

The drugs log-jam

Duncan Campbell explains how new experimental drugs can slow down the onslaught of Aids

Few scientists believe that the HIV virus will remain unbeaten, but any wholly effective treatment or vaccine is probably eight to ten years away. A million or millions of people will have become sick or died by that time. There have, however, been medical advances; but they have come largely from doctors and activist patients who have organised urgent, rough-edged trials and found treatments that worked, or worked most of the time, rather than from intricate long-term studies of, say, cellular immunology.

Most of these frontline trials have taken place in the highly informed Californian and New York gay communities. San Francisco's *Aids Treatment News* recently listed 101 therapies that its readers were following, ranging from conventional drugs like AZT to meditation and prayer; New York's Community Research Initiative is studying alternative approaches to containing HIV infection and Aids.

Martin Delaney, co-founder of Project Inform in San Francisco, is confident that existing anti-HIV treatments, although far from perfect or free of side effects, can dramatically reduce "progression" to full-blown Aids. "HIV infection is a manageable chronic illness," he says. "But a lot of people leave it too late—until they get an opportunistic infection or Aids diagnosis."

Some dozen conventional drugs have shown promising activity against the HIV virus, anecdotally or in the test-tube at least. Only a few have been through clinical trials for use with Aids patients, let alone on the far larger population of HIV-infected people who are "medically well" or only mildly affected. But, as I argued in my article, "Race against time" (NSS 6 January), research begun now into treatments for HIV infection could save 50,000 lives, and £20 billion, in Britain alone.

AZT is the best known, most tested and most expensive of the conventional drugs. It has been of proven value to people with Aids, but it frequently causes heavy side-effects and is possibly effective only for one or two years at most. AZT is increasingly used at lower doses in non-Aids patients in the hope of preventing "progression", and its success is now being tested by a three-year £3 million trial, "Concorde", on 2,000 patients in Britain and France—the only trial of its kind. But critics say it is going to take too long, is too complex, and is immoral—for up to half the patients, whose identity is unknown to them or their doctors, will be getting a placebo in place of AZT.

HIV-positive people in Britain are also using other drugs which American experience suggests have some potential in combating progression. Among them are AL721, a food-like non-toxic substance, which was thought to make it more difficult for the HIV virus to get into target cells; Naltrexone, very low doses of which have an apparently beneficial effect on the way the body's nervous system regulates the immune system to fight HIV; and dextran sulphate, a

cheap and simple drug which may stop HIV-infected cells in a person's blood from clumping to and destroying other cells.

There are other areas for research. Doctors believe that avoiding alcohol, taking exercise, sleeping enough and having a "good" diet may slow HIV disease and Aids. But these remain homely observations, not scientific findings.

Both anecdotal and scientific reports have found that people with HIV infection or Aids tend to feel better and stay healthier if they feel psychologically strong. Also meditation, "visualisation" (concentrating the mind on the body's internal battle against the disease), chanting, prayer, and religion have been seen to provide that strength.

But after years of living with Aids and HIV, the Californian gay community has learnt that early "intervention" saves lives and slows sickness. This has brought about a reversal in attitudes on testing: most people at risk are advised to get tested, despite the agony of a positive result.

Martin Delaney's confident view that HIV infection is a manageable chronic disease—and the confidence that Project Inform and some physicians place on the carefully monitored use of experimental drugs—is based on close surveillance of the markers of gradually growing immune deficiency which can be detected in a person's bloodstream. By monitoring the body's key T4, or "helper", cells, both patients and doctors can judge the effects of a particular experimental treatment while the patient is still well. And if the count falls to danger level, then other drugs can be taken which don't necessarily stop HIV, but which can stop the development of full-blown Aids.

There is evidence from individual reports and group analyses that this rough-and-ready approach is working. Positive Action Healthcare, an "early intervention" group in San Francisco, reported late last year that using a combination of drugs, including AZT, dextran sulphate and "transfer factor" (an experimental anti-cancer agent), their first 174 patients had shown an average 28 per cent rise in T4 cell counts. This summer I obtained the raw data on these patients from PAH and showed them to Dr Andrew Moss, a leading US Aids epidemiologist. He said the turnaround in T4 cells was definitely "statistically significant".

PAH's results are replicated by other HIV-infected people like Martin Delaney's lover, Mark. Four years ago he hovered precariously on the edge of Aids. From a low point then of about 100 T4 cells and severe shingles, Mark's experimental use of drugs steadily raised his T4 cell count to above the danger level, 500, and up to 900, normal count, last summer.

The absence of systematic research means that valuable information learned by PAH, Mark and others in the US, and by people like Paul, Derek, Stuart and Janet in Britain (see Claire Sanders's article) is continually being lost.

draughty place at the top of endless stairs doesn't help your health. The Thatcherite housing policy means that we are going to get people with Aids living on the streets of London."

Paul is the only person I spoke to who has decided to take AZT. "In July my T4 cell count plunged to around the 200 level; I felt dreadful, really, really serious fatigue. I didn't have enough energy to get across the room. And I had a rash on my hands and face." He is taking AZT along with dextran sulphate. "In the test tube, dextran sulphate appears to stop one of the mechanisms that damages the helper T4 cell lymphocytes, but it doesn't affect antigen levels—which is what AZT does. So I decided to take them together and my doctor agreed that that was a shrewd clinical decision." (Paul's approach corresponds closely to promising treatment methods used in California—see Duncan Campbell's article.)

Dextran sulphate is not available in this country and Paul has to rely on a friend bringing it over from the US, "and that is a source of stress, to worry constantly that you might run out". He also takes isoprinosine which is a potential immune stimulant. "My T4 cell count has slowly risen and is now just over 400, which is lower than normal, but getting out of the danger category. AZT made me very nauseous at first and in the long-term there is a problem of toxicity—that is why I went on it reasonably early on, while I was still strong enough to cope. My T4 cell count started to rise before I went on AZT, and I attribute that to a reduction in an area of great stress in my life—my job."

Because Paul, who is a statutory health worker, had taken time off work, he got better. It is another example of how social factors can seriously damage the health of people with HIV antibodies. "You can talk about stress management, but if you have external sources of stress that are always there, and one of them is a homophobic climate that would like to see a lot of us gone, then it is very difficult to cope." Paul says that, at work, "I am considered more or less dead, socially dead, whereas I think I've got years and years and if I haven't, I shall come back and haunt them."

He doesn't go to support groups that often: "They are very important but there can be a downside, if you just sit around and discuss your ulcer stories."

Someone who shies away not only from ulcer stories, but also from doctors, tests, laboratories and hospitals is Derek Jarman, the filmmaker. "Nothing would get me into St Mary's, Paddington, unless I was actually keeling over. I did have a GP whom I liked but he moved away and I thought, 'I'm never going to see a doctor again because Arnold's gone, and I'm not prepared to be part of this battery hen thing.'" His approach to being HIV positive could not be more different from Stuart and Paul's, although what he did share with them was a strong and positive frame of mind.

I spoke to Derek in his small cottage by the sea. As I arrived he came out to greet me, offering his hand, and warning me that the car could be about to sink into the shingle. Before we could talk about HIV we discussed the nuclear reactor behind his house, and his garden that resembled a lunar landscape with the plants marked by gaunt, grey sticks. ▽

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He was diagnosed HIV positive two years ago: "I remember, of course, the date, one always remembers these things: it was 22 December. I went to get tested simply because I felt that I was in a situation that was stable enough to know, and the reasons for not finding out are all negative. I really disagree with all the secrecy. All my life has been an attempt, through work and other things, to come to grips, first of all with being gay, and then also, in my own way, with this."

He doesn't spend a lot of time thinking about the virus. "It actually doesn't interest me, but sometimes when I am alone here I think about it." When he is out: "A lot of people come up to me, obliquely, and say, 'I'm in the same situation as you' and a few words are exchanged." I ask if this is because he appears to be able to talk about it so calmly: "I'm not really any more alright than I ever was, nothing has altered. Perhaps I never was calm."

Doubt and uncertainty have always been an important part of his life and work long before HIV came along. He knows that his films are not accessible to all, that they offer no easy answers or formulas: "They are elitist, and thank God they are, because to be of any interest to anyone in the end art has to be pinpointed—it can't be understood by everybody at any one time". And doubt, fear and uncertainty surround the HIV virus—partly because of the way papers like the *Sun* have treated it which he sees as "hellish and depraved".

"Being HIV positive works on two levels. It works as a scientific formula and it also works on the imagination." And it is how the imagination deals with it that is particularly hard to grasp—and that really interests him. "I hate to say it, but in some ways finding out that I had HIV antibodies was a very positive experience. True, I was thinking, 'Oh bloody hell, I'm going to keel over,' but then I realised it was crazy. The way I was living, I could've fallen out of the sky or had a car crash. We are all going to die some time anyway. I really reacted against the level of phobia.

"My mum died of cancer so I've lived with illness before and I watched the way she coped with it. She lived four times longer than any of the doctors said she would, and I never saw her look unhappy; she was always full of life. All one's work is around death; any artist's real work is about death, that's all that matters. I've always tried to work on that level, so I suppose I was already involved in that way.

"What we are talking about is what people should be doing all the time, anyway. If everyone stopped and thought for a moment, they would realise that we are all in the HIV position—only certain people have been given that knowledge absolutely.

"Ultimately, we all have to deal with impermanence. And when you know you are dealing with it, you value things so much more: you become aware that peeling spuds is really wonderful, much better than being dead."

Derek's attitude towards HIV was most similar to that of Janet, the only woman I spoke to. They both dealt with it in their minds rather than through a great stress on diet or medication. Although they both eat reasonably healthily, they both smoke.

Janet was a drug abuser who became HIV positive through a shared needle. She was

tested without her consent and she received no counselling. After six weeks in hospital she was discharged without any follow-up or referral. She was simply told that she had Aids, there was no talk of being HIV positive and its implications. She is a friendly, direct and straight-forward person who speaks with a broad Scottish accent. She sits curled up in an armchair as she talks, and between cups of tea and a stream of phone calls she tells her tale.

Initially her main concern was survival. She went for support to organisations like the Terrence Higgins Trust but felt isolated: "They were brilliant organisations, but when I went along to the support groups there'd be me and, say, ten gay men." At the same time she went to a rehabilitation centre where she made the mistake of talking about Aids: "I was asked to leave as they were worried about losing their fee-paying patients.

"I kept waiting for the big organisations to do something for women, but nobody was. So I thought, 'I'll do something about it.'" This, more than anything else, has kept Janet alive.

She now lives in a small groundfloor flat in south London with her lover, whom she met after being diagnosed. Five weeks ago she gave birth to Laura, a healthy 8lb baby. She decided to have Laura after she became pregnant by accident.

"Since I got this virus I have valued life so much more. I just couldn't, I really couldn't kill the baby. And I wanted a baby so much." Although Laura was born HIV positive, it is not yet clear whether the antibodies in her blood are her own or her mother's—so nobody knows yet whether she has the virus or not and whether she will become sick.

Janet has set up Positively Women, and organises monthly meetings attended by over 30 members. She supplies them with all the latest information, as well as a day and night counselling service.

She is in contact with over 100 women outside London; the isolation of many is so great that they will drive 100 miles to talk to her, "they're that desperate". Initially the people who contacted her were drug users—increasingly they are woman who have become HIV positive through heterosexual contact.

She is proud of what she has achieved. "I always liked to be the agony aunt and by talking to other people, I was actually confronting HIV within myself. I have seen people really change, some women come to me in such a state and now they are up and doing things and volunteering with the Terrence Higgins Trust." She believes that some form of fate has kept her alive: "I am a great believer in things being meant to be, sounds a bit religious but that is my own faith and that has helped get me through—the belief that I was meant to have started up Positively Women, and meant to have helped an awful lot of people."

Everyone I spoke to saw hope as a crucial factor in staying alive. This didn't mean that they buried their heads in the sand or ignored the fact that many of their friends and lovers had already died. "I know I could be dead in three weeks," Janet says. "I know that for a fact, but I don't believe it. If I thought every day that I was going to die, I wouldn't be the person I am now, I wouldn't be so strong." ●