



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."

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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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