

From Chapter 3: Like Medicine Six Hundred Years Ago

At the beginning of 1981, Dr Tony Pinching was working in his lab at Hammersmith Hospital, London, when he got a call from a friend in the United States. Though he originally set out to be a neurologist, Pinching, 22, was now working almost exclusively with diseases that affected the immune system. His friend in America was working in a similar field and had heard at a meeting some interesting news of specialists who were seeing rare diseases that had no apparent cause and pointed to a total immune system breakdown. They were baffled: Why were these guys getting so sick?

Pinching hoped this might turn out to be a useful mystery. The biology of immunosuppression had reached a sort of plateau: so much was unknown about the immune system, about cell information and function, about the correct use of steroids and other treatments; they needed either some more advanced techniques or some new ideas. He thought: 'This new disease, whatever it was, might tell us something.'

A few months later, after the first clinical reports of active homosexuals falling sick in California and New York were published, Pinching received two more memorable phone calls. A houseman at St John's Hospital, London, asked if Pinching could run any tests on a patient he had with a skin disease, probably a cancer infection. The second was from Willie Harris, the senior genito-urinary physician at St Mary's. Harris had heard that Pinching might soon be joining St Mary's as a consultant in clinical immunology and told him about a group of patients at St Mary's Praed Street Clinic. These were sexually active gay men, regular users of recreational drugs, no strangers to sexually transmitted disease – in fact just the sort of people who were becoming unwell in America. The thinking was: if this disease is going to happen over here, we should get in quick and investigate what's going on. If it wasn't going to happen, then the reasons why not might also be interesting.

So Pinching joined the St Mary's virologists and microbiologists on the study, which soon included more than a hundred men answering intimate questions and submitting to endless blood tests. Funding of the study, the first in Britain, came initially from existing resources and later from the Wellcome Trust and the National Kidney Research Fund. The Medical Research Council (MRC), the government-funded body, also considered supporting the project, but then turned it down. The official reason was that the study was too wide-ranging, but there was another explanation too: 'They thought it would be purely an American thing,' one of the St Mary's researchers remembers. 'They said, "We haven't got anybody ill, it's not important. If we do get people, we'll fix it later."'

The initial results of the study were inconclusive, but gave sufficient cause for concern. The men showed none of the Aids marker illnesses, but there were plenty of immune cell abnormalities and evidence of decreased T-helper cells (the standard marker of the body's ability to fight disease). In their report, the researchers concluded that the weakened immune systems they had detected might represent 'a latent phase of Aids'. They didn't have to wait long to be proved right.

Within weeks, Pinching had seen his first Aids patients. Pneumocystis pneumonia, then Kaposi's sarcoma, then encephalopathy, a progressive brain disorder. Most fitted the pattern: many partners, some travel to the States, some previous STDs. Many died within weeks of admittance.

Within St Mary's, most of Pinching's fellow doctors found it hard to come to terms with this syndrome; it was still an American thing, still a freakshow. So he decided to bring a patient along in person to one of the hospital's case presentations, a regular forum for rare disorders. Often this kind of thing was just done with slides, but Pinching mentioned to one of his patients that it might help demystify matters:

I just wanted them to know that this wasn't a Martian. This was an ordinary bloke, only he happened to be a gay man, so what. So he came in, and I can still hear the drawing in of breath, the hush that descended. Here was the moment of reality for that audience; this wasn't just a strange disease that we read about in the journals with a strange sort of people who do bizarre things. This was an ordinary bloke, you could have met him anywhere, and he was terribly straightforward.

Across town, at the Middlesex Hospital, Professor Michael Adler, a genito-urinary specialist, was also seeing his first patients. 'I can remember his face,' he says of the very first, 'I can remember every sort of skin lesion he had.' And he can remember the prejudice shown towards his patients:

It was very difficult to get them hospitalized, it was very difficult to get patients treated as normal human beings. People were frightened, they thought it was contagious, the patients had to be put in side wards, you couldn't get the domestic staff to go in, you couldn't get the porters to go in. We treated people extremely badly. It was like medicine six hundred years ago.

Dr Ian Weller worked in the same department. Weller was still relatively new to infectious disease, but in February 1983 he had attended the first postgraduate course on Aids in New York, where he had visited the Memorial Sloan Kettering Hospital and the Veteran's Hospital and had seen the rising toll first-hand. One of the first things he read on his return to London in March 1983 was a brief note in the *Lancet*. The headline read: 'Acquired Immunodeficiency Syndrome: No UK Epidemic'. It explained how serious Aids had become in the United States, but quoted a statement from the Communicable Disease Surveillance Centre which said that it 'has not so far detected an important problem in England and Wales'.

The following week Weller met Carl and Ray, his first Aids patients in the clinic. In the hospital he recalls

Enormous problems with staff at all levels. Every step of the way was a battle. The fears then were not necessarily unfounded, as we didn't know what we were dealing with. There were doctors and surgeons deciding not to do a certain procedure because it was deemed to be 'inappropriate'. This was largely influenced by an anxiety or fear. This fear would go right across to the domestic staff. One night I was sitting

in a patient's room, and this hand came round the door with food on it, and just dumped it. I laughed with the patient, who said 'it happens all the time.' Within five minutes a bunch of flowers flew across the room – whoosh! That time I didn't even see the hand.

Whenever that happened we just got a hit squad together to deal with the specific problems when they occurred, just to explain to people. At one hospital there was even a move to have a committee of three wise men who would meet to decide whether a given operation was appropriate or not. As if the physician looking after the patient couldn't tell.

In July 1983 Weller, Adler and others applied to the MRC to fund a cohort study of men each dayxxxx??. Again the MRC turned it down. They reapplied, and a year later were awarded £160,000 - about £110,000 less than their original request. It was an intensive study, examining many aspects of natural history and immune abnormalities, and it attempted to establish an antibody test for markers that might identify patients at risk. As in all these early projects, the patients were open about their lifestyles and eager to help. 'Like us,' Weller says, 'they were optimistic at that time that the people who were dying were going to be the minority. They thought, "It's not going to happen to me." There was a wonderful optimism. Slowly as the natural history studies published their results, we saw the doubling time of cases, and you suddenly realize what sort of epidemic you have.'

It wasn't long before these doctors began seeing women with Aids. The first case Tony Pinching looked after was a heterosexual English housewife who had one partner – her husband:

It turned out he'd been having a few others, mainly in Africa, on the side. And she told us lots of things about herself and it was quite clear that she'd just had conventional, heterosexual intercourse and she'd never injected drugs, and everything was unremarkable. That told us that there was going to be a heterosexual epidemic. I didn't need any more convincing, though it took a lot of people a bit longer to convince our health officials, and possibly quite rightly so. But as a clinician you're in a privileged situation of hearing very early exactly what was going on.

Taken from *The End of Innocence: Britain in the Time of Aids* (Faber, 1994)