew up a National AIDS Plan that was regarded as probably the best in the world? Or that Nkosazana Zuma was a key figure in focusing the ANC on the problem of AIDS before the first elections? Or that AIDS activists rejoiced when Thabo Mbeki became president in 1999 and appointed Manto Tshabalala-Msimang as health minister, because both had such a good track record on HIV and AIDS?

I didn't. What happened to derail government's response to HIV and AIDS, and to create the bitter antagonism between AIDS activists and their supporters and Mbeki and Tshabalala-Msimang? The power of *Side Effects* is that it tells a compelling story about these shifts and how they happened.

### PATTERN IS SET

The first rupture happened with the *Sarafina 2* debacle in 1995, when the health department commissioned popular playwright Mbongeni Ngema to write and stage a play with a strong HIV/AIDS message.

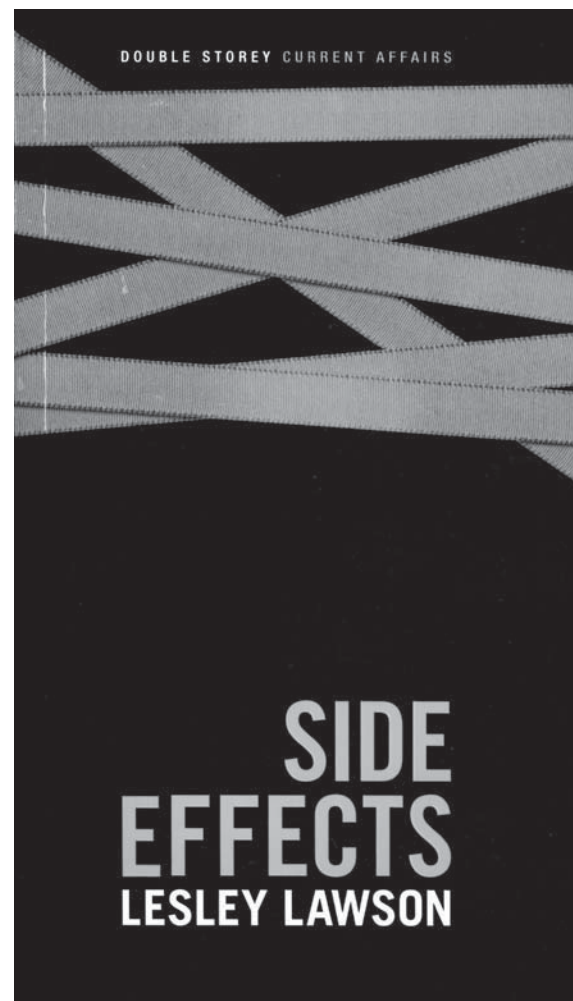
A series of well-meaning blunders resulted in government paying R14 million for a play with weak messages, with inevitable accusations of financial

irregularities. Minister Zuma was attacked by the Democratic Party in parliament and in the press in a paroxysm of vilification and racist imagery. AIDS experts and activists also criticised the play. Government saw them as part of a generalised onslaught which included interests such as the pharmaceutical and tobacco companies that were threatened by Zuma's radical reforms.

This was a turning point, as one of the AIDS researchers comments: "*Sarafina* really broke apart the trust that existed between the medical community, the AIDS community and the government. Completely. It then became very hard to push for anything because there was always seen to be an ulterior motive."

The antagonism generated by the conflict over *Sarafina* framed the next crisis - Virodene. A group of bogus researchers bypassed all research procedures and managed to convince the Cabinet that they had found a cure for AIDS. It turned out that the cure was an industrial chemical which had no impact on HIV/AIDS and was dangerous. Lawson explains government's gullibility in terms of Nkosazana Zuma's ongoing struggle to reform the pharmaceutical industry. Virodene held out the promise of a cheap indigenous cure, and Cabinet fell for it. Years later, Cabinet Secretary Jakes Gerwel could remember the excitement: "The thing I will always remember is that pride in South African scientists."

Once again, the opposition parties, the press and medical experts criticised Zuma. She had



been through this before, though, and being a tough and combative personality she would let nothing shake her confidence in Virodene. By now the pattern was set, and it repeated itself over and over again in the coming years in relation to AZT and nevirapine, drugs which could reduce the rates of transmission from HIV-positive mothers to their children, and over Zuma's threat to make HIV/AIDS a notifiable disease.

## DENIALISM EMERGES

Although there were high hopes in the AIDS community when Mbeki appointed Tshabalala-Msimang as health minister, the pattern of accusation and counter-accusation was quickly re-established. It was fuelled by an acute sense of betrayal on both sides.

By now the AIDS world was split into two orthodoxies – the government line versus the NGO orthodoxy. Government was increasingly paranoid, and felt it was under attack by the forces of white privilege in the media, and in parliament allied with the pharmaceutical multinationals and the Treatment Action Campaign (TAC).

AIDS activists were animated by moral fervour about the growing number of AIDS deaths, and had no time for the hard questions government figures were asking. These were about the affordability of mass antiretroviral treatment, the relationship between AIDS and poverty, and about why HIV/AIDS in Africa was following a different course from the pandemic in the US and other northern countries.

This was the context in which Mbeki, at first reluctantly, and Tshabalala-Msimang turned to AIDS denialism. The denialist clique in the US emphasised the role of poverty in Africa, made radical claims about the toxicity of AIDS drugs (with some evidence for AZT), and denounced HIV/AIDS as a fiction constructed by the pharmaceutical companies. Mbeki found these claims attractive.

The tragedy is that, in his reaction against racial and sexual stereotyping and the dominance of Western discourse about Africa, he turned again to a group of scientific American charlatans. Ironically for his Africanism, he failed to consult our own African experts such as

Professor William Makgoba or the Ugandan scientists who could have answered many of his questions.

Mbeki's denialism was not simply a personal aberration. Lawson argues that during the early days of the pandemic there was a wider tendency in the left, in the media and in the NGOs, to avoid thinking about HIV/AIDS and its catastrophic implications for the new South African democracy.

I was as guilty as anyone of this form of denialism when I coordinated Cosatu's September Commission in 1997 which failed to say anything about the AIDS crisis. By then 23% of pregnant women were infected with the HI virus. At the time we were overwhelmed by the range of issues that Cosatu had to address. The implications of AIDS was simply too great to think about, which does not excuse a dramatic failure in foresight.

Lawson points out that the new government, too, was overwhelmed by the tasks of building a functional democratic state and addressing the legacy of apartheid, and this made it difficult to maintain a focus on combating HIV/AIDS. This general national avoidance of the issue provided a fertile context for Mbeki's more bizarre denialism, as Lawson argues.

## TAC'S ENTRY

In many ways it was the TAC that achieved the most important breakthroughs in the fight against AIDS. It was able to mobilise medical professionals and people living with AIDS and to break the walls of isolation they experienced in the face of a seemingly uncaring government. An AIDS counsellor living with HIV/AIDS told Lawson: "It was just a blossoming excitement. It was a new day, a new era... for the first time I saw the

unity between healthcare workers and civil society... you could feel the spirit."

Using an innovative combination of public protest and legal strategies, the TAC played a crucial role in undermining the legitimacy of the pharmaceutical industry and pressurising them to withdraw from their challenge to the Medicines Act in 2000. In 2001 it went to the High Court, claiming that the government had a constitutional duty to provide nevirapine to prevent mother-to-child transmission and won. After a series of appeals and counter-appeals, the Constitutional Court upheld this victory.

By this point within the ANC, leadership opposition to the denialism of the president and health minister became great enough to dictate a shift in policy. Lawson reveals that this shift was influenced by a growing recognition that the scale of death in South Africa, if AIDS was left untreated, would have a devastating impact on socio-economic development. Government announced large-scale funding for a massive roll-out of antiretroviral treatment for those living with AIDS.

## FASTEST SPREADING PANDEMIC

This seeming-victory is not the end of the story. Apart from the challenges of gearing up a dysfunctional public health system to roll-out treatment on such a scale, there was the challenge of preventing the spread of HIV/AIDS. AIDS prevention strategies in South Africa have been relatively ineffective, and we have the fastest spreading AIDS pandemic in the world.

*Side Effects* explores the reasons for this. Violent conflict that attended the end of apartheid, institutionalised migrant work, rapid urbanisation and the breakdown of

community and family structures, poverty, unemployment, transactional sex, and the prevalence of domestic and sexual violence, all make South African society uniquely susceptible to the spread of HIV. As Dr Liz Floyd, head of the Gauteng government AIDS directorate, tells Lawson, conventional prevention strategies which focus on changing individual behaviour make little headway against the structural disempowerment of women and alienation of the youth. "We have to reinvent prevention," she says arguing that sex cannot be treated only as a medical event (as a moment of exposure to infection) but must be seen as a social event structured by power relations.

Lucky Mazibuko, the courageous columnist for the *Sowetan*, points

towards the implications of this: "HIV is not a problem for me. The problem is the family structure. There is no harmony, there is no peace. There is a lot of discomfort and lies and secrets... we grew up in broken homes... so the fabric of the family is shaky ground and when AIDS creeps in, it causes all these divisions. What we need now is a societal revolution, to create a new mentality and identity among our people. A cleansing of some sort... a healing."

Lawson has written an extraordinarily powerful biography of a disease interspersed with agonising personal biographies. But *Side Effects* is more than this, it is a biography of our society. It is a story of denial, foolishness, prejudice, suffering and courage.

It is also a story of the struggle for liberation, the persistence of racial confrontation and stereotyping, and of how the discourses of struggle we inherit from our past can blind us as well as facilitate collective mobilisation. It is the story of reluctant state structures and profound social crisis and fragmentation. It is the story of a specific crisis concerning an awful disease, but it can tell us much as well about other social epidemics – crime, and most recently the wave of xenophobic violence – and our failure to address these.

Read *Side Effects* as soon as you can.

LB

*Karl von Holdt is acting director of the Sociology of Work Unit at the University of the Witwatersrand.*

## Excerpt from 'Side Effects'

*Personal Biography: Florence*

Florence Ngobeni was 23 years old when she fell pregnant and discovered that she was HIV positive. She has written a moving account of her experiences:

"I called my baby girl Nomthunzi, the Zulu word for shadow. At the age of three months she became ill. It was only when she was tested for HIV that I found out that I was HIV positive. My partner George, the father of my child, died of AIDS in the same month that I found out that our baby was HIV positive.

People used to come to my house to see a child who was dying of AIDS. Watching her die slowly every day was heart-breaking. Nomthunzi died in February 1997; she was five months old. I cried day and night, surviving on little sleep and less food. Fortunately, some of the neighbours let me play and read stories to their children, and this was a healing process for me and I continue to be grateful to them."

Just a few months after her baby died, Florence became a counsellor at the Chris Hani-Baragwanath Hospital's Perinatal HIV Research Unit. Increasing numbers of women were coming to the unit for help, but without drugs there was little that could be done.

"Sharing my personal experiences during counseling sessions has helped both my patients and me. People feel that it is the end of the world when they find out that they are HIV positive. I try to help them continue their lives by sharing some of my past and help them tread this path of survival gently and carefully. I encourage them to find the courage to report cases of rape and violence and to address issues of gender power by inviting their partners for counseling."

Florence became a prominent spokesperson for women living with HIV, giving educational talks at home and abroad. "And that's a choice. I dedicated my life to making sure that somebody who's HIV positive can be empowered to know that they can make the difference to their own lives, to make sure that they can negotiate safer sex."