

AIDS - The First 20 Years

On 5 June 1981, a medical journal reported a mysterious illness that had killed five young gay men in Los Angeles. A lot has happened since then.

The Observer, June 2001

Part one: The Memory

1 Dan versus Danny

Soon it will be time for Danny La Rue to sing. At the Pleasance theatre in north London at the beginning of May 2001, the 73-year-old entertainer stands onstage in a blue dress and high white hair and announces that he has been in show business for 51 years. He has some personal observations about Bill Clinton ('He propositioned me in the Oval Office!') and Zsa Zsa Gabor ('She was wearing so many feathers you could have stuck them up her arse and she'd have flown home'), and then he launches into a suggestive song he used to sing on the Good Old Days. As he sings, the occasional glittery bead and sequin drops from his dress. This, bizarrely, is rather good entertainment, and is relished by an enthusiastic audience of sweet-smelling moneyed gay men, tonight being a fundraising night for the Aids charity Crusaid.

Tickets cost £30 per head, including a smoked-salmon titbit in the interval and a post-show video-signing session with Danny in the foyer. The night is divided into two parts. In the first, 'Danny La Rue' shimmies around doing his rude-marrow song and Marlene Dietrich routine, and in the second 'Dan' comes out in black shirt and gold medallion and slightly less make-up, and talks about his friendships with Barbara Windsor, Ronnie Corbett and his eventful and unique career as an actor, singer, club owner, window dresser and drag artist.

'I have never taken a frock home - not once,' he says at the very start, lest anyone suspect he actually wore this stuff around the kitchen. 'When I did Through the Keyhole, some young TV girl asked me if I would come to the door wearing a frock and I said: "Fuck off!"'

He talks about his religious upbringing in Ireland, his memories of 60s Soho, his loving relationship with his manager Jack. He is prompted by questions from the audience, written on pink cards during the interval and collected in a champagne bucket. 'Ask him anything you want!' the invitation said, so I asked him a question about Aids.

I wrote, 'This is a big night for Crusaid. How has your own life been affected by Aids?' I was told that the questions were edited before his warm-up man put them to him on stage, so I wrote on the top of it, 'I love you, Danny! Please don't ignore this one!' He didn't, but there was quite a pause before he answered.

'I have a Filofax,' he began. 'A very tired one? On one of the pages all my friends have gone, and every time I try to put a pen through their names I find it impossible. One of my dearest friends, Wayne King [the flamboyant pianist], fell very unwell in Australia last year. It took me 31 hours to get there, and I used that time to prepare myself. He used to be such a brilliant, handsome man, and when I met him he was very gaunt. He was about four or five stone. I spent 11 days from morning to night with him, and we got him walking on two sticks. But then I had to leave, and I was working on a cruise ship, and I got a call in the night that Wayne had passed over. He was two-and-a-half stone. Bobby Crush was also on the cruise, and he did a tribute to him - Wayne had a big hit with 'Cavatina', and when Bobby played it, the audience went mad. Wayne would have loved it - he was very vain and wonderful. Our friends?' At this point, Danny La Rue's voice begins to crack. He resumes: 'This dreadful, dreadful disease that has taken so many people away. I don't think anyone in this room tonight hasn't lost a friend. One day, probably, it will all be something silly and we'll all be fine. I have a deep feeling that it will all be fine.'

2 The toll

At the head office of the Terrence Higgins Trust in Victoria, the prognosis is a little more precise. It is exactly 20 years since the first reported case of Aids. Nick Partridge, the Trust's chief executive since 1991, has a file above his desk containing the most recently published Aids and HIV tables. These figures, compiled by the Public Health Laboratory Service and the Scottish Centre for Infection and Environmental Health, contain the cumulative data to the end of March 2001. In the coldest of lights, they tell the history of the disease over the past 20 years.

This is what the figures show: there have been 44,988 reported cases of HIV in the last two decades, of which 14,038 people have died. Of the HIV total, 25,806 are believed to have resulted from sex between men, 11,667 from sex between men and women, 3,695 from intravenous drug use, 1,351 from blood-clotting factor used predominantly to treat haemophilia, 751 from mother to baby transfer, and 314 from blood transfusion and tissue transfer (1,404 remain undetermined). Of the 44,946 case reports in which sex was stated, 36,398 were men, 8,548 women.

We may view these figures in a number of ways: a terrible tragedy, an awful waste, the effects of HIV/Aids stretching far beyond those immediately affected. But we may also view it as a relatively lucky escape. For a number of reasons, the UK has not suffered from the devastation that some once feared. The current rate of HIV infection is still a serious cause for concern, but it is nothing compared

with the situation elsewhere in the world. The United Nations estimates that 36.2m people worldwide are presently living with HIV, and that 20m people have already died from the virus. Cumulatively, this is almost as many people as the entire population of the United Kingdom. At the end of 2000 it was estimated that 25.3m people in sub-Saharan Africa had HIV, 5.8m in South and Southeast Asia, 1.4m in Latin America, 920,000 in North America, 700,000 in Eastern Europe and Central Asia, 640,000 in East Asia and the Pacific, 540,000 in Western Europe, 400,000 in North Africa and the Middle East, 390,000 in the Caribbean, and 15,000 in Australia and New Zealand.

The stories that come out of Africa - of negative population growth, of battles with the drug companies for cheaper drugs, of the desperation for even the most untried of vaccines - are the big Aids issues, and appropriately figure large in today's news agendas. But the story of Aids in the UK is an instructive one. From it we may learn much about the nature of panics, about health education, about how a government talks to its citizens about sex and what citizens do when they find out that sex can kill. And in a troubling way, we can learn that even in the UK the story of Aids is far from over. This year it is predicted there may be more than 3,000 new, avoidable infections. Last year, when many with Aids were benefiting from great advances in drug treatment, there were 3,434 newly reported cases of HIV. This is more than in any year since the epidemic began.

When Nick Partridge, a gay man, considers the figures in his file he remembers, among many things, a trail of disaster. 'The really key thing to remember is how young everyone was, and how unusual and shocking it was for us to see people of our own age becoming so sick, so thin, and dying so quickly. The fact that it was also transmissible, and transmissible through the most intimate part of our lives, quadrupled that shock. Before Aids, the doctors in the clinics and hospitals were used to working in an environment where mostly they were helping people get better.'

Above all, Partridge remembers the relentlessness: a continuous stream of bad news, new terrors, heartbreaking funerals. 'For a long while, Aids was the only thing in our lives.' And for many months, the vast majority of the country knew almost nothing about it.

3 The terror

The first indication that something was wrong came from America on 5 June 1981. On the the second page of the Morbidity and Mortality Weekly Report (MMWR) from the Centers of Disease Control in Atlanta, there was a straightforward story that a rare illness, *Pneumocystis carinii* pneumonia, had killed five young gay men in Los Angeles.

The pneumonia was not yet linked to another unusual symptom that had also struck gay men in San Francisco and New York, Kaposi's sarcoma. This was a cancer that usually only afflicted old men from Mediterranean countries. It would

be two years before a causative agent, which came to be known as human immunodeficiency virus (HIV), was isolated.

Within weeks of the MMWR bulletin, the gay community began to do what it had learnt to do very well: talk in secret. Before Aids was Aids it was a 'gay syndrome' and then GRID, (gay-related immune deficiency) and then ACIDS (acquired community immunodeficiency syndrome). There were many possible causes: recreational drugs, a genetic predisposition, an overload of familiar sexually transmitted diseases that had finally wrecked the body's defences. There seemed to be one seriously advocated method of prevention: don't have sex with Americans. Within a very short while, British gay activists and medical researchers realised that Aids was already among them.

In 1981, Dr Tony Pinching, a 33-year-old specialist in the workings of the immune system, helped to conduct a study at St Mary's Praed Street Clinic in London. One hundred sexually active gay men were asked intimate questions about their lives and took a battery of blood tests. The men displayed none of the Aids marker illnesses that had been evident in the United States, but their blood samples showed many immune cell abnormalities and a decreased ability to fight off disease. Within weeks, Pinching was seeing his first Aids patients.

These men were the cause of much speculation, and so Pinching asked one of them to accompany him to a case presentation for fellow doctors. 'I just wanted them to know that this wasn't a Martian,' he remembered. '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.'

In London's genito-urinary medicine (GUM) clinics, highly confidential places frequently attended by those with infections such as syphilis and gonorrhoea, gay men began appearing with purple lesions on their faces and bodies, the telltale indicator of Kaposi's sarcoma. 'It was very difficult to get them hospitalised,' one GUM doctor told me. '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? It was like medicine 600 years ago.'

Another young doctor, Ian Weller, remembered: 'The fears then were not necessarily unfounded, as we didn't know what we were dealing with. One night I was sitting in a patient's room [in hospital] 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.'

Not long afterwards, Pinching saw his first case of heterosexual Aids, an English

woman whose husband had been having sexual contact in Africa. 'That told us that there was going to be a heterosexual epidemic,' he says, although it took time convincing government health officials. One said, 'Where's the epidemiology?' Pinching replied, 'Well, I'm telling you the anecdote, and today's anecdote is tomorrow's epidemiology. Your move.'

One of the earliest male patients was 37-year-old Terry Higgins, a computer programmer. His partner, Rupert Whittaker, recalled that Higgins had complained of frequent headaches and that he was prone to collapse and unfamiliar symptoms. At the hospital, Whittaker remembered the doctors as dismissive: 'I was not next of kin - I was not worth considering.' One of the house staff told him that if he wanted more information he should wait until the case was written up in one of the journals.

Five months after Higgins's death in July 1982, Whittaker and a group of his friends founded a new charity to raise money for research, beginning with a themed party at the gay nightclub Heaven. The news of the charity, and the fact that three other Londoners had died from Aids, was announced in Capital Gay under the headline 'US Disease Hits London'. Another publication, Gay News, wrote how most people still thought of Aids as 'a media import, like Hill Street Blues'.

The early meetings of the Terrence Higgins Trust took place in the London flat occupied by Tony Whitehead. Whitehead was a teacher and a member of Gay Switchboard, and along with a few friends, a few of whom were medics, he organised more fundraisers and public meetings. He also helped produce the Trust's first Aids information leaflet. It began by outlining the symptoms: swollen glands, fever, night sweats, pink to purple lesions. Other sections were helplessly naive. There was no mention of condoms or the risks of anal sex. 'Have as much sex as you want,' it stated, 'but with fewer people and with **HEALTHY PEOPLE.**' The leaflet concluded with the message 'Help yourself!' The subtext was: because nobody else will.

'I don't mind telling you, I was very, very scared,' Whitehead remembered a few years later. He described the educational and support work of the Trust and other gay groups as 'essentially a crucial survivalist policy formulated by a community that believed it was being left to slowly die'.

In the spring of 1983, BBC Horizon made a film called *The Killer in the Village* concerning the situation in the New York. It was one of the first programmes with the message that gay men's lives were worth taking seriously, and it raised many unanswerable questions. Martin Amis reviewed it in *The Observer*: 'With Aids? it seems to be promiscuity itself that is the cause. After a few hundred "tricks" or sexual contacts, the body just doesn't want to know any more, and nature proceeds to peel you wide open. The truth, when we find it, may turn out to be less "moral", less totalitarian. Meanwhile, however, that is what it looks like. Judging by the faces and voices of the victims, that is what it feels like, too.'

Within a few months, it was clear that the (as yet unisolated) virus had already found its way into other sections of the population. By the end of 1983, two British haemophiliacs had been diagnosed with Aids. In November, the health minister Kenneth Clarke declared that 'there is no conclusive evidence that Aids is transmitted by blood products', but there were worrying signs from America. Sixty per cent of the UK's blood-clotting concentrate Factor VIII was imported, most of it from the United States, where donors were paid for their blood; some US-supplied plasma may also have been gathered from Africa. Before a screening test became widely available, there was no way of knowing; the British Medical Journal reported that the majority of opinion held that the risk of a person with haemophilia suffering a haemorrhage by not receiving their clotting agent far outweighed the risk of contracting Aids from it.

The true picture only emerged in the middle of 1985. Dr Peter Jones, the director of the Newcastle Haemophilia Reference Centre, tested 99 of his patients with severe Haemophilia A, all but one of whom had received commercial Factor VIII. Seventy-six tested positive for HIV. Jones had befriended these patients over many years, and now had to tell them the news. 'You see a child who five years ago you knew was going to live a normal, lengthy life and a high-quality life, and he's suddenly infected and dying. You feel anguish for a nurse who's taught somebody how to inject themselves, or has injected them herself, and then she realises she must have been injecting the virus at the same time. And it must be horrible to be a mother who's done that to her son.'

Dr Jones's patients were part of a total of almost 700 haemophiliacs who were HIV positive at this point, and by the end of 1986 there were 1,062 reports of infection among haemophiliacs or those who had received a transfusion or tissue replacement. A few of their partners were also infected. When the extent of the problem first appeared, Barney Hayhoe, Conservative minister for health, announced with robust authority that 'Aids is a very serious disease.' He considered it 'vital we do all we can to control the further spread? and to help those who have already been exposed'. And so a prolonged battle for compensation began.

In Edinburgh, another calamity was unfolding. An informal Lothian region Aids group had obtained some testing kits from the United States, and used them on stored sera from local haemophiliacs. A few came up positive, which was surprising because Scotland had been self-sufficient in blood products for several years. The tests were repeated, this time using injecting drug users as a control group. A vast number of the drug users had HIV.

In subsequent tests, the prevalence of HIV infection was 50 per cent or higher. Of the 3,695 HIV cases resulting from intravenous drug use, 1,173 are believed to have been acquired in Scotland, the majority in Edinburgh. This represents more than one-third of all the 3,022 HIV cases in the region. The reasons for this are rooted in three concurrent events of the early 80s: the increasing popularity and cheap supply of heroin; the methods by which heroin was injected (a system

known as 'booting' or 'flushing' whereby the drug is washed out of the syringe into the bloodstream by repeatedly drawing back the plunger and injecting the user's own blood), and the frequency of sharing equipment owing to the difficulty of obtaining sterile needles. The Lothian and Borders police had been tough on drugs for years: along with drugs, all drug paraphernalia was also seized, and chemists and other surgical suppliers would be prosecuted if it was believed that their equipment could find its way to drug users. And so people shared their needles and spread disease. In fact, grim experience with an earlier hepatitis outbreak showed that there was no more efficient way of doing so; in one particular story, a needle was passed around one estate in Muirhouse for three months.

In the tabloid press, hysteria raged. The story of the haemophiliacs presented a handy counterpoint to those concerning homosexuals and drug addicts. The prejudice was transparent: gay men and drug users had brought the disease upon themselves and deserved condemnation, while haemophiliacs, the 'innocent' victims, deserved all the sympathy and compensation; at last, some papers found a way of legitimising their homophobia. And so a woman was scared because a plumber she thought was gay had recently fixed her cistern; pathologists refused to conduct autopsies; firemen banned the kiss of life; footballers wouldn't share the communal baths at Wembley; you could get it from Communion wine; BT engineers refused to fix the phones at a lesbian and gay advice centre for fear of catching Aids from the wiring. And in the pub, the jokes: How many gays does it take to change a lightbulb? None: in intensive care they do that kind of thing for you. And what turns fruits into vegetables?

4 The iceberg

At the close of 1985, the Conservative government decided it could ignore the problem of Aids no longer. Gay activists had already mounted their own health education campaigns with vigour and success for three years, but their funds were limited and their efforts were often marginalised and censored. Many gay men believed they were being left to fend for themselves, and lobbied for a nationwide health education programme that would de-stigmatise what was still widely regarded as a gay disease; from now on, HIV became an 'equal opportunity virus'. The campaign that resulted featured television advertisements that none who saw them would easily forget.

Mrs Thatcher, who had rarely expressed much interest in the plight of gay men, had finally been persuaded - in part by the plight of haemophiliacs, in part by the frantic attention of the press - that something might have to be done for the population as a whole. Personally, she found the subject distasteful, and delegated the subject of Aids first to Norman Fowler, the Secretary of State for Social Security and later to Deputy Prime Minister William Whitelaw. Both received the shrewd advice of the Chief Medical Officer Sir Donald Acheson and a group of vociferous doctors who had seen the early stages of an epidemic on their wards.

The problem was, the government had not addressed its people about sexual health since it had tackled the issue of syphilis during the First World War. The language of the bedroom, much less the backroom, was not something it felt entirely at ease with.

The first Aids campaign was to take the form of full-page newspaper advertisements over one weekend in March 1986. Almost five years into the epidemic, a group of earnest people thus sat down at the DHSS to discuss the topic of anal sex. According to one civil servant, one minister 'had real problems. He was deeply ignorant about sexual matters - he was unable to pronounce "vagina". You've no idea what a problem it is to talk to someone who doesn't believe in sex anyway.' On another occasion, the subject of oral sex arose. 'Oral sex?' one minister asked. 'Do we know how many people do this sort of thing?'

What readers finally saw in the newspapers was almost unrecognisable from earlier drafts submitted by the agency TBWA. The text was preceded by a warning, signed by the four chief medical officers, that what was to follow 'may shock but should not offend you as we are talking about an urgent medical problem'. At this stage, there were about 7,500 cases of HIV.

One of the drafts contained the following frank explanation: 'During sexual intercourse, minute breaks may occur in the walls of the vagina. It is through these that the infected semen passes. As the rectum is far more delicate than the vagina, it is more easily damaged. This means anal intercourse is the easiest way of being infected.' But this was excised from the final version on the firm instruction of Margaret Thatcher. On her suggestion, the term 'anal intercourse' became first 'back passage intercourse' and finally the approved 'rectal sex'.

'The department tried to keep her out of it as much as possible,' one civil servant remembers. 'At one point, after she had seen a draft, we got a message from Nigel Wicks [her Principal Private Secretary] which said, "She wants to know if they have to go in the newspapers." We asked him where else they were supposed to go. He said, "She was wondering about lavatory walls."'

There was no mention of the words 'condom' or 'rubber', both of which were considered too explicit. Instead, use of a 'sheath' was advised, a word that many people cruising the clubs had never heard before. Even Norman Fowler would soon acknowledge that the advertisements had little effect. One survey of 300 people at Southampton General Hospital suggested they may have been damaging: before the campaign, 5 per cent thought there was a vaccine against Aids; after it, 10 per cent did. Before, 10 per cent believed the infection could be spread by sharing eating and drinking utensils - this had risen to 14 per cent.

And so a bigger, brasher new £20m campaign was announced, and John Hurt's agent was called about availability. Now, fear was the key. 'There is now a dreadful disease,' Hurt narrated against a backdrop of icebergs, tombstones and exploding mountains. 'It is a danger to us all. Anyone can catch it through sex

with an infected person. You can't always tell if someone is infected. You should protect yourself against it. Don't die of ignorance.' The final frame was of a tombstone with 'Aids' chiselled on it, an image which graced the front of another unprecedented public education campaign: a leaflet dropped through every letterbox in the country. The wording again caused sleepless nights. In the hope of not offending the elderly, there was talk of withholding the leaflets from anyone whose first name was Gladys, Albert or Daisy.

In this way, the United Kingdom went from a country which publicly talked about Aids very little to one which could talk about nothing else. The late newspaper columnist Peter Jenkins wrote of one meeting with the Cabinet Secretary Robert Armstrong at which 'anal sex was mentioned during the avocado, buggery in Her Majesty's prisons as we ate our beef'. His colleagues predicted doom: 'Aids: The New Holocaust' ran a headline in The Sunday Telegraph.

The projections of Aids death multiplied each week; towards the end of 1986 it was reported that there were already more than 100,000 people infected with HIV who didn't know it. New advertisements soon appeared with a slightly lighter touch: in one, the word 'Aids' was gift-wrapped in festive paper, and beneath it ran the words 'How many people will get it for Christmas?' Another showed a T-shirt with 'Sex & Drugs & Rock'n'Roll' scrawled across it; beneath it was the message 'At least rock'n'roll can't give you Aids.'

The campaigns were accompanied by a week of educational and Aids infotainment programmes on television, during which anyone who was anyone turned up to put condoms on cucumbers. In time, health educators did find a way to speak to those they most needed to reach. The words 'arse' and 'cock' appeared in government-financed campaigns aimed directly at gay men. Even the general public would soon learn 'It only takes one prick to give you Aids.'

It is still impossible to gauge the effects of this unprecedented care-a-thon on the sexual behaviour of a nation. The first adverts are principally remembered for causing panic and confusion, but it is agreed that even the most cautious, nervous education was better than doing nothing. Another question is: what was happening to the people for whom the campaigns had already come too late?

Part two: The Present

5 The escapologist

Above all else, Tony Whitehead knows one thing for certain: he should be dead by now. Whitehead is 47, still handsome with silvery hair, not as agile as he was. He was diagnosed HIV positive in 1984, as soon as the first primitive test became available. 'I did have a real sense of foreboding,' he says. 'It was often a strong personal sense of foreboding, which is why I was so strongly motivated to do something with the Trust. I would have felt terrible if I had the opportunity to do something and hadn't. But it wasn't all altruism: being at the forefront benefited

me enormously. I knew all the doctors and exactly what was happening. With Aids, as in so much else, information is power.'

He is sitting in the bright flat near Olympia he shares with a long-term partner, also infected. His eyesight is poor, and he jokes of how he has a magnifying glass stuck down the side of every chair. He looks back with horror and wonder: 'Quite how everyone's life would change was impossible to foresee, not least how our lives would be suddenly defined in terms of medicines and hospital appointments.' A great many of his friends died in the late 80s and early 90s. He is the only person he knows to have had the virus for so many years.

His first symptom of Aids showed itself in 1993 - a purple mark on his chest. 'I had lived with the thought that I would develop Aids for so long that it didn't worry me at all.' In April 1994 he went hiking and canoeing in Zimbabwe, but it was when he returned that he noticed something unusual.

'I know a lot about Aids,' he remembers thinking, 'but what was happening to me was like nothing I had ever heard of. I was finding terrible weakness in my legs, and losing my balance. I got down in a crouch and couldn't get up. I rapidly got worse.'

This was followed by chest pains and high fevers and frequent hospitalisation. He lost the sight in his left eye, and the peripheral vision from his right. He received injections directly into his eye, which he says made it look like a piece of steak.

Drugs didn't seem to help much. There had been some improvements in treatment since the first toxic Aids drug AZT had emerged with some fanfare in 1987, but their efficacy was usually modest and their side-effects often severe (AZT has been discredited as an effective sole treatment, although it is generally effective in preventing the transmission of HIV from mother to baby). Tony Whitehead took AZT in combination with 3TC, both drugs acting as dummy building blocks that disrupted the construction of infected DNA. But his immune system failed to respond. His count of CD4 T-cells - the white blood cells that play a key part in the orchestration of the body's immune system, and which in a healthy person stands at between 500 and 1,200 - had fallen to zero. He was, he believes, very close to death. But then something came along that has transformed the whole story of Aids in the developed world.

In 1996, Whitehead was one of the first to try what would become a revolutionary new treatment. He was given a new drug, called a protease inhibitor, to be taken alongside his other pills. This drug, indinavir, worked against HIV in a different way to the older anti-retroviral treatment, attacking another, later stage of HIV reproduction, essentially blocking any virus that escaped the attentions of the earlier drugs. It took a few weeks for this new combination therapy to take effect, but then the improvement was dramatic; his CD4 cell count recovered, it became possible to consider resuming a normal life. He was already feeling better when the trial results of this new treatment were announced to thunderous applause at

the International Aids Conference in Vancouver in July 1996. This was clearly the breakthrough that everyone concerned with Aids had been waiting for; within months, the death toll began to fall dramatically.

'Oh, I think there's no question that they saved my life,' Tony Whitehead says. When I first visited him at the beginning of 1997, he was taking 17 different pills per day, and there was a strict regime of compliance. There were also other pills to alleviate the side-effects of drowsiness and nausea, and he was unable to eat anything containing fat two hours before or one hour after he had taken them.

Today, this burden has decreased and his drugs have changed. The indinavir began going wrong after 18 months, so his doctors augmented it with an additional fourth drug. 'Within a few weeks, everything was going haywire. The blood results were terrible, my blood was like goose fat or something, and I was getting chest pains.'

But then a new successful combination was found - d4T, 3TC and dmp266 (efavirenz) - and his CD4 count went back to 600. He now takes seven pills - two at 9am and five at 9pm. 'The ones I take at night have given some people some very wild dreams,' he says. 'But my dreams have only been pleasant - flying over islands, swimming with fishes.'

Recently, Whitehead's doctors at the Chelsea and Westminster detected gentle signs that he may be becoming resistant to efavirenz, but this is something he takes in his stride. Soon, he hopes, there will be something else to replace it.

He says he manages all right on income support and disability allowance. 'I try to accentuate the positive, because I remember what things were like before. Now we get out and about; we have lunch out sometimes; I did a Spanish A level last year - didn't do very well, but I passed. But having said that, this isn't how I wanted to be. I'd have liked to have gone to work and pursued a career and earned a good living and all those things that most people are able to do.'

Whitehead maintains contact with the Terrence Higgins Trust, the organisation he once used to run. Later this month he plans to attend a fundraising dinner at the Hilton, and he'll work his table and tell his story. 'They don't wheel me out very often,' he says. 'A lot of people don't know who I am now.'

Across London, in a garden heady with flowers, a woman called Caroline Guinness is also on efavirenz, and it's been a similarly eventful journey to the drug. She tested positive in 1986 after sleeping with a bisexual man, but remained healthy for a prolonged period. She worked in music management and films, and helped organise the first big Aids fundraising concert at Wembley Arena in 1987: Holly Johnson, Boy George, Jimmy Somerville. Elton John sang 'Will You Still Love Me Tomorrow?'

She became ill in 1995. There was muscle wasting, chronic fatigue, night sweats,

hair loss. She then contracted pneumonia, and e-coli septicaemia 'which just about finished me off'. She had been resistant to taking drugs, but now had no choice; even before the triple-combination breakthrough with protease inhibitors, her dual combination of d4T and 3TC worked well, at least for a while.

'After 18 months I began to get lipodystrophy, that strange condition where all the fat on your body gets redistributed - from your bum and legs and arms it all goes to your stomach and breasts. It's a weird thing, because you feel very well but you look like someone suffering from starvation.'

Many other people presented with this, a side effect from one of the drugs. Her new cocktail seems to be working better, although she is aware of reports that indicate long-term toxicity. She has a teenage daughter who has not contracted the virus, and who has invited her to address her A level classmates about her life. Her mother has given these types of talks before, often to medical students. 'I give them advice about how people with HIV like to be treated,' she says. 'I tell them there is still plenty of bigotry and racism, and explain that if they come across as an understanding person they're far more likely to be told the truth. Then I talk about my story, which now encompasses 15 years, and so takes quite a while.'

The first question the students always ask her is about relationships. 'Recently my husband has come along, so I tend to point him out. Life does go on. But then I tell them that I still can't get a mortgage.'

6 The new world

The chief executive of the Terrence Higgins Trust is being asked to do something he doesn't get asked to do very often: to reflect on a British success story. The new drugs have meant that Nick Partridge has not attended a funeral for almost two years, whereas once he went many times a month. But beyond the new treatments, there are other reasons why he has had to reconsider how his charity provides its services, other peculiarities of the British Aids epidemic that ensured we have not seen his worst fears realised.

'We had some advantages. We had a shared language with the country that was most immediately affected; there were very close links in both the gay community and the medical community between the UK and the United States. And the GUM [STD] clinic network was being well used by those gay men who were most likely to become infected, so there was one healthy and immediate link between the medical community and gay men.' There are others: the appointment of Sir Donald Acheson as Chief Medical Officer, a forceful, diplomatic man with a good grounding in epidemiology; the implementation of needle-exchange programmes for drug users; the impact of a trip that Sir Norman Fowler took to San Francisco in 1986, where the scales fell from his eyes.

Partridge observes that the impact of HIV has coloured many aspects of British society in unexpected ways. It has changed the way we talk about sex, the way

patients interact with their doctors, the way treatment activists interact with drugs companies. It has increased the visibility of gay men. 'There is a huge difference between [London's] Old Compton Street or [Manchester's] Canal Street then and now,' he says. 'In 1982 there was not a single gay bar which didn't have smoked or blacked-out windows.'

Last October, the Terrence Higgins Trust became Terrence Higgins Trust/Lighthouse, the product of a merger with the west London hospice and treatment centre. In recent months the Trust has also negotiated mergers with 10 other Aids charities, another indication of the changing priorities in the wake of combination therapy. One of Partridge's tasks is to help people re-engage with society and work again. 'To see a 70 per cent drop in the number of people dying in a two-year period was wonderful,' he says, 'but it doesn't mean that the personal impact of the epidemic has changed for that many people.' Those who benefit have had a large impact on drug costs in the NHS - up to £10,000 per patient per year - which has squeezed budgets for long-term support in the home and future prevention campaigns. While care in London has been generally good, the regional picture has been far more patchy.

Partridge says he has several significant challenges. He hopes to develop better services for Africans with HIV in the UK and promote health campaigns among other communities at risk. And he must try to engage younger gay men again. 'If you were 18 now you'd have been about four when the icebergs were on telly,' he says. Despite the vociferous efforts of several gay activist groups, many now view Aids as an old man's affliction. Recently there has been an increase in the number of sexually transmitted diseases, which suggests a lack of condom use.

There is also the risk of being infected with a new drug-resistant strain of HIV. 'We have all the elements for a potential second wave of an epidemic,' Partridge believes. 'The lesson from abroad is that if you do nothing, HIV spreads with remarkable speed. You only have to look at Africa to be absolutely convinced that you can't walk away from Aids work, because it will come back to haunt you in the most terrible of ways.'

There is another problem: most people just don't care much any more. Despite the record increase in HIV infections last year (and the 493 new reports in the first three months of 2001), Aids is widely seen as yesterday's disease; red ribbons aren't much of a fashion accessory these days. Accordingly, public fundraising is very difficult. As with most causes, it is hard to overestimate the continued importance of celebrity. The Terrence Higgins Trust acknowledges that even the presence of Tamara Beckwith rattling a bucket in Selfridges makes people more likely to donate. It is entirely possible that most people's understanding of the effects of Aids comes not from information campaigns, but from the HIV storylines in soap operas and the deaths of famous people. In America, the message hit home with Rock Hudson; in the UK it was Freddie Mercury. Princess Diana also made a difference - her bedside vigils, her handshakes with Aids patients, the message that Aids was a virus not a crime.

Those who raise money for Aids say that her death robbed them of an ambassador who has yet to be replaced. Elton John? Some generous and invaluable work, quite clearly, but as yet he is still not a member of the royal family.

Five days after the Danny La Rue extravaganza, the events manager at Crusaid was fielding calls about the Barbra Streisand film that evening at Planet Hollywood. 'I could have charged twice as much,' says Michael Berg. 'It sold out within 24 hours and people have been going hysterical.'

Since its formation in 1986, Crusaid has raised £19m, distributed to such diverse organisations as Positively Women, the Uganda Youth Support Unit and the African Church Leader's Programme. On Michael Berg's walls are the souvenirs of some recent events: premieres of the big musicals, an audience with the writer Armistead Maupin, celebrity auctions where you can buy something unusual from Graham Norton. Last November, bucket collections by African performers at the end of The Lion King raised £36,000.

'Last year we worked hard and we did OK,' Berg says, 'but the climate has changed. The days when people would come to any event just because it was Aids have long gone. You have to offer people something they really want.' He estimates that the Danny La Rue show will raise in excess £5,000.

Berg mentions a troubling Mori poll conducted at the end of last year. Among other things, this asked members of the public two questions: would you give time or money to cancer charities? Eighty-four per cent said Yes. Would you give time or money to an Aids or HIV charity? Eighty-six per cent said No, under no circumstances.

Why does he think this is?

'Who knows? I guess people think it's over.'

7 The view from Barts

At the end of May 2001, Tony Pinching can be found in the same office he worked in when the epidemic was young, but the name of his employer seems to have changed every fortnight. In this feverish climate of merger and management restructure, he is now Professor of Immunology at St Bartholomew's and the Royal London School of Medicine and Dentistry, Queen Mary.

For Pinching, well versed in the extensive biography of disease, the Aids epidemic is still young, two decades after it was first observed. But the advances have been considerable. 'If you look at it in terms of the stick of rock of medical history, the drugs came incredibly fast,' he says. 'You just don't normally get from the discovery of a disease to a transforming treatment in a period of 15 years. Incredibly slow, of course, for the people in the first waves of the epidemic, but in

the wider context, it was remarkable. I think it justifies that early advocacy for putting considerable money into basic research.' Pinching is also more optimistic than he has been for years that the technical barriers to vaccine protection maybe surmountable, although a fully protective vaccine that all countries can afford is still many years off.

When he looks back to his first patients, he remembers learning vast amounts from them: 'It was clear that they were telling us things that were going to guide us for the next 20 years.' He would use this knowledge to inform his discussions with ministers and the Department of Health in the first tender steps towards the public information campaigns. Justifiably, he feels a sense of achievement. 'I think the approach that was followed in this country was broadly right and reasonably accurate, although sustained intermittently. The flat-earthers will say that the worst-case scenario would never have happened anyway, but I think the public health campaigns made a substantive difference. If you look at some countries in southern Europe that did not engage in such sustained campaigns you can see that they got into a much worse epidemic. I think it's sad that we've never celebrated that, because the tenor of debate in this country is always so pervasively negative.'

At the beginning of 1999, the UK had 16,468 cases of Aids, compared with 50,112 in France, 43,936 in Italy (mostly drug users) and 18,479 in Germany.

In the last few years Professor Pinching's caseload has changed. The majority of new infections is in African heterosexuals; we are palpably part of the epidemic that is happening in the rest of the world. 'It's quite wrong to think that the real problem is over there, because it's over here, too,' he says. 'I feel that very strongly here in east London, where we see people presenting with late disease, the sort of stuff we saw right at the start.'

His African patients are a potent reminder: the drugs have come too late for many, and are unusable by others; for all the improvements in education, an incalculable number of people are not being reached; the UK epidemic has some way to run.

'The imperfections of human beings and the imperfections of knowledge are such that we will inevitably give HIV opportunities to escape,' Professor Pinching says. 'The question is, can we always stay ahead of it enough?' After 20 years, he reckons it is still too soon to know.

• For a comprehensive guide to symptoms, treatments and further sources of information on HIV and Aids, go to www.aidsmap.com.

www.tht.org.uk

UNAids

British HIV Association