

The Birchgrove

THE BIRCHGROVE GROUP, P.O. BOX 9, ABERTILLERY, WALES NP3 1YD. TEL: 0345 697231

An open letter

Dear All.

Why after all these years am I still angry, I know that I am, but why? Surely after all these years of working within the voluntary self help system, of trying to offer support to those who like myself live with something society has forced us to deny. Why when I talk to certain people do I get the feeling I'm being patronised. Why after over 10 years of offering help and support do others treat me like an imbecile. Why when I answer the phone does a voice on the other end talk about the stigma, the isolation, the loneliness.

Who in society looks after those that seem to have been forgotten, I see millions of pounds going into work relating to a reason for existence, but why are there so many that can't even exist. Why do people have to deal with a bereavement process that is a lie. Denying a cause, because society will understand better if a presentable side of death is portrayed.

Why do agencies who, with their remits of help and support shit on those who firstly do not fit within the core group or will not tolerate those having to go cap-in-hand pleading for help. Help for what? Understanding of something society will not allow them to say. How can you live with something you are forced to continually deny. You need to except what's happening before you can begin to deal with the complications that come with it.

Why do I see month after month a conference on this and a seminar on that, and why do I feel every month that this is not aimed at me this is not related to the problem I'm experiencing at the moment. Why don't you target the people who really need to be educated, and that is the millions of JOE PUBLIC out there who will not allow me to live with my problem openly, honestly and how I want to live it.

All these why's and what I hear you say are the answers. Well the first is other haemophiliacs and society + HIV Groups thinks were being cared for by.

1. The Haemophilia Society
2. The Macfarlane Trust
3. The Haemophilia Centres
4. Somebody Else

Well let me tell you now. Non of the above offer what we have

needed for over ten years now and that is understanding.

Understanding of our unique and individual needs for acceptance; you see its not only gay men that have a problem with acceptance. We as haemophiliacs have had to deal with this 'acceptance' all our lives and until HIV we were making a good job of it. But when the going got tough during the early days of the Virus, what happened - the Haemophilia Society failed to recognise the emotional and peer support that was needed. The centre directors wanted us to all go away and die. The other members of the Haemophilia Society who were not affected by HIV did not want anything to do with us. We were and still are a piece of dirt that these people have step in and they need to get rid of it.

If the society or other agencies were doing their jobs properly then why was there a need to set up a Haemophilia HIV support group (Birchgrove). And the failure by a lot of people to really take an interest in what this group can offer, will remain as a deep felt anger by those who have struggled to offer what they can on a very limited budget. All you other National Support Networks, groups, agencies take note the whole of the National Birchgrove Group is run on a shoestring budget of only £10,000 a year, with no paid staff, and by positive haemophiliacs only.

It started with anger and yes, I'm still angry, but so many, many things and so many people and quite a few organisations have pissed me off in the past. I'm no longer sure where to channel that anger and as time goes by and the virus takes a hold I'm not

continued on page 2

In this newsletter, we have incorporated more of a local interest feeling with articles coming directly from those who matter, so I would suggest you just get on and read. As time goes on, this newsletter takes longer and longer to produce, we really need more contributions from you — the people it's aimed at.

We really need more of you to send in regional bits of information that will help us to create a publication that is written by you for you.

COMMENTARY

Due to illness and the problems that living long term with HIV brings, we at the National office have decided to try and combine the National newsletter with bits on regional events and topics. It has become clear that the workload needed for not only this publication, but of the local newsletters has become too much so we are trying to bring all aspects of Birchgrove into the one publication. As you will notice most of the regional material comes from Wales in this issue. With your help, the next one will be full of bits from around the country.

We would like to apologise to everyone for the change of date of the National Conference this was down to a double booking at the hotel and was out of our control. A booking form and conference outline is contained as an insert in this newsletter, so if you are interested then send in your booking forms soon.



You may be aware but over the last few months the Haemophilia Society has seen some changes and what worries me is the lack of input into the day to day running of the society from those people who are co-infected with HIV & HCV. It would seem that members of the Manor House Group have taken some form of control on the board of trustees and the minutes of these meetings make very interesting reading indeed. Birchgrove has started to offer support to those infected with HCV and are in the process of extending our remit to cover those infected with HCV only; this is already happening in Wales and we will be meeting soon to discuss the change of constitution to enable us to raise funding for our HCV work.

So if you would like to offer some support then get in-touch with us at the office.

And remember we have over ten years of experience in the self-help field and the infrastructure is already in place.

We would also like to extend an invitation to the Manor House Group to come along and maybe pick up some tips on what self-help is all about.

Recompense is fine, but the emotional support that is needed can only come from those people who care with a capital C, Birchgrove is full of such people.

Look forward to being inundated with local bits for the next Newsletter.

G Lewis

continued from front page

really sure if I really want to be angry anymore. But until we have in place a system of genuine support for the few HIV+ haemophiliacs left, I will continue to direct my anger at the people I believe are here to offer that help/understanding and kindness. My anger will continue to be aimed at those who turned their backs on us many years ago and my anger will be used to make a lasting difference to those who have to live with HIV 46 or Hep Z in the future. Because believe me, the viruses of today will be nothing compared to what could be around the corner. To the Haemophilia community I asked you to sit down and ask yourself 'What have I done to help someone with Haemophilia & HIV?' To the gay community, sit down and ask yourselves 'What do I know about The Birchgrove Group?'

To the Chairs of the Big Ones, NAT, UK Coalition, Body Positive, THT, when have you ever really shown an interest in what we as HIV+ haemophiliacs really need or want from your organisations. Let me tell you now, it not a phone call when you need the support of haemophiliacs who are HIV+ for a funding bid of yours and it's not a token gesture of space at a conference because it has been pointed out to you that the needs of not only HIV+ haemophiliacs but the need of heterosexual positive people are not being addressed.

To everyone who works within the field of HIV & AIDS, we as a group of 'positive' people are never going to have an other chance to implement the services we would like to see in place; we do not have any new members walking in through our doors; we do not have the anger and energy of those who are newly diagnosed; we only have the time of those who have been living with this virus for many years; we only have the memories of those who have sadly died; we only have the feeling of isolation not only as a group but as individuals. We sadly recognise that the nature of the group will change and the main remit will become bereavement. We only have a certain amount of time to offer what little we can. I plead with you to take the time to talk to us; to try and understand the needs of our group; to include us in your process of thoughts to offer us the financial stability that we require for the few years remaining. From rates of deaths forecasted, within the Haemophilia HIV community, it will give us possibly a life span of only another 5 years - bereavement will be the remit of the group.

And who will be able to honestly say we did as much as we possibly could to help. I will! Will you?

Gareth Lewis

Founder Member Birchgrove Wales and
National Birchgrove Group.

THE BIRTH OF BIRCHGROVE

By Mary Dykes

1986

The germ of an idea

Four far-sighted men approached their Centre Director to talk about their common needs. They knew their HIV status was going to be tough to live with. They had already witnessed the discrimination suffered by the first two men with haemophilia to die of HIV in Wales and wanted to end the isolation and secrecy. They knew that if they were infected, so to were many of their fellow haemophiliacs who had also had treatment during the risk years 1978-1984.

An immediate response was not possible but a bid had been made to The Welsh Office for funding to include Social Work support to the Centre.

1987

The Seed

In January 1987 I took up that Welsh Office funded post and returned to the clients I had got to know in 1974-7 before I'd left work to have a family. During that first year we met – sometimes only 2 or 3 of us to discuss how to proceed. We met in the evenings, out of the hospital setting and the only rule I had to follow was that this was their group, I was to be their facilitator/co-ordinator.

The concerns ranged widely. How to assist the lobbying of MPs to gain some recognition – this was before the ex-gratia payments. How to reach the other infected men, who we knew must exist but confidentiality meant we didn't know their identity. How to respond to AIDS jokes. How to deal with direct questioning about HIV status. How to live with uncertainty and constantly changing medical opinions.

The Centre wanted to assist but didn't want to break confidentiality. A letter was sent out from the embryonic group saying that they would like to contact fellow patients living with the virus. The letter included choices:

- (1) For their name and contact point to be given to the Group.
 - (2) For them to hear more, via the Social Worker.
 - (3) For no Group contact but Social Work support.
- or
- (4) For no contact at all.

Most people responded though many were wary and needed those four options and took slow steps toward the Group. However, the letter triggered informal discussions in the Waiting Room and soon people began to realise they were not alone.

THE SAPLING

By the end of 1987 we had arrived at our eponymous venue – the Birchgrove public house. We met monthly. We had speakers on occasions and funded ourselves with each placing one pound in the kitty to cover costs!

1988

The Tree Matures

Brought social events which included family members and a second Social Worker, who promised to help by particularly looking to the needs of wives and partners. The Group made moves to link in with the other organisations in Cardiff, such as the AIDS Helpline. In doing this it found a sympathetic and powerful advocate, who has since played a large part in the funding and Health Authority support for the work of The Group.

1989-92

The trees spreads its Branches

The Group in Cardiff grew to include most of the Welsh men infected by the virus.

Some meetings were arranged so that boys, together with their parents, could come along. From our modest first meetings we were now holding weekend conferences in London and inviting men along that were to become the focus of self help groups in their own areas.

I shall always remember the way people looked after each other whether it was helping someone settle into their room who had never stayed in a hotel or even visited London before or collecting meals for those who could not queue at the Carvery, to those who needed a shoulder to lean on, after a couple of drinks reduced defenses and made it possible to share their worst fears.

THE BIRCHGROVE

It was with some concerns that I left the job at the end of 1992. Each death caused Birchgrove ripples through The Group and when members felt down or unwell they hadn't always got the energy they needed to devote to The Group. However difficult and sad it could be to attend another funeral, most agreed the gains far outweighed the losses. With my departure, The Group became National. Two of those original four men became expert fund raisers, organisers, negotiators and leaders. Others are now discovering these skills.

It was a happy coincidence that the name chosen to preserve confidentiality should be the ancient Celtic symbol for 'leading the way'. Silver birch trees were planted because the moonlight would reflect on their white bark and illuminate the path ahead. The Woodland Project is a fitting memorial.

LETTERS TO THE EDITOR

Angry from Lancs

Dear Editor,

I received the Birchgrove Newsletter today, Saturday 11th October, and after reading it may I say I'm both appalled and truly disgusted, firstly the article on the front page – is bordering on soft porn and the bad language is not needed at all.

The piece about the childless couple wanting a baby I found that very upsetting and distressing. My late husband and I were also childless and after being widowed for the passed seven years and on my own without children, it really upset me. So what do you think it would be like for someone who is going through the same thing of wanting a baby – or more recently lost a loved one, it is enough to send them over the edge.

The piece on page 8 "A Summers Day" I found it a very powerful piece – but thought it should have been kept to the person's private thoughts because there was a lot of detail about sex in it that side of a relationship should be kept private there was too much intimate detail in it which I think should be private also and kept to themselves. What I find most offensive is the point he made about haemophiliacs' sex lives not being all that brilliant – I totally disagree with that point – and I know for a fact that if my late husband was still alive he would totally disagree with it as well for 13 years our sex life was wonderful 'thank you very much' despite his HIV.

I find the whole thing very distasteful and I'm sure I'm not the only one – I don't wish to stay on your mailing list so please don't send me anymore newsletters – Also do you consider haemophiliacs thick or what! There surely is no need to explain how to use a condom it is pure common sense, no one needs to explain the use to the general public so why haemophiliacs? The very fact of that article makes out that they have no common sense.

Please make a note I wish this letter to be put into the next newsletter

Yours Sincerely

C A Fielding (Mrs)

REPLY FROM THE EDITOR WITH NO COMMON SENSE

Dear Mrs Fielding,

Firstly I would like to thank you for taking the time to write to us here at the office.

It's so nice to have some feedback from our readership.

To try and answer some of your complaints, and by the way you were the only one to write complaining about this edition.

Firstly how can you say the article on the front page was verging onto soft porn, when you must have read the previous *THE BIRCHGROVE* edition that was dedicated to sex and found nothing wrong with that. Articles in our newsletter are from real people and are about true life situations that are written from the heart so we print with the honesty they deserve.

A summers day! I really think you need to read this again. This piece was written by someone who also had lost a loved one and it was about the pain of that loss. I admire the author for the courage in being honest about his feelings.

Your objection to the condom thing, our readership is not only haemophiliacs and a lot of teenage children of haemophiliacs read this newsletter, and I'm sorry to disappoint you but safer sex education goes on every day within the community you call *the general public*.

I'm glad that your sex life was so good with your late husband. But lots of haemophiliacs have problems with sex, due to painful joint deformities from consistent bleeds.

I'm sorry you will not see this newsletter and by sticking to your wishes of being removed from the mailing list. I wonder if I'm wasting my time again as I'm also a haemophiliac who is dying of AIDS.

Thank you

Gareth Lewis
Editor.

Blame the Furniture

Do you sleep with your head beneath a beam? If so, don't. It could give you migraine. And what if the beam is further along the ceiling, say above your stomach? It's bad. Ulcers. When you open the door of your living room to an angle of 90 degrees to the wall, can you see at least 80 per cent of the interior? Well, you should be able to. If not, re-hang it. And then there's the small matter of your front door. Coming down the stairs, is it facing you? It shouldn't. Place a large, rectangular mirror on the inside of the door so that you can see yourself descending.

Feng Shui and the art of furniture placement is doing a roaring trade in Britain. Long considered integral to architecture and interior design in the East, this ancient Chinese practice, which seeks to divert geological currents and geopathic stresses in the interests of harmony, is now being applied by builders to hotels, office blocks and housing.

In Hong Kong, where it is both a branch of natural philosophy and an adjunct to religion, no one would dream of renting a flat or buying a house before it had been surveyed by a *Feng Shui* practitioner. Everything from the direction in which the house faces – preferably with its front door facing south – to the positioning of beds and sofas, even the colour of the kitchen ceiling, is regulated by a shaman of *Shui*, who has similar status to a financial consultant or hospital surgeon.

Here, ignorance is compounded by Western scepticism. It is difficult for a bank manager or an engineer to believe that the position of his child's desk (ideally facing away from the wall, with the door to one side and the window to the other) can mean the difference between a B and an A in a GCSE.

Arto ("just call me Arto") a 58-year-old of Armenian decent, acknowledged as one of the leading *Feng Shui* specialists in this country, understands British reticence. At the same time, he sees great potential here and is engaged in lectures, workshops and correspondence courses – all aimed at spreading the word and creating a body of qualified practitioners.

He argues that the British, beneath their fabled reserve, remain a mystical people. In many parts of the country, he says, locals will not build on a plot unless sheep are willing to graze on it, believing that bad currents from deep beneath the earth's surface can be picked up by the animals. He also points to a persistent belief in ghosts.

Arto, a Buddhist lama, who first came to England in 1958 and has also lived in Spain, India and Tibet, does not promote *Feng Shui* as a branch of the supernatural, simply as a means of affecting interaction between the physical and non-physical worlds, both of which are governed by elementary laws.

"Chinese *Feng Shui* is very superstitious." He says. "The Chinese won't live in a house with a four in the number, because the Chinese character for '4' is the same as for death. But it doesn't have to be that way. I prefer to regard it as a kind of acupuncture for the environment – diverting physical energies in the way that acupuncture diverts bodily energies. It is not always suitable. You need to know what *Feng Shui* can do and what it can't do.

"Problems can be karmic in nature, or they can just be unfixable. I told one Indian shopkeeper in Crawley recently that all he could do, if he wanted to make money, was to sell up his shop and get out. Everything was wrong and he would have bankrupted himself trying to put it right.

"It can be the same with ghosts. In one house I went to, I refused to exorcise the ghost of a dead child because her twin, now elderly, was still alive and living in Australia and could have been harmed by the exorcism."

After 42 years as a Buddhist, and so reverential of life that he will not even display cut flowers, Arto takes *Feng Shui* seriously. He wants people to believe in his arcane art and to be guided by its precepts to a more fulfilled existence.

The signs are that he is making inroads. Builders call him in to advise on hotels, office blocks and domestic housing. Home-buyers make appointments to have intended purchases checked out. Existing owners seek his help in making their dwellings more responsive to what are perceived as the earth's natural energies.

It takes him a day to survey an average home but a hotel might take several. It may make no obvious sense to those who believe only in the here and now. Arto, for his part, only smiles. As a man who believes he may be reincarnated as a thousand grains of pollen blown across a hundred gardens; the 'here and now' is here today and gone tomorrow.

FURTHER INFORMATION

For details of consultants, talks and short courses, contact

Feng Shui Network International, P.O. Box 2133
London W1A 1RL