



Birchgrove

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the drugs issue...

The following article is a transcript based on an interview which was carried out with the assistance of a Birchgrove member. We asked him if he had any experience of recreational drugs before HIV?

I'd smoked dope before that, I'd smoked dope quite regular. I'd go out with the boys, I was a big drinker then, drink a lot, get into trouble through drinking, drunk and disorderly, fighting, snorting a bit of speed on the weekend, going night-clubbing, dancing my bollocks off all night. You're whizzing away, that would be Friday and Saturday nights. But when I was in hospital I was a bugger for the painkillers. I was addicted to painkillers, but I wouldn't go out looking for stuff on the streets once I was out of the hospital. When I was in there, I was on it, I wanted to be on it, but when I came out, I could stop it. I had a positive side to me, even though I had a problem, I could still sort it out.

When I got told I was HIV, I was on the ward and when I came out I felt alright, until a couple of months went by, and then I thought "Fucking hell, I'm going to die". So I thought, "let's go out big". I started taking a lot of speed, not only weekends, but taking it daily. Into a paranoia state, and I couldn't sleep. I was thinking about dying and HIV, "Oh my God," I thought.

A couple of years ago, I didn't want to live, I wanted to die young, but not with HIV. I wanted to die through another cause, drugs probably, but not with HIV. I didn't want have the headlines out on me "He's dying of AIDS", you'd hear things on the news, the local headlines, haemophiliac dying of HIV. It'd be on the news, an iceberg falling into the water, and I thought "Fuck this, I've got to get out of this world, I gotta get out of here, I can't handle this no more, my heads going". I started taking a lot of speed. Speed kept me awake, and the only way I could come down from the speed was to whack

some sleeping tablets, loads of sleeping tablets. I thought I like this side of it. I like the sleeping side of it.

I started getting into the sleeping tablets, buying them, buying palfium, then buying morphine tablets on the street. You get in so deep, you see people who can get heroin for you. Start taking it, then you start getting it yourself, going to who they're buying it off and on down the line to who they're buying it off, until you get to the main source. Then you buy it in bulk, enough to last you. There was just nothing positive to stop me.

But after the HIV, I started taking as much as I could get. I used to get palfium from my GP or dexamoride, very, very strong, much stronger than pethidine, about the same strength as morphine.

Pethidine was no good anymore, I'd started to abuse it, it was just blanking everything out of life. I thought I can cope with this, I can handle this, but I couldn't handle coming down and being back to HIV. Well, they just wouldn't work anymore, so my GP put me on palfium, I'd been on and off them in the hospital, morphine, palfium. When I was in the hospital it was hard to get enough pain relief. But, in the end, I did cry wolf and when I was in genuine pain they didn't want to know. So I had to go to my GP and he'd give me palfium and that, but in the end he wouldn't give me no more.

The morphine was nice, but pethidine was bloody horrible, it's a chemical, it makes you go doodle alley, it doesn't last two seconds. But heroin is the real McCoy. My contacts for amphetamines were no good for heroin so I had to go travelling, Bristol, London, there are people up there who know where to get it from.

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Inevitably, any discussion focussing on drug use and abuse is bound to provoke strong opinions. What is interesting in terms of the HIV/AIDS debate, is how much the polarised viewpoints one normally associates with recreational drug use has spilled over into the arena of therapeutic and prophylactic drug treatments. Of course, certain clinical drugs have always provoked controversy, the tragic consequences of the use of thalidomide in the '60s, or the more recent scare about certain forms of contraceptive pill. But in the case of AIDS, there are so few effective therapies, that almost anything that appears to offer hope is seized upon as a possible life saver.

Remember the early feedback from the AZT trials? The initial indications seemed so compelling, seemed to indicate that it could prevent a progression to AIDS. Remember the clamour for positive people to be allowed access to the drug before the completion of the trials? Were the medical establishment right to believe that it is morally wrong to deny access to a drug that seems to have such positive benefits? Or were they equally guilty of clutching at straws?

Whatever the subsequent findings, the Concorde Trial has left a bitter taste in the mouths of many. And what have we been hearing recently? A new set of endorsements for the early Delta Trial results, a new call for positive people to be able to access combination therapy, and all this despite the trials going ahead without a control group. I am beginning to get that déjà vu feeling.

Many people might throw up their hands in horror and exclaim, "Drugs! haemophiliacs don't do drugs." But most haemophiliacs are used to regularly injecting themselves with factor VIII, a form of dependency which few of us like to acknowledge and with long-term side effects from which few of us have managed to escape. Some haemophiliacs have also been exposed to a vast range of recreational drugs including alcohol, cannabis, amphetamines, barbiturates, heroin, ecstasy etc. and this is alongside the prescription drugs such as the pain relievers, pethidine and DF118's, antibiotics such as Septrin and Fluconazole and anti-virals such as AZT, ddi, and ddc.

Whilst we neither endorse or condemn any of the drugs under discussion in this newsletter, we believe that drug use is an issue of common concern and that there is much to learn from people's individual experiences. We hope that we have presented these views in a rational and readable form and that the issues involved will encourage wider discussion amongst those who are concerned about the welfare of positive haemophiliacs, their families and friends.

THALIDOMIDE DRUG "MADE IN WALES"

Following media reports over the last few months that the controversial drug, thalidomide, was being used in trials to treat HIV and AIDS related illnesses, Gwent drug company Penn Pharmaceutical, is to begin producing the drug for use by HIV sufferers in the United States. The Tredegar based firm is reported to have signed a major contract with US corporation Celgene, which could pave the way for a massive clinical trial involving tens of thousands of people using thalidomide. The agreement will make Penn the sole supplier of thalidomide to Celgene, which has gained approval for its project from the US Food and Drugs Administration, which controls the sale of medicines in the United States. Penn's managing director, Dr Roger Jones, said thalidomide had been found to help in preventing HIV sufferers developing full-blown AIDS. The drug is said to act as a suppressant to the production of cells in which the AIDS virus develops.

Thalidomide is also said to help ease the pain of sufferers of rheumatoid arthritis, leprosy and ulcers, but is perhaps best remembered for the terrible side-effects inflicted on the newly born infants of mothers who had taken the drug as a supposed treatment for the effects of morning sickness.

"We have been working with thalidomide for about nine years, we probably know more about it than its original manufacturers," said Dr Jones. "We have made it available in the United Kingdom to selected patients with conditions where it can be of help. The Americans want to learn what we have learned and under this agreement, bootleg thalidomide coming to the States from such countries as Brazil will be stopped. We will be the sole suppliers. HIV positive people in America are being advised to take thalidomide and if they want to they can get involved in a clinical trial. The FDA is planning to get every Aids patient in the States into an open clinical trial."

However, Dr Jones sounded a note of caution when he said, "We cannot just be euphoric about this deal, because of the suffering that has taken place previously, because of thalidomide." He added, "We have to think of the terrible suffering it has caused, but hopefully it can now be put to a positive use."

"The really bad lot of it started when I had the money from the Trust, that was a bad patch, that's when I went right off the rails."

The really bad lot of it started when I had the money from the Trust, that was a bad patch, that's when I went right off the rails. Through the week I could manage on small doses of heroin, like £10 bags here and there, and a lot of temazepams - sleeping tablets. There were tons of them where I live. At that time the doctors were giving them out like smarties. So I started injecting temazzies to get the same buzz, breaking it down with water over a flame. I used to buy the works from the chemist, the syringes and stuff for factor 8 was no good. You have to have 1ml syringes with the needle already attached to them, you buy the works in a pack of twelve from the chemist.

On the weekends, I'd spend a couple of hundred quid on heroin. Then again, if there was nobody about because somebody had been caught, or if they were laying low because somebody had died through it, there'd be nothing about. So I'd go on a bit of crack, freebased cocaine, cocaine that's been purified to get a 100% buzz. It's not morphine, but it's enough to get you going, it makes you feel like a superstar, you could take on the world then. HIV was nothing, nothing, that was the thing.

Through the week, I'd be sleeping most of the time, sleeping all the time, day and night taking sleeping tablets. By this time, its taking me 10 to 15 sleeping tablets to get off to sleep. At the weekend I'd get smashed out of my brains. Friday night would come on a Thursday afternoon and I go and pick up a couple of mates. We'd all be in my car and we'd go off, travelling about, picking up here, picking up there, seeing what we could score. If we couldn't score one place, we'd score at another. When you get involved you seem to score anywhere, it's like going up the shop to buy a paper, except you've got to go further. We'd stop in service stations on the way home and do it, sat there blown out of our brains. And when we got back, we'd go to somebody's house and we'd shoot up all night.

"I wouldn't go up the hospital anymore, I wouldn't even go if I had a bleed. I'd just hope it would stop on its own, I was in a hell of a mess, that's why my knees are in a mess now. I just didn't want to go there. It's funny though, I didn't seem to have many bleeds at the time and if I did, I'd rest up, I'd be sleeping all day and when I finally woke up it would be alright."

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When I did go up the hospital I was usually pissed up, drink, amphetamines, head gone, go in there, say I'd been in a fight or something. I might only have a scratch, but I'd say I wanted something more. I'd want painkillers and when they refused to give them, I started arguing, started aggro about it. I can't remember, it's just blanked out now, it's embarrassing to look back on it and think "Christ, how could I have been like that?" To even think of doing the things I done.

There was one night, I was living in a caravan then, nice place, bought it myself. I had it all comfortable, had a three piece and that. And one night, I thought, "Bollocks, I want to finish with it, finish with it all". I'd really had a guts full. I was on a methadone prescription then, from the CDT. I'd been out and then I'd had my own stuff, I also bought a load of tablets. I ended up taking a bottle of temazzies, I had a couple of joints and a chase of smack. It's funny, I usually injected it, but this time, on the silver paper, I had a chase of it. I remember falling asleep and waking up in the morning, about five o'clock, freezing cold, absolutely freezing cold, shivering like hell. I thought, I feel weird, really, really weird. Out of it, but not out of it like I'd always been in the past, as if I'd gone too far, too far and I couldn't get myself back together. I remember phoning up my mother and saying, I can't walk, I can't walk. I'd got no legs, as if somebody had cut my legs off.

She came over to the caravan and the ambulance had to break in to get me out 'cos it'd gone too far. I remember coming to the hospital and being up on the ward. Then I can't remember anything more, until the following week, when I woke up in intensive care. I'd nearly ended it, another 10 minutes I had left to live, they had to rush me into intensive care with oxygen on and everything. I was in intensive care for a couple of weeks, on life support for about a week I think. And I knew from the day when I woke up in intensive care, that I'd never go back to it, I knew. I been out of it ever since, I would never go back to it, never ever go back to it.

The next issue of the "Birchgrove" newsletter - "Rock and Roll" will actually be on the theme of death and dying. We would be pleased to publish people's views, experiences and recollections. Please send any and all contributions to the address below.

The views expressed in each of the articles are those of the individual authors, and not necessarily those of the Birchgrove Group. The Birchgrove is a forum for discussion and seeks to encourage debate on the issues that affect people with haemophilia and HIV. We would encourage anyone who may have strong views regarding any of the items published in this newsletter to write to the Editor: "BIRCHGROVE" is published by:

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THE BEST HOPE YET

Every time I visited my haemophilia centre I was always told, "You should consider starting on AZT, it's the best hope yet!" After each visit, I went home and thought it through. I always arrived at the same decision that it wasn't for me. But eventually, I gave in to the continual pressure that AZT was my only option. In fact, I had little choice but to take the treatment. On the 13th of February 1992, I finally said "Yes" to AZT. I was prescribed 1200mg daily, with an initial course of six weeks and told to come back for my next prescription when I had finished those.

At first, I didn't think that I had any problems at all. But very gradually my memory began to let me down. Trying to recall telephone numbers that I called regularly became almost impossible. If I wanted to ring someone, half way through looking up the number, I'd forget who it was that I wanted to call. Small things that we all take for granted, such as making a cup of tea, became impossible. I'd get to the kitchen and put the kettle on, then I'd go back to the living room, sit down, desperate for a cup of tea, but having totally forgotten that I had already put the kettle on. On more than one occasion, my girlfriend managed to stop me from burning the house down.

As time went on I became so lethargic and washed out that I no longer cared about my failing memory. While halfway through my second prescription of AZT, I caught a cold which wouldn't seem to clear up. So I found myself seeking help for my general ill-health. Luckily, I was seen by a doctor whose knowledge of HIV came from outside a haemophilia unit. He knew exactly which test to do before advising me to stop taking the AZT. He also asked me to come back the next day for a blood transfusion, because I had become so severely anaemic.

It was almost three months before I bothered to go back, and by this time there was a new consultant. He was more than happy with my T4 cell count which had improved dramatically since my last test. When I explained the problems that I'd had, and that I'd stopped taking AZT, he suddenly realised that my improved cell count was due to stopping the treatment, rather than a benefit of it.

Upon reassessing the situation the consultant felt that I was an ideal candidate for combination therapy, in this case AZT with ddi, with a smidgen of Seprin thrown in to keep PCP at bay. His suggestion left me fucking speechless! After all the trouble I'd had on AZT, there was no way that I'd even consider taking it again, especially not in combination with some other bloody wonder drug!

Marijuana has been used for thousands of years as a medicine. According to a recent report in *Nature*, ashes from a fourth century tomb near Jerusalem suggest that marijuana may have been used in ancient times as an inhalant aid in childbirth. As an herbal remedy, it is well documented in cultures as diverse as the Chinese pharmacopoeia of 2727 BC and 16th century BC Egypt.

In the 20th century marijuana has been used for a variety of indications, including controlling nausea, arresting glaucoma and spasticity, and increasing appetite. Other anecdotal evidence has shown marijuana to provide symptomatic relief of HIV-related agitation, appetite-loss, spasms, chronic pain, and depression.

Because marijuana, like most herbals, is a complex substance, many users of marijuana argue that the synthetic form (Marinol) is only marginally effective when compared with the smoked variety. Smoking marijuana provides its own dangers, however, because many PWA's suffer from poor lung function. Potential heat irritation or damage to sensitive lung tissue in persons with pulmonary problems can be ameliorated by use of a water pipe or use of herbal teas. Fungal and bacterial infestation (salmonella, for example) of mouldy herb can be easily dealt with by heat-treatment for one minute in a microwave oven. This is done by those who distribute marijuana to the PWA community through an informal network of ad hoc buyers' clubs.

Some 35 studies have been conducted on the effects of marijuana on the immune system. Based on these studies, the *Journal of Psychoactive Drugs* determined marijuana has no significant effect - negative or positive - on the immune system, cell mediated, or humoral immunity.

Because of its classification as a controlled substance, little research on the use of herbal marijuana has been done on PWA's. We do know from long experience that the substance is nontoxic and is active, since it is widely used to alleviate nausea caused by chemotherapy (such as AZT, ddI, ddC, and drugs used in the treatment of opportunistic infections). And it is commonly used for appetite increase from its widely-known property in recreational use of causing the "munchies."

Portrait of a piss artist

Early in 1994 my centre director informed me that the non-A non-B Hepatitis virus had now been identified as Hepatitis C, and that it appeared to be active in my system. Initially this didn't mean a lot to me. I'd long been aware that I'd been exposed to various hepatitis viruses, none of which had apparently caused any lasting damage. But this one was different though, this time there was a payback.

The doctor explained, as best he could, the implications of the disease, detailing the various symptoms, long term prognosis and possible treatments. As I sat there, trying to take it all in - a mere 15% recovery rate from infection, the rest going on to develop a cocktail of chronic hepatitis, cirrhosis of the liver and liver cancer - something else he was saying gradually impinged itself on my consciousness. He was telling me that the best advice he had to offer in combating Hepatitis C was to cut down on, or give up entirely, the consumption of alcohol!

You're sixteen and already well into your apprenticeship; maybe you can't do all the things your friends can do - soccer, rugby, cricket, boxing, whatever, you name it, you can't do it any longer - but by God you can drink with the best of them. It's a Saturday night and you're out on the town with your buddies. You get the first round in, lagers for everyone, it goes down well, and within minutes its someone else's turn to get them in. A couple of hours pass and you can feel that buzz of confidence and well-being; you belong here, in this environment, with these people; they accept you for who you are, even though they may not necessarily know what you are. They treat you as they do each other and it's that sense of belonging, of not being someone apart, that you begin to associate with alcohol. It is almost as if for those few hours, you undergo a transition from being a 'bleeder', to being a normal, healthy person. For that short period of time, all the physical and psychological problems that stem from your haemophilia, are erased, and you can drink, fight and fuck just as well (or as badly) as any of your peers. The consequences - joint or muscle bleeds, not to mention a sick head - seem almost inconsequential when compared to the few hours of relative freedom that booze permitted you to enjoy.

No way! That was my first, instinctive reaction. Impossible. After all, drink had never done me any harm, I enjoyed it; it was so inextricably bound up with different aspects of my life, not only the social side. I saw the pleasure I took from drink as being a sort of resistance to, or unwillingness to compromise further to the pervasive influence that HIV had already had on my lifestyle. Having previously changed my diet, incorporated safer sex principles into my sexual relations, committed to a thrice weekly workout at the gym, made a conscious decision to avoid recreational drugs such as dope, speed and so on. I had come to

realise that a line would have to be drawn somewhere if I wanted to retain any sense of identity. And now I was being told - in effect - that if I wanted go on with the same level of health and well-being as I'd previously enjoyed, I would have to let go of something that seemed to be intrinsically bound up with that very identity. "Isn't there something, anything I can do?" I asked, clutching at straws.

You're twenty-two and it's your wedding day. All your family and friends have turned up and you still feel the need to show them that you're in control, that it's you that makes the decisions that direct your life, and not some lousy genetic mutation. The ceremony over, the party begins. You tell everybody to eat, drink and be merry. You're the centre of attention; people listen to what you have to say, they laugh at your jokes, they wish you well for the future. It feels good to belong, to feel that you mean something to these people, that you have something to contribute.

Perhaps you might have a few regrets tomorrow, those knee joints are a little stiffer, but you didn't want to admit that you weren't quite the John Travolta you used to be. Maybe you've started to ask yourself just why it is you need booze to express yourself more freely, but hey, tomorrow you're off on honeymoon and this is no time to start getting introspective. Afterwards, everyone tells you what a great time they had, best piss-up they've ever been to, and everything they say goes to reinforce that latent connection between your sense of self-worth and alcohol.

The "something else" turned out to be Alpha Interferon, and I was duly offered this as therapy whilst at the same time being informed of the rather hopeless statistic that only 10 - 25% of those who were Hep C positive but not HIV positive would have a long term response to therapy. The prognosis for those with both Hep C and HIV was even more depressing. Still, after listening to the possible side-effects, including flu-like symptoms, I decided to take the treatment for a six month period. Anything, even a subcutaneous injection into my belly three times a week, rather than cut down on my drinking.

You're twenty-eight, working, mortgaged to the hilt and you have a two-year old child. Your wife works full-time and you only get to see each other in the evenings, by which time you're both too jaded to make the effort needed for meaningful communication. On top of this, you've been living with the knowledge of your HIV diagnosis for three years. Life is, as they say, a bitch. But nonetheless you get by. It is after all, a bit late to admit that maybe you can't cope, that just maybe things are getting on top of you. You've spent most of your relatively short life combating the effects of haemophilia, fighting the idea

I WAS TOLD NOT TO WORRY

BY MIKE DIBBLE

On the 2nd of May 1995 I was informed that I had recently been infused with a drug that had been exposed to a potentially fatal contaminant. This is the fourth fatal disease I have been infected with from Factor VIII concentrate.

I have never experienced a life-threatening bleed, and have used pooled factor concentrate on the advice of haemophilia centre doctors to reduce damage to my joints. Prior to 1975, when I had a serious joint bleed, my doctor administered cryoprecipitate, a blood product made from a small number (typically 5), of volunteer donors. Cryo was always effective for me, but it required my doctor to administer it and it made no profits for the blood industry. To the best of my knowledge, properly manufactured cryo has never been associated with the transmission of any disease.

In 1975, I was informed that I would be using a new "miracle" product to control bleeding. This was called concentrated Factor VIII, and was made available only through government-funded haemophilia treatment centres. Factor VIII was made by pooling large quantities of blood. Up to 100,000 units from paid donors went into a single vat, that was then fractionated and divided into individual doses. If any unit was contaminated with a virus, the entire batch would be contaminated. My family doctor told me that he thought the product was dangerous, but that the haemophilia centre doctors were specialists, and should be trusted.

The treatment centres called Factor VIII concentrate a "miracle cure" because patients could be trained to administer it themselves, whereas cryo had to be administered by a doctor. In the late 1970's, I developed hepatitis B, as did virtually everyone else who used the concentrate. Records show that researchers knew that thousands of haemophiliacs would eventually die as a result of hepatitis. The first I knew about this was when the treatment centre informed me that I had developed hepatitis B. I was told not to worry. Nobody mentioned that hepatitis B is frequently fatal; nobody mentioned that hepatitis B could be transmitted sexually.

In 1983, I was making a good living selling advertising by telephone. I read something in a newspaper about AIDS and haemophilia. I asked the treatment centre about it and was told not to worry, the chance of getting AIDS was less than one in a million.

In 1985, I tested positive for HIV. I was told not to worry. Exposure wouldn't mean that I would develop AIDS. I also recall being told that if I brought a suit against the manufacturers, they would be forced to stop making blood clotting products and I would be responsible for the deaths of many children.

By 1990, I had developed full-blown AIDS and was unable to work. Stress was causing a rapid decline in

my health so I bought a holiday home and moved to the mountains. The stress-free lifestyle, mountain air, and herbs stopped the decline in my health, and by 1994, I felt healthier than I had in years. But my blood tests now showed that I had picked up hepatitis C from my Factor VIII concentrate. I was told not to worry. Nobody mentioned that hepatitis C is frequently fatal; nobody mentioned that hepatitis C could be transmitted sexually.

On the 12th of September 1994 the Institute of Medicine held public testimonies in Washington. It was here that I first met some of the mothers and children affected by the blood industry. I had coffee with two women who had haemophiliac children. Both of them had trusted their doctors and felt that they had injected poison into their own babies. One of them no longer had a son, the other had a 14 year old with her, a really nice kid. Although he looked healthy, his mother told me he had almost died a few months earlier, and he had a current T-4 count of one. I found out that his family had been having difficult financial times and had recently been evicted.

When they were leaving, I heard the boy ask his mother if he could stop at MacDonald's for a burger on the way home. When she told him no, that they didn't have enough money, he didn't complain. I had the opportunity to talk to him several times, and not once did he utter a complaint. Here was a young man whose body had been turned into a toxic waste dump, who was dying, who knew that to ever love a woman could be to kill her, and who couldn't even afford a burger. And he never once complained.

I talked to a man who was trying to take care of his small children alone, while dying from AIDS. He had mild haemophilia and had used concentrate once on the advice of his doctor as a "safety precaution". By the time his centre had informed him of the danger, he had already infected his young wife with AIDS and she had died.

I met a woman from Japan who had infected her son with AIDS, as thousands of American women had already done. She demonstrated to me that the contaminated medicine that she had infected her son with was a product that had already been recalled in the United States. The government allowed the blood industry to take hundreds of millions of dollars worth of contaminated products and sell them to Japan and Costa Rica.

BY GARETH JAMES, HEAL TRUST

An overview of the last millennium teaches us that truths and realities about science and medicine have never been fixed or set. As inhabitants of the late twentieth century we now have sufficient historical 'memory' to appreciate that what we believe to be 'reality' during any given era, is neither absolute nor enduring. Our hi-tech world lends immense credibility to the authoritarian voices of our medical profession.

But, however highly skilled we have become at convincing ourselves we are nearing an end point of knowledge, history still predicts that our contemporary medical obsessions will, in time, pass away and join the likes of leeches, daily blood letting and the crude mercury misadventures of centuries gone by. We will move on again.

Already, we can have little doubt that in the virtual-virology world of AIDS, the realities of HIV infection are becoming evermore negotiable. Relentless research efforts, with a clear agenda to pin everything on HIV, have repeatedly failed to bring us to any point of certainty. AIDS has not only seriously called into question the one microbe - one disease - one cure, twentieth century medical ideal, but it has also caused us to question the very ways in which we have chosen to interpret health and the disease process.

In the present day, our experience of reality relies upon, and has developed alongside, language. Even our ability to think is dependent upon the use of language and words in our own minds. As is well illustrated in 'AIDS and its Metaphors' by Susan Sontag, the use of military terminology in the understanding of disease has persuasively shaped and moulded our entire belief systems surrounding health and germs. We now speak of disease with exactly the same language that we use to describe military manoeuvres and political paranoia. This use of language creates and forms our realities.

We speak readily of 'the war on AIDS'. Modern medicine has conditioned us to view the body as the 'battlefield'. Germs are the 'enemy' which 'invade' us and against which we have to mount 'defence' strategies. We are encouraged to hand over responsibility for our well-being to the 'military intelligence' of our medical doctors who 'attack' our disease symptoms with the aggressive 'weaponry' of pharmaceuticals. We even credit microbes with the same human attributes of intention and cunning as we would any national enemy.

Since the birth of the germ-theory, disease has become named in accordance with the microbes found to be involved in the manifestations of symptoms. The upshot of naming diseases in terms of microbes means we have 'actualised' the processes of

disease to the point where we imagine it to be a tangible entity, a 'thing' that we 'get' or 'have'. For example we say that he or she has 'got' cancer, 'caught' a cold or 'has' AIDS - they are all thought of as objects or nouns. The phrase 'he has AIDS' immediately implies that the complaint is external to the person, the person is removed from being involved in the complaint and that the person has been standardised within this system of disease names. However, diseases are not nouns - they are closer to being verbs. Diseases are processes that we do, rather than being things we get. In this sense, it would be more accurate to say that he or she is cancering, colding or AIDSing.

Modern medicine has also succeeded in separating us out into little bits and pieces, limbs, organs, connective tissues, the nervous system, the blood stream etc. Applying the dissection of the body to the manifestations of dis-ease, however, relies heavily on the bizarre assumption that parts of the human body operate independently within our constitution. Modern medicine has also teased apart the mental and emotional spheres of the person from the body and recognises no role for these influences in the development of illness.

Earlier this year, a joint report published by the Royal College of Physicians and The Royal College of Psychiatrists, claimed that a staggering 50% of all illness may have its roots in anxiety and stress. There is now no shortage of studies confirming stress and other psychological influences to have a major role in predicting the outcome of microbial disease. The implications for a positive HIV-antibody test result become self evident. Any medical model which fails to take these factors into account will be fundamentally flawed.

How we choose to treat disease is entirely dependent on the ways in which we decide to interpret it - one stems from the other. In the late 1700's, a German physician called Samuel Hahnemann developed the notion that there may be two ways of treating illness dependent upon this choice. The first is the way of 'opposites' or heteropathy this has now evolved to become orthodox Western medicine. By its very nature orthodoxy distrusts the body's reactions during disease and believes symptoms to be unintentional, purposeless expressions of microbial attack, that signify nothing more than an alien invasion. It prescribes drugs designed to prevent the symptoms expression in the body.

The second way of interpreting disease is the way of 'similars' or homeopathy. This model views the body as the finely tuned end product of millions of years of

Dear Editor,

Many congratulations on your fine publication. I refer of course to the Birchgrove Newsletter no. 7 the issue about Sex. My own feelings about this topic are many, varied and complex, and I believe that you've thrashed out the subject in a fine and scintillating manner without resorting to such titillation as one finds in other, less savoury publications which shall remain nameless - publications such as "Pussy Galore", "Furred Escort", "Rhina Plasticine," and "Trunk Male". Not that I have ever seen such magazines; God forbid.

I found all the articles by turning the pages, they were quite interesting but the photos were too blurred and obscured for my taste. I see the necessity for making them 'artistic', but as they were primarily of a medical nature, I would have thought that in the interest of enlightenment, you could have made them more explicit.

Cybersex sounds like a great idea. Does one have to be on the internet to participate? Or is there a number one can ring? We should have more articles of this sort. I would try sperm washing but I am not sure which brand of washing powder to use? The biological ones all seemed to neutralise the sperm and hanging the little bleeders out on the line sounds like murder.

Keep up the good work and let's have more issues like this, full of controversy and sticking it up Johnny Foreigner.

Jarvis Stewart

Dear Editor,

It was with profound shock and disgust that I scrutinised the Birchgrove Newsletter No.7 "The Sex Issue." Having once been a keen supporter of the aims and work of Birchgrove in the past, with particular regard to its work with children, I must say that I found the contents and tone of issue 7 particularly disturbing. It is unsurprising that many of the so-called articles remained anonymous, and is indicative of the lack of courage of both the authors and you the editor, that you would not put your names to such depraved rubbish.

Never in all my born days have I had to read through a once respected journal, only to find myself knee deep in verbal dung. Do you not realise that children may read this publication? Must they really be subjected to stories about sex with our bovine friends? And what about masturbation? Yes, yes, I'm aware that in your schoolboy minds, the term 'hand jobs' might seem hilarious, but to most responsible adults, it marks a sad preoccupation with the seedier side of a sacred act.

What makes you think that HIV positive haemophiliacs need a 'spiced-up' sex life? Most haemophiliacs I know take a responsible attitude towards sex and practice abstinence in the privacy of their own homes. If more HIV positive people took this line, then we'd all have less to worry about.

The "Birchgrove" has in the past, always followed a sound editorial line, but I detect a change in editorial policy, it has become clear to me that smut, innuendo and provocation have been embraced and manhandled onto the agenda. Why

weren't we, your subscribers, consulted about this? Articles about members splitting during copulation, oral sex, and the condom survey, were all in extremely bad taste. The woman who wanted to leave her husband when she found out he was HIV positive should receive every encouragement as she obviously deserves the chance to make a new life for herself with someone more worthwhile.

If I encounter future articles promoting an immoral lifestyle, I shall have no choice but to cancel my subscription. We, as parents of haemophiliac children have a duty to protect the little darlings.

Mrs P H Jones

Dear Editor,

I was interested to read your recent coverage of the opinion that HIV does not cause AIDS, and the resulting letters. However, I take exception to Garry Davies' suggestion that my reports on the use of co-trimoxazole (Septrin) in NAM's newsletter "AIDS Treatment Update" have been "over-enthusiastic".

"AIDS Treatment Update" aims to present full and balanced information, the accuracy of which is checked by our Medical Advisory Panel. The potential for allergic side-effects to Septrin has been properly reported; indeed, last summer I devoted a front-page article to strategies for overcoming toxicities. The restrictions recently placed on the use of Septrin, which do not apply to its use in treating and preventing HIV-related infections, were also fully reported in "AIDS Treatment Update" last August.

The fact remains that Septrin has been proven highly effective in preventing PCP pneumonia and is associated with longer survival. The choice not to take Septrin can itself have potentially life-threatening consequences, in the form of avoidable cases of PCP.

Perhaps, I could also take this opportunity to mention that "AIDS Treatment Update" is available free of charge to people affected by HIV each month, simply by sending us your name and address.

EDWARD KING

Editor, AIDS Treatment Update

Dear Editor,

Well, bloody, done to you all at Birchgrove, for having the balls to print an entire newsletter on the subject of Sex! Safer sex for the positive person is something that often tends to get overlooked when safe sex literature is produced. Prevention at source, surely makes sense. And the more information and openness that can be brought to bear the better.

Sex doesn't stop just because your HIV positive, but it does take on a different role within a relationship. When you are a HIV positive person you need to carefully consider the effects that unsafe sex could have on your life. The importance of readable and honest information on safer sex for positive

PORTRAIT OF A PISS ARTIST continues...

"after a while you learn that if you drink enough you can obliterate a whole lot of the pain and a whole lot of the fear"

that you're a special case, that you need looking after. You've decided how you live and how you take care of your health and that has always been a source of pride. But that HIV diagnosis, that was a real set back. You needed to draw on every resource, every bit of strength you had. It's not always easy fighting the good fight, putting on a brave face, but down the years you always knew you could rely on your old friend, the booze, to help you pull through. Lately though, the way things have been going, the way you've been feeling, all you really want to do is forget. And after a while you learn that if you drink enough, and keep drinking enough, you can obliterate a whole lot of the pain and a whole lot of the fear. You sought nirvana but you'll settle for oblivion.

So I took the interferon and the initial results looked promising. At the same time I did make a vague commitment to cutting down on my alcohol intake, mainly to placate the doctor and my wife. After six months my liver function tests seemed to have returned to normal, but there was no guarantee that it would stay that way after the cessation of treatment. And neither could the doctor say for certain that it was the interferon regime which had brought about the improvement.

A large part of that positive response, he said, might be due to my cutting down on alcohol. In truth, I didn't see it that way, after an initial lowering of my weekly intake, after about three months, I was drinking almost as much as I ever had. The question is, why? Why, given that I had found out as much as I could about the disease, and that every piece of information I came across had spoke of the incompatibility of Hep C and alcohol, why, given my awareness of the long term consequences, did I continue to subject my liver to such systematic and suicidal abuse?

You're thirty-four. You're still surviving, after a fashion, despite having been told you have liver damage due to Hepatitis C infection. Some things in your life have settled into what might be called a pattern of normality. Your relationship with your wife is better than it has been for a long time, and so too with your child. Somewhere along the way, you've attained a level of insight into the way you function as a human being; you've allowed a little honesty to infect the way you look at and respond to the world. You realise now that your friendship with alcohol may be a double-edged sword. Much as it may have given a bolster to your confidence, much as it may have provided a fillip to your social life, and as much as it may have helped you get through some difficult times, there is much that you have lost along the way.

Were you really the guy laying in his own puke at someone's party because you had to go over the top to get people to accept you? Did their acceptance

really matter that much to you? After all, if they were ever going to be real friends they would have accepted you whether or not you were the life and soul of the party. Were you really that weak that you needed an alcohol crutch to get you through the last twenty years?

What surprises me is that my case is not atypical of haemophiliacs. In fact, there are quite a significant number of people out there whose experiences with alcohol are remarkably similar to my own. What does this mean, or what does it prove, if anything? Well, first of all it doesn't prove that if you drink a lot of alcohol over a long period of time, you'll do anything to fight off either Hep C and HIV. Too many people - both drinkers and abstainers - have died along the way. Nor does it mean that alcohol makes no difference either way. The medical evidence is clear that alcohol misuse, whether or not you're carrying a viral load, is definitely bad for you.

Perhaps many of us are relying on alcohol as a means of forgetting the reality of our situation, but somehow, I don't think that's the whole picture. Throughout a lifetime of striving to be as good as the next man, or no different to him anyhow, alcohol is just one tool some of us have employed to shield ourselves from the blurring of our identities, to allow us to blunder through the question of who we really are.

You have attained this insight, and still you drink what you know is too much for your system. Sometimes, in the privacy of your own thoughts, you ask yourself, what lies behind this? Do I have a self-destructive urge, or do I see myself as invulnerable? Maybe even immortal? Or maybe just fucking stupid? It's late in 1995 and I'm still surviving. Maybe this is some sort of achievement, but I don't feel that it's a big deal. I'm still drinking, and though I drink less now than I used to do, that's as much to do with the fact that I can't physically cope with the alcohol, as it is with conscious choice.

In my own case, I've spent so long constructing personalities that are not so much me, as representations of who I really am. Take away the scaffolding - the "hale to you me hearty," the bluff, the bonhomie, the bullshit, the piss-taking, and most of all, the booze which for a long time has fuelled it - and what's left behind is...? I don't really know. And that scares me. And that, I suspect, lies at the heart of why I continue to drink. It's not just the enjoyment of drinking, though that is a large part of it, or a defiant laughing in the face of death, but the fear of what might be left behind when all the alcoholic artifice has been drained away.

"the question is, why? why did I continue to subject my liver to such systematic and suicidal abuse?"

SMOKING TO LIVE

The following is extracted from a report entitled, Smoking to Live, which was first broadcast on CBS News as part of "The 60 Minutes Show."

Marijuana is not good for you. It's an axiom. But for some people, marijuana could be the difference between life and death. That's what they and their doctors say. The doctors prescribe it and the patients smoke it to live. There are among only 14 people in the United States who have had it prescribed by their doctors. For Ken and Barbara Jenks, marijuana is but one more of the myriad of prescription drugs they must take every day.

I asked them how often do you smoke marijuana? "We usually smoke - well, I usually smoke at least three to four joints a day." And what would happen to you physically, both of you, if you went for a couple of days without smoking marijuana? I asked. "We'd throw up all the time." said Ken, "I would get sick to my stomach, I mean, I can't face eating food - and if you don't eat you get sick, and then you can't take your medicine, its a constant battle to maintain weight - and then I'd start losing weight again." "Having AIDS is like a wasting syndrome, with the virus and everything. The smell of food, just even thinking about food can make you feel nauseated." said Barbara.

Ken and Barbara Jenks are dying. He is a haemophilic. Eleven years ago, he was given blood contaminated by the AIDS virus. He unknowingly infected his wife. They are both too ill to work. They live on disability, barely able to cope. Without the marijuana, they would probably be dead, or they would have wasted away because of the nausea brought on by their chemotherapy. Before they got marijuana legally, they bought it on the street, or grew it, until last year, when police burst into their home in Panama City, Florida, and got the goods on them: two marijuana plants. "And then they started going through my house, I mean, just dumping drawers and tearing the cabinets up." said Barbara.

The police thought they were onto something big when they found a suitcase filled with syringes and other drug paraphernalia. Ken tried to convince them that the syringes and the pills were prescribed by doctors. He didn't tell them that marijuana was the only medicine that enabled them to take the chemotherapy without being violently ill. "You're talking to somebody that never wanted to take an aspirin for a headache. It's a relief to know that there's something that you can take to relieve the nausea from all the medications that you're on," says Barbara. The Jenks were charged with growing marijuana and possession of drug paraphernalia. In court, their lawyer, John Daniel, tried to prove that for the Jenks, marijuana was a medical necessity.

asked. "None whatsoever, in fact, they even stipulated that in Kenny and Barbara's case it was beneficial for them and that they would die without it," said John Daniel. "But you lost the case because you couldn't prove medical necessity, that doesn't fit somehow?"

"The Judge said there is no such doctrine as medical necessity in Florida, that it's a matter for the legislature to promulgate a statute that says that it is or is not." But the judge was not an unsympathetic judge? "He was a super judge. The sweetest sentence I've had in 20 years of criminal defence work." The judge found them guilty, but sentenced them to 500 hours of community service. Their only task? To look after each other. As decent as the sentence was, the Jenks were outraged that they were still considered criminals. They decided to appeal.

"Kenny and Barbara said, 'Go for it. we're going to be gone soon. There's going to be people following in our footprints and in our pain and suffering, and there needs to be some law made one way or the other on it.' That's why they took it up on appeal". "Why? They're not exactly the wealthiest clients in the world." "No their not, but I'm not exactly charging them, sir."

The Drug Enforcement Agency classifies marijuana as a highly dangerous drug, in the same class as heroin and LSD. And the only way to get it legally is to face a bureaucratic jungle. Applications have to go through the DEA, the Food and Drugs Administration and the National Institute of Drug Abuse. If all approve, the legal marijuana, grown on a government farm in Mississippi, is sent to the patient's pharmacist, a month's supply of cigarettes at a time.

Only 14 people are now able to get marijuana legally from the government. It took Ken and Barbara Jenks almost nine months to get their first prescription. Many doctors are reluctant to make the effort, fearing that the ramifications of even applying for marijuana will affect their reputations. Three years ago, the DEA's administrative law judge, Francis Young, wrote of marijuana, "In light of the evidence, it would be unreasonable, arbitrary and capricious to stand between those sufferers and the benefits of this substance." But the DEA rejected its own judge's opinion and stands firm that doctors shall not prescribe marijuana.

Except, of course, for those few who are willing to go through the agonisingly long process of applying. Desperate patients say they would rather live by buying marijuana illegally than die by playing by the rules. Dr. Ivan Silverberg hears that all the time from his cancer patients in San Francisco. "I have yet to hear of a patient who can't find it. I have heard loud and clear from patients who resent having to go on the street when they're feeling sick, when they're