AIDS AND DISCRIMINATION (1999)

In August 1999 I gave this speech on AIDS. The subject was then very topical and socially divisive. My conservative contacts took a punitive view of the HIV infection generally; I did not.

A metaphor came up in a film called Il Postino. It was a magic film in which, inter alia, the man pursued the woman with metaphors taught to him by a poet. So what is a metaphor? It is defined in the dictionary as:

Application of name or descriptive term or phrase to an object or action to which it is not literally applicable.

HIV/AIDS has been a metaphor.

Now what do I mean by that? Well, the infection has exemplified some issues and problems. Face HIV/AIDS and we were facing those issues and problems. We had no choice. The infection has forced us to address some old issues in new ways to the benefit of a wider group than just those with the particular virus infection.

One example has been in the area of discrimination. You have not had a session devoted particularly to this matter. Discrimination is as old as humankind and has appeared throughout history. But in 1992 I sat on the Anti-Discrimination Board and we found that discrimination against men infected with HIV was so great that we wrote a book about it and formulated some rules about discrimination that have now been accepted widely.

By examining discrimination in HIV/AIDS, we learned something new about the extent of discrimination in society. We learned about it as a general problem—and learned how to do something about the general problem by learning how to address discrimination against people infected with the virus. So today I will take the analogy of the metaphor a little further.
Let us digress a little. Randomised clinical trials were the rage over a quarter century ago. They were the way to determine if something worked. They were referred to often as ‘the gold standard’. The way they operated was simple. One divided a sample into two by some random method and if possible one had a random sample of the population under study. One gave the treatment being tested to half the group and did not give it to the second half. One then compared the results in the two groups and showed whether the group receiving treatment did better than the control group. Louis Pasteur used the randomised trial with devastating results to prove that he could prevent anthrax in sheep.

When HIV/AIDS appeared, scientists had the problems of treating the infection and of preventing the infection. They thought it would be business as usual, that randomised clinical trials would allow a simple determination of whether or not a treatment worked and whether or not a prevention program was effective.

But HIV/AIDS was *sui generis and* it occurred in a special population. There has seldom been an infection like it. It is a slow virus and the infected people remain well for many years. Not only that, but antibody testing allows people to know that they are infected and that they will die eventually. The infection is serious and almost uniformly fatal. And they know this fact for many years. It tells you a lot about the courage of people just to realise that. Mind you, life is fatal too. It has been described as a fatal sexually transmitted condition—but more of that later.

Not only that but the infection occurred in a special population. The people in Australia who became infected in the 1980s were gay men—younger, articulate, educated men who knew how to use the media. They were not prepared to sit quietly and do nothing, to die with stoic indifference while society pretended that they did not exist.

Let me tell you just how much denial the community is capable of. First, the community dislikes having to face and consider deviance, sex and death. HIV/AIDS actually involves all three. President Reagan managed not to allow the name of the disease HIV/AIDS to pass his lips in five years—quite an achievement in a nation where infection is widespread and where the epidemic was raging even while he was refusing to utter the name of the disease. If any of you is interested in HIV/AIDS you may care to read the book *And the Band Played On*,1 which gives a graphic history of the epidemic.

But back to denial. Denial is a human coping mechanism—just pretending something does not exist when it does. We all use it. We teach little children to use it. Many of you deny that the old men and women you see are you with

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1 Shilts (1987).
50 years added. Many of you deny (or ignore) the fact that each of you will die. You laughed about life being a fatal sexually transmitted disease, but you probably felt it did not apply to you. If so, you were using denial. It is not that you are bad—it is simply that it is easier to leave those matters to another day and to pretend that they do not exist now.

Now let me come back to the randomised clinical trial and tell you about a famous trial in the 1960s. Up to this time we did not really know whether treating high blood pressure made a difference. In that famous trial some investigators divided a group of people with high blood pressure into two groups. One group had treatment for hypertension; the other group did not. The results were dramatic. Deaths from heart attack and stroke were high in the control group and low in the treatment group. So, for ever more, from the day that the trial was published, we knew that treating elevated blood pressure was worthwhile.

Now you help me. I will assert that the trial was ethically disgraceful. You tell me why.

When HIV/AIDS appeared, gay men, articulate and educated, examined the randomised clinical trial and did not like what they saw. They understood that if a treatment was ineffective, then no-one would be better off or worse off. But if a treatment was effective, then half of them would benefit and half of them would die as usual. They reasoned that the investigators would use death, or the complications of the infection, as the ways of assessing effectiveness. And they realised that they would be helping, not themselves, but some future generation of people, to get more effective treatments.

They denounced randomised clinical trials. They demanded a different kind of trial. They demanded trials with proper informed consent. They questioned the levels of evidence which medical scientists required. They demanded that everyone got effective treatment immediately. They got together in groups and pooled tablets—so that no-one got dummy tablets and everyone got a half dose of the active drug. They substituted a new equity for old benefits. They emphasised individual needs and rights against group needs and rights. They preferred present rights over future rights. They also demanded in Australia that public subsidy be made available to pay for their drugs. They used HIV/AIDS as a metaphor for understanding clinical trials.

Clinical trials have changed as a result. Not just for HIV/AIDS, but for everything. Today, a control group will receive the best standard treatment. Today, a running statistical assessment will be made so that people can stop a trial early—as soon as a watertight result has been obtained. Today, proper written informed consent is mandatory and enforced by law. Gay men forced
us to see, almost for the first time, that the ‘gold standard’ we were using was unfair to people being tested today, even if the system helped future cohorts of sufferers.

Perhaps it was just time, but perhaps it was this group that led us towards the use of meta-analysis in which we combine many small trials to allow the detection of results which were ‘hidden’ in some smaller trials. And thanks to the HIV/AIDS lobby, we now have a better understanding of ethics, of the need for ethics committees, of the need for investigators to listen to those committees, and so on. So clinical trials were altered by the virus, and our understanding of the issues raised by trials was advanced.

Now let us turn to vaccine trials. Early in HIV infection the virus is present in the blood. Late in the disease, virus is also present in the blood. In between, virus is hidden away. So there are two ‘windows’ available for a vaccine to work—at the two times when the virus is present in blood.

Classically, vaccines have been used for the first purpose, to prevent infection. Most childhood vaccines do not prevent someone picking up the agent; they ensure that it can be destroyed quickly and efficiently by the body. So for a long time now we have been searching for vaccines against the HIV. Work continues and vaccine possibilities are becoming more and more practical and likely.

And there are two types of vaccines: those to prevent the illness by destroying virus when first it enters the blood and those to help treat people by destroying virus late in the disease when it ventures back into the blood.

But there is a great disadvantage of vaccines for this disease. The test for HIV is based on the presence of antibodies. Antibodies develop within (say) eight weeks of meeting the virus—22 days if you followed a recent Melbourne blood bank story. We say someone is HIV positive if they have antibodies to the virus in their blood.

And it is the presence of HIV positivity that is the basis of much discrimination. So anyone receiving a vaccine is likely to develop antibodies and to become HIV positive, even if they have never been exposed to the virus naturally. We expect that those people, who might not be infected, will then, sadly, be subject to all the discrimination that society levels at people with infection.

The question is: will the extra discrimination that we know follows people who are HIV positive make worthwhile the benefits that a vaccine might confer? Will a person’s life be so awful from mindless discrimination in housing, in employment, in police services, in medical services, in dental services,
in hospital services, in education, in funeral services, in ambulance services, in the military, and so on that the benefits from vaccination will just not be worthwhile? This is the question that continues to bug us.

Today, treatment has advanced and HIV/AIDS is rather like *Diabetes mellitus*—a chronic illness with bad effects but one lasting a long time for which much can be done. Complicating the picture is the fact that the rate of infection has dropped now in Australia to about 600 new infections a year. It is possible that denial will rule again and that people will pretend that AIDS does not exist. It is almost as if we never learn.

So today we have considered several matters: first, that the traditional clinical trial is no longer acceptable, and secondly, that discrimination against HIV infected people is widespread and not yet coped with.
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