



## AIDS SURVIVOR SKETCHES TREATMENT PITFALLS

A middle-aged Gauteng biologist, now leading a full and normal life after antiretroviral (ARV) drugs rescued him from full-blown AIDS and a certain death, is using his broad experience to counsel doctors on the pitfalls of treating people who are HIV-positive.

Peter Adams speaks passionately about his medical nightmare and confronting his own mortality after being diagnosed HIV-positive in 1995 and beginning a roller coaster ride during which his CD4 cell count dipped to as low as 69 (viral load 446 000).

He virtually loaned himself to science as an ARV drugs guinea-pig, in the process saving his own life and helping doctors discover a great deal about resistance testing.

Today he religiously takes his 10 pills a day, his cell count is 853 and still rising, and his viral load is undetectable.

His doctors confidently predict a 1 000 CD4 count within eighteen months as his immune system continues to recover on the custom-built drug regimen they have settled on. His prognosis has been revised from seven years (when he first started on ARVs) to 20 years.

Adams recites a litany of harrowing experiences as largely ignorant doctors battled to come to terms with HIV-positive people when the epidemic first erupted in this country.

His lessons remain highly relevant, especially to doctors in the public sector where the provision of ARV drugs by the state is imminent and to many private practitioners only now coming to terms with appropriate holistic treatment for HIV-positive patients.

Adams helped establish Treatment Helpline Direct, ran a drug adherence programme for a major drug company, has written 60 patient information sheets (translated into several languages) and is a regular lecturer at

the Foundation for Professional Development.

His advice does not always go down well with doctors, for reasons varying from professional pride to occasional downright arrogance. Especially when he tells them that they should be dealing with all chronic conditions 'by going back to the principles of treatment 60 years ago — when you were the family friend who brought people into the world and wrote their death certificates'.

'I tell them it's a journey you go on together and that if they don't strike up a relationship from day one, especially with this disease, they ultimately risk losing the patient.' He believes the pandemic will ensure that the practices that suffer the most will belong to those doctors who don't have the time or the patience for people living with HIV.

Like the doctors he teaches, Adams has been on a steep learning curve.

Unlike most of them he has been on the sharpest end of the virus and borne the stigma of those infected by it.

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As many of his close friends died around him between 1981 and 1995, he remembers being tested for HIV without his permission, being sent to a liver specialist when his liver began swelling and re-admitting himself to hospital with severe breathing difficulties.

'I lived in total oblivion and denial for many of those years. I once entered the emergency room and threw up at one senior doctor's feet.' He said in a loud voice that everyone could hear, 'this is either cancer or AIDS'.

A deathly hush descended on the busy unit and Adams was rushed off for chest X-rays before being admitted to a private ward where he was told that he had pneumocystis and oral thrush.

'I noticed that they all stood at the foot of the bed, wore rubber gloves and that the other patient who was in the ward with me was sent out.'

His counselling consisted of being bluntly told he had full-blown AIDS and that he'd have to change his lifestyle.

'They said that from now on I'd have to wash my apples and my lettuces — they just simply didn't know how to behave,' he said.

He was discharged after six days, immediately went 'into the shakes and hot and cold sweats', and promptly re-admitted himself.

He was finally wheeled out in a wheel chair, having lost 13 kg and 'looking like something out of a concentration camp'.

His own doctor was at a loss and referred him to Dr Dennis Sifris, who after initially giving him three months to live, was to prove pivotal in Adams' survival.

'When he advised me to sort out my affairs, say my goodbyes and take a holiday and enjoy myself, I angrily gave him the two fingers and told him I'd be back.'

After a further two-week course of Bactrim, Adams returned to Sifris and begged him for some of the then limited available drugs.

He was initially given AZT and improved — before suddenly declining again.

Sifris had in the meantime heard of a clinical ARV trial (1996) but had one problem — Adams' CD4 count was above 300, too high to be considered a candidate.



The doctor/patient duo took a decision — Adams came off treatment so he could qualify.

'When I dropped below 250 I was the happiest man in the world. Not only was I on the trial, but the drugs were free.'

The double-blind trial used AZT, 3TC and nevirapine but because Adams was already AZT-experienced, d4T was used.

With the importance of adherence not yet fully established, Adams first improved rapidly, then failed.

'I was pill-adherent but not time-adherent and there was no extensive counselling then.'



Peter Adams.

A fourth drug, indinavir, was added to his failing regimen and he promptly ended up in hospital with kidney stones.

'I once again went through that embarrassment and indignity of having to tell the hospital I was HIV-positive and in a clinical trial on ARVs they'd never heard of.'

When Adams ran out of treatment options in South Africa, he travelled to Europe in a last-ditch attempt to save his life.

'It was nerve-wracking. All I was concerned about was keeping it from my (British) Mom and wondering how she would cope if she found out,' he said.

Adams and Sifris sourced a successful treatment, but not after a gruelling and expensive session of more tests including one for resistance.

***'Your first-line treatment is not only your best chance of suppressing the virus but it's the most efficient from a psychological point of view as well.'***

Adams had resistance to AZT, 3TC, indinavir and initial cross-resistance to the protease inhibitors, ritonavir and saquinavir — but none to nevirapine.

'Every time you fail you have to come to terms with your mortality all over again and then pick yourself up. Each time you fail it gets worse and the sense of hopelessness looms. You think, here we go again, are these drugs really going to work?'

Adams said this is why it is so vital to counsel patients from the outset of treatment. 'Your first-line treatment is not only your best chance of suppressing the virus but it's the most efficient from a psychological point of view as well.' In the USA 5% of all new HIV infections are drug-resistant strains while in Europe 11% of all new HIV infections are from a broad drug-resistant virus.

Adams is now in his sixth year of continuous undetectable viral load.

Research (Fiona Lamp *et al.*) has shown that if the virus remains undetectable in patients for three and a half years and adherence is excellent, chances of viral rebound are negligible.

Adams says every HIV-positive person has the potential to achieve what he has.

He handles patient-advice-resistant doctors with aplomb.

'A lot of them initially didn't like the idea of a patient presenting,' he says.

One drum he beats loudly and consistently is that of doctors 'coming off their pedestals'.

'If you want your patient to adhere and co-operate you've got to get out from behind your desk and stand next to them — otherwise they'll just tell you what you want to hear.'

Becoming a patient's friend does not imply any loss of status, he adds.

It might save their life.

Don't take Adams' word for it.

Ask Sifris.

Chris Bateman

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