

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

NAM UPDATE

In many cases, the effects of anti-HIV drugs decrease over time. At some point you and your doctor may decide that your current treatment is failing and that it is time to switch to other drugs. Different people may choose different definitions of treatment failure:

- Some people decide to try to suppress their viral load to below the *limit of detection* of current tests. If their viral load has not been suppressed this far after a few months of therapy – or if it increases again after initially being suppressed below detection – they may decide that their treatment is failing.
- Others are content with suppressing their viral load to low but detectable levels. They may not consider that their treatment is failing unless their viral load increases above a specific level.
- Others may decide to try to keep their CD4 count sufficiently high to protect them against major opportunistic infections, and may only change therapy if their CD4 count falls too low.
- Most people would agree that their treatment is failing if they develop new or recurring HIV-related symptoms or opportunistic conditions.

Possible causes

In many cases, treatment fails after HIV develops resistance to one or more of the drugs. Resistance is less likely to occur if you change more than one drug at a time whenever you modify your regimen. For example, the benefits of a protease inhibitor are likely to last longer if you change one or two other drugs at the same time.

HIV that develops resistance to a specific drug that you are taking may also be less susceptible (or 'cross-resistant') to related drugs. For example, HIV that has developed resistance to one protease inhibitor may be less susceptible to other protease inhibitors. It is possible to become infected with HIV that is already resistant to one or more drugs.

Your current therapy may not work adequately if you are not absorbing enough of each dose of the drugs in your gut, or if your body is breaking down and excreting the drugs very quickly.

HIV may also be more likely to develop resistance to a drug if its level in the blood is too low.

Problems with compliance, such as missing doses or taking lower doses than prescribed, may also result in inadequate blood levels of drugs.

What to do

The best response to treatment failure will depend on the reason why your current regimen is failing.

If you are having problems with compliance or side-effects, it is essential to discuss them with your doctor

immediately and see whether you can switch to a more convenient regimen. If you regularly fail to take your medication correctly, you may simply increase your risk of developing drug-resistant HIV strains. This may shorten the duration of benefit from your current regimen, and limit your future treatment options too.

Some clinics may offer blood tests to measure whether you are getting high enough drug levels. If you are not, despite taking your drugs in the recommended way, it may be necessary to increase the doses or try other ways of improving drug levels. For example, you might be able to take a combination of drugs which interact and boost levels of one or more of them.

If it seems likely that you have developed resistance to some or all of your current drugs, the best course may be to switch to new drugs. It is important to consider which other drugs your HIV may be cross-resistant to, and to aim to choose a new combination consisting of at least two drugs which your HIV is still likely to be susceptible to.

Some doctors recommend switching to a new regimen as soon as your current therapy seems to be failing, because the longer you stay on drugs to which HIV is becoming resistant, the greater the risk of developing cross-resistance to other drugs. However, you may run the risk of working through the available drugs too quickly.

Tuberculosis (TB)

Tuberculosis (TB) is illness caused by a bacterium called *Mycobacterium tuberculosis* (M.Tb).

It can be transmitted when someone with lung TB coughs, expelling the bacteria. People infected with M.Tb were usually exposed during childhood, although people can become infected at any time of life. M.Tb sometimes causes illness soon after the initial exposure – this is called primary TB – but usually a healthy immune system can prevent M.Tb from causing disease. However, the organisms remain in the lungs and in some cases may cause disease years later – this is called reactivation TB.

People with HIV are at greater risk of developing primary TB when first exposed to the bacteria, and the weakening of the immune system makes them much more likely to develop reactivation TB.

TB most often affects the lungs, causing symptoms such as shortness of breath, cough, weight loss, weakness and fever. The bacteria may spread to other parts of the body, causing many different symptoms. TB is a potentially life-threatening condition.

Active TB can cause a large increase in HIV viral

A Place of rest in Bodmin

The Bethany Trust in Bodmin, Cornwall provides respite care. It was launched thanks to the sisters of the Convent of Mercy in Bodmin who in 1986 received a call from a man living with Aids who requested a break at the convent. The caller was the first of several people living with the virus to stay in the next two years.

The Bethany opened in 1990 and is independent from the convent although located in its grounds. It is intended to provide a place of respite which can cater for the emotional, spiritual and physical needs of people with HIV/Aids. It is situated on the outskirts of the former county town of Bodmin, within easy reach of the rugged granite moorland, picturesque coves, creeks and beaches of the south coast and the wilder beauty of the north coast. The Bethany itself is surrounded by its own private, well-maintained gardens.

Guests arriving by train can be met from the nearby railway station and taken to Bethany by a worker or one of the many volunteers. It is worth checking what alternative routes and modes of transport access the project

Upon arrival guests are made to feel very welcome, offered refreshments and given the grand tour of the building and shown their room. There are single, double and family rooms which are well furnished and comfortable, each with a TV and en-suite shower/bathroom.

There is a large dining room and lounge which is pleasantly furnished with a welcoming, open fireplace.

The few rules include a ban on recreational drugs and smoking is only permitted in the conservatory.

Staff are on duty 24 hours a day if needed. Bethany does not offer nursing care but has the support of a local health centre which can help with the temporary prescribing of medicines or medical care.

Complementary therapies are offered including reflexology and massage and there are plans to introduce stress reduction therapies which people can continue when they return home such as art therapies, music therapies, movement therapies and meditation.

The Bethany will be expanding its service provision by combining the holistic disciplines of respite care with an equally holistic approach to rehabilitation. This development will be needs-led and its nature will be determined through consultation with those who are living

with the virus and with those who are caring for people affected by HIV and AIDS.

There are structured meal times (except breakfast) and the cook will accommodate vegetarian or cultural dietary requirements, as well as restricted diets due to medication and those who have to eat at other times for medication compliance. The kitchen is accessible 24 hours a day and there is always a fridge full of goodies.

My visit to the Bethany coincided with starting combination therapy including saquinavir and I was impressed to find a supply of grapefruit juice in the fridge. What is more, I received two morning calls, to remind me to take my ddC and another an hour later to wake me again to attend breakfast and take my saquinavir

Your stay at Bethany can be restful; if you wish, you can go sightseeing. Volunteers are happy to take guests by car or minibus to local places of interest such as Bodmin Prison, Tintagel, St Ives, Bodmin Moor and The Jamaica Inn made famous in Daphne Du Maurier's novel of the same name.

For those with the health, energy and motivation there are a couple of pleasant pubs and restaurants in the town, but if clubbing is your thing you might end up travelling a long distance. Horse riding is available from a local riding stables and it is suitable for experts and novices alike.

One of the great things about Bethany is that there is the possibility to either be incredibly quiet and find a space to relax or you can socialise with the other guests. You will find the staff friendly, the food great and the building clean and homely. For a well earned rest, a safe place to unwind or a place to recover from illness, the Bethany is worth a visit.

Funding for your stay can be provided by your local social services department depending on the local eligibility criteria. Funding may also be obtained from various charities including your hospital charity if they have one. Referrals need to be made by your consultant or social worker.

Bethany

St Mary's Road,

Bodmin,

Cornwall

PL31 INF

Tel: 01208 - 9035 Fax: 01208 - 75179

BLEEDING KNEE

By H Lewis

Morning fellow bleeders, Day Four aye, I have lost count of how many Day Fours I have shared a bed with over the years. So I decided to invite my computer along to spend the day with us. Seemed a bit strange at first, the computer just sat there looking at me willing me to turn it ON. I stubbornly ignored it with my face in a good book, my knee comfortable straddled over a pillow with the quilt pulled up to my chin.

Due to my short span of attention after only one chapter of my book I soon became restless and my attention turned to the playmate I had invited to my bedroom earlier. After finding the right buttons to press the computer came to life with a loud THAANG sound, within a few minutes of foreplay on the keyboard I had worked out how to keep it happy! All I had to do was keep writing on its screen and it just sat there happy as a sand boy. Finding myself happy in this unfamiliar role I decided to try and write down how I feel during a typical knee bleed from Day One onwards.

Day One

The first day started like any other day, got up had finished the three S's (shower, shave and shredded wheat) but on my second trip down the stairs I twisted my knee due to a faulty handrail coming away from its fixing on the wall. The pain from bending my knee past its normal range of movement lasted a while but once it settled down I tried to get mobile again, it did not seem so bad at first and decided to plod on.

Two hours into the morning the first signs started. No swelling yet just an all too familiar feeling that something was going on in the knee department and wishing I had given myself a injection when it had first happened in the morning.

There was nothing left to do now except get to bed and try to make myself as comfortable as possible by controlling the pain with medication when needed which is rather a lot at first due to the fact that I get a bit of a grumpy so and so, when I'm in pain.

Day Two

As dawn breaks over the houses across the road Day Two begins, the swelling had reached its peak and the medication was numbing the pain to a degree. I had spent a sleepless night with it but the signs were good that the worse of the bleeding was over, so I set to the task of mixing my injection deciding the same dose as yesterday should be enough to keep the bleeding under control.

Day Two drags by slowly broken only by the ever cheery face of my wife popping her head round the bedroom door with questions like, are you comfortable? Can I get you anything? Do you need something for the pain? And do you need a wee? I try not to eat too much as getting to our downstairs toilet from the bedroom is a task I try to avoid for as long as possible.

By late evening base camp has moved to the downstairs settee, more convenient for the toilet, as bedtime nears everything I might need through the night are brought close to hand (reading matter, drinks, drugs, fags and the remote for the television.)

The second night passes in much the same way as the first except the pain is a little better, this confirms to me that the bleeding is under control for the time being. After giving my injection and setting a challenge to lengthen the time between painkillers I set off on Day Three.

Day Three

I decide to give the knee one more day of complete rest and the day is spent being waited on by whoever is in the house at the time; try to get my nose stuck into a good book while every one carries on with the day to day running of the house. The day passes quickly with a few visits from some family and friends. Night time draws closer and as the pain has eased considerably, I am hopeful of getting a few hours of sleep. It's Sunday morning now and I had a fair nights sleep.

Day Four

My wife is up early and gets my injections ready from the fridge. The pain is bearable now without too many painkillers. I decide with the cover of the factor V111 to try and get some movement back into the knee joint, the first thing I do is some gentle massaging around the effected area followed by trying to flex the joint slowly. This turns out to be quite painful so I restrict my self to gently contracting the thigh and calf muscles every 30 mins. I carry on with this throughout the day concentrating on trying to get the joint as straight as possible.

Any exercise at this stage of a bleed should be done with extreme caution as the risk of re-bleeding is very high, little but often I find is the best way, let your body be the best judge if movement becomes more restricted and the pain increases STOP and rest, there's always tomorrow. Every thing seems to be going well, no adverse reaction from the exercise, so I finish the evening trying to get the knee as straight as possible, ready to try some weight bearing the

continued from page 8

next day. It's time to try and get some sleep so I settle down with a good book.

Day Five

Everything in the knee department seems the same as the night before so after giving my injection I work the knee into the straight position ready to try and walk on it. This is always a very nervous time for me and I spend quite a long time just standing there making sure that the knee feels ready to take these first few steps. I take this stage very carefully and if the signs change stop and get back on the bed. The trip to the hospital and back went very well but by the time we return home I am glad to get back on the bed and give the joint and myself a well earned rest so I go back to my feet up phone answering duties, looking forward to treating myself with a nice hot bath before I retire to bed for the night.

Day Six

Prof Bloom always got in a paddy if he ever found out that I had taken a hot bath while having a bleed, something to do with hot water bringing blood to the surface of the skin, I think! The only thing is my knee always felt better after having one, so I had one and went to bed. Day 6 arrives and the knee has got no worse as I mix my daily injection. I think of the days ahead. I call this stage of a bleed the Playdo Period, have you ever played with clay on a potters wheel? Well, the knee feels like that at this stage.

The playdo period can last many days, even weeks in the case of weight bearing joints. It's a case of getting the balance right, too much exercise and you risk starting the bleed off again or not enough and you prolong the time it takes for you to get the knee back to the full range of movement you had before the bleed commenced. So listen to your body and read the signs if they are good proceed. If they are not then rest. I find hydrotherapy the best way of exercising the joint during the playdo period. You can't beat walking up and down a swimming pool with a pair or one flipper on your feet. Well it's thirteen days now since the start of this bleed and I'm just about coming to the end of the playdo stage the knee has held up well to the daily muscle building and mobility exercising, a few more days should see me back to the full movement the knee had before the bleed interrupted myself and my families normal life style. Time to get back into the swing of things and try to return some of the help and encouragement I received from all my family and friends over the past few weeks.

Co-Infection HIV & HCV

People who were infected with HIV through contaminated blood products are very likely to have also been infected with hepatitis B virus (HBV) and/or hepatitis C virus (HCV). Most people who were infected with HIV through injecting drug use are also co-infected with HBV and HCV. There is no convincing evidence that co-infection with HBV or HCV affects the rate of HIV disease progression at least during the first decade after infection.

However, in a proportion of infected people, HBV or HCV can cause chronic (long-term) infection, which may result in liver damage. HCV may also infect cells elsewhere in the body, such as in the lymphoid tissue. There is some evidence that HIV-positive people who also have HCV are more likely to suffer liver damage than HIV negative people with HCV. Among those who do develop liver damage, it can have a significant impact on their HIV treatment options.

The liver helps to filter foreign substances including some drugs out of the blood. If the liver has been severely damaged by chronic hepatitis virus infection, it may be less efficient at filtering the blood. This may allow drugs to reach higher levels for longer, increasing the risk of toxicities.

Liver damage may show up in the form of unusually high levels of liver enzymes in the blood, although some people with HCV-related liver disease may not show any signs of abnormalities in these blood tests. Viral load tests for HBV and HCV have also been developed, although these are not yet widely used, and their usefulness remains unclear.

The clearest way to detect liver damage is to examine a sample of liver tissue, taken using a needle through the skin.

Treatment with certain anti-HIV drugs may not be recommended for people with high liver enzyme levels. For example, protease inhibitors may worsen the liver damage. In a Canadian study of the combination of ritonavir and saquinavir, HIV-positive people who were co-infected with HBV or HCV were more likely to suffer liver toxicity, and a quarter of co-infected people have had to stop treatment because of it.

Dr Ray Brettell of Edinburgh's City Hospital treats a large group of injecting drugs users who are co-infected with HIV and hepatitis viruses. "I have never withheld anti-HIV treatment from a patient because of their liver disease," he told us. "My approach is to offer treatment to people who need it and then monitor their liver enzymes carefully. People taking nucleoside analogues alone hardly ever have problems, but since we've started to use protease inhibitors we've had to stop therapy in quite a few cases, and try to restart it later when the liver settles down."

Continued on Back Page

by Johnny Pompous

How are things down at your local Haemophilia Centre? Are you satisfied that you're getting the best available treatment for your HIV and/or your Hepatitis C related problems? Are you happy with the information provided on CD4 Cell counts? Liver function tests? Viral loads? You have been offered a viral load test, haven't you? And drugs – I assume that all the various types of drug, from nucleoside analogues to NNRTIs, from PCP prophylactics to protease inhibitors, have been explained and offered to you? Yes? Very good, but is this actually the case for HIV+ haemophiliacs?

Whilst I'm sure – or at least I hope – that some centres are providing a good service to their 'clients', there does seem to be, at best, a lackadaisical attitude, at worst, an almost complete ignorance of the latest developments in HIV treatment and care, among a number of Haemophilia Centres up and down the country.

In this new post-modern *fin de siecle* NHS of ours, we are of course, no longer 'patients' but clients or consumers of health services and as such, perhaps we should apply a consumerism approach to our health care. After all, like it or not, you are paying for it. It may be that you are still well enough to be in paid employment and therefore you feel that you have more of a right to proselytise on the health service and other political matters than those of us no longer able to work. You may think to yourself "Just who the hell does this pompous fellow think he is? He doesn't work, he just sponges off the state with his DLA and Incapacity Benefit and Mac Trust payments, so he should just keep his mouth shut and take whatever treatment that kind Mr Blair offers him."

Yes but – counters Mr Pompous – every time I go out and 'consume' I am not only purchasing the visible goods I come home with – cigarettes, petrol, alcohol, electrical goods, cinema, theatre and concert tickets, CDs and tapes, cars, mobile phones, legal and financial services, meals in restaurants and such luxury items as water and heating – but I am also contributing (that is to say, purchasing a stake in) through VAT and other forms of indirect taxation, to the NHS. And I wouldn't want it any other way, but, given that Hospital Trusts want to treat me like a consumer, I don't see why I shouldn't act like one. So, if I'm not happy with the service provided, then I have a legitimate cause for complaint.

Which brings me back to where I came in – the quality of service offered by Haemophilia

Centres to their HIV+ patients, oops, I mean 'clients'.

A case history: Client – "Doctor, when do you think you'll start offering Viral Load testing?"

Doctor Blood – "What's that then?"

Client – "It's a test developed to ascertain the amount of viral activity in the blood. Been around for a while now, apparently. Supposed to be a more accurate indicator of disease progression than just a CD4 count."

Doctor – "Yes, I think I've heard of it. Still, no need to worry yourself about that. We'll take good care of you."

Client – "But Dr Blood, some friends who go to the G.U.M. clinic are already being offered the test. Why can't I have it?"

Doctor – "Oh you don't want to be listening to those people. You're a haemophiliac, not like them."

Client – "You mean we're still dying?"

Doctor – "We're doing everything we can, trust me."

And other variations along the lines of "It hasn't been proven to be of any use yet." "Your read about that on the Internet, did you? Must get a computer myself, one of these days." Or, "Stick with your seprin, son, it'll do you a power of good."

Well, Mr Pompous says, it's not good enough! If you want me as your client, then at least offer me a service as good as that available at G.U. clinics.

Don't fob me off with a six monthly gawk at my tongue and a quick grope under my armpits – talk to me about combination therapy. About what a viral load test result means for my future health and when and what drugs I should take to stay relatively healthy. Discuss with me – don't dictate to me – what my options are and whether I need to make any changes in my lifestyle; should I drink less, smoke more, eat less spicy food, have more sex, develop an interest in outdoor pursuits, take up trainspotting, do more or less or any volunteer work for Birchgrove, travel to Tibet, meditate, start pumping iron, cultivate more esoteric sexual habits, campaign for the legislation of crack cocaine or admit that the game is up and lie down and die.

Monitor my health, let me know how I'm doing. Advise me on which drugs might best suit me; let me know their side-effects and how you

continued from page 10

might counter them. If I'm seriously ill or the immediate prognosis doesn't look too good, tell me. Don't treat me like a child by assuming that I can't take the bad news – I can. Do ask about my partner, my family, my friends. Do be human. And if I decide to experiment with alternative therapies such as aromatherapy, acupuncture or amaroli, don't start taking the piss, but encourage me or at least support my efforts to take control of my health.

Outrageous, you say? Can't be done? You're already getting the best care money can provide. Pull the other one, says Pompous. There are, I'm sure, some centres that do provide a good level of service such as I've described, but I'm just as sure that there are many haemophiliacs up and down the country whose quality of service leaves much to be desired.

It's not my intention to condemn Haemophilia Centres out of hand, but rather to give the slackers among them a good kick up the rear. If they don't start shaping up, you'll begin to see a haemorrhage of patients to G.U. clinics, if it hasn't already started happening! Or maybe I'm missing the point; maybe the more mediocre centres have developed a cunning plot to offload us pesky AIDS infected Haemos on to the G.U. clinics. If this is the case, at least have the honesty to tell us. Then we can get on with our lives and you can get on with whatever it is you're supposed to be doing. Oh yes, providing health care to haemophiliacs. All haemophiliacs.

So just remember, if you're not getting the level of service you expect, complain, nag, threaten, blackmail, demand. Whatever. Alternatively, write to me and let me know. I might even start mentioning Centres by name. Thanks for your time and keep getting yours.

Johmy Pompous.

DISCLAIMER

The views expressed in each of the articles are those of the individual authors, and not necessarily those of the Birchgrove Group.

"THEBIRCHGROVE" is published by: Birchgrove Group,

P.O. Box 9, Abertillery

Gwent NP3 1YD.

Tel: (0345) 697231 (Helpline)

(01222) 387960 (Admin.)

Editor, Gareth Lewis

NAM UPDATE

continued from page 6

load, which usually decreases again once the TB is properly treated.

Preventing TB

For HIV-negative people there is a live vaccine against TB known as the BCG vaccine, although its effectiveness appears to vary in different populations. It should not be given to people with HIV, in whom it may cause a disease similar to TB.

It is important to avoid contact with people who have active lung TB until they are non-infectious. If you are exposed to someone with TB, see your doctor as soon as possible. If you are HIV-positive and have already been exposed to TB and are latently infected, some doctors recommend a course of the drug isoniazid. This has been shown to reduce the risk that you will develop active tuberculosis.

Tests for TB

Doctors can use a skin test called a PPD test to see whether you have been exposed to M.Tb. A positive test result means that you have been exposed to the organisms, although they may not be active and causing disease. However, some people with HIV do not respond to skin tests such as the PPD test, because of immune damage. If you have had the BCG immunisation against M.Tb you may get a positive result with the PPD test even though you have not been exposed to M.Tb. Tests such as physical examinations, chest x-rays, testing phlegm, and (sometimes) examining the lung via a fibre-optic bronchoscope are needed to diagnose active lung TB. TB in other parts of the body may be found by testing samples of, for example, lymph node or liver tissue.

Treating TB

Active TB is treated with a combination of antibiotics. Successful treatment usually requires at least six months of therapy, without missing doses, and using drugs to which the organisms are susceptible. Like HIV, the TB organisms can develop resistance to treatment drugs, and some strains are resistant to several different drugs. These strains can cause very serious disease called multi-drug resistant tuberculosis (MDR-TB), and can be transmitted to others. MDR-TB can usually be treated successfully after identifying which drugs the organisms are still susceptible to. Protease inhibitors can interact with some TB treatment drugs, so alternative TB drugs may have to be used, or the protease inhibitor may have to be stopped until the TB treatment is completed. In developing countries, doctors often use a way of treatment known as DOTS – Directly Observed Therapy, Short-course. Volunteers or health-care workers are present every time a dose is due, to ensure none are missed and maximise its effects.

By Prof. De' Ath

Just when you think it is safe to go back in the water, along comes Professor De'Ath to take another one of us away. After several weeks of mental torment and worry, when I thought I had just about got my head together, another HIV positive haemophiliac dies and all my insecurities come rushing back. This year has been a total nightmare for me, with a funeral a month for the first quarter of the year. I had all the usual questions and worries stored up in my head: "Why me? Why not someone else? I'm a good father and husband so why not some other guy who beats his wife and treats his kids like shit? That's the sort of guy who deserves this, not me."

The grieving process is different for us all. I bottled up my feelings all through the summer and kidded myself everything was fine.

What with all the long days playing with the kids during the summer break, with them running here and there, so full of life, and then all the excitement and stress of a package holiday to Spain, I managed to keep my feelings stuffed away in the back of my mind.

September came, the kids went back to school and I found I had too much time on my hands, so much so that life seemed suddenly empty. So what did I do? Simple, I went off my head.

My self esteem and sense of well being was at an all time low. I turned my back on all the people that I knew could help me and wandered off to some place where I could be a miserable twat all own my own.

I didn't particularly want to talk to anyone and was a bit of an arsehole to those few people who were close to me. Then it happened, at a Birchgrove Wales Regional meeting in Crickhowell. The day passed well enough with plenty of work and discussions about the future of the group, but nothing about our individual feelings.

That evening we had an excellent meal and a few beers and all my feelings came pouring out, all the fears and worries, all the stuff I'd

kept bottled up inside for the previous six months.

I awoke the next morning with an aching head, but also with a sense that at last I'd told someone how I really felt.

The morning session, which was supposed to have been devoted to a business meeting, was thrown over instead to a talk on how we felt about each other and how we were all coping with the different stages of this disease.

After much discussion, it seemed that it was all pretty straightforward; after almost four years of dealing with other people's problems it was time to step back and deal with our own worries and anxieties. Birchgrove has been a lot of things to a lot of people, but the people who run this organisation are often forgotten. We are all positive people; I have no special counselling skills, but I find myself talking to other positive people, trying to help them cope and get on with there lives.

We at Birchgrove don't have all the answers, life is sometimes a struggle for us too, but we all have in common the simple fact of trying to live with this virus. If at times I need to go off on my own and not be around for Birchgrove or any one else for that matter, it's O.K.

It's taken me a long time to be all right with this situation, but I need to put my health and family first and for once, this I what I intend to do.

I can really understand what's being said here, as 1997 will go down as one of the worst years of my life too. I also started to wonder if it was all a dream and would I wake up and find I still had a life that was not related and controlled by HIV & AIDS.

In my case it was the love of my family and the friendship from Birchgrove members that pulled me back into reality, what ever that is. When living with Haemophilia, HIV/AIDS and Hepatitis C.

(Editor)

Question to a 12 yr old daughter of a father with haemophilia and HIV: Which do you think is worse — living with HIV or haemophilia?

Daughter: Well, both have their pros and cons. Haemophilia, is a pain in the neck because my Dad can't walk too fast when I go somewhere. He's got to sit down. Problems with his joints really get on my nerves, and he's like, "O.K., I'll treat tonight." And then the next morning, he wakes up, he didn't treat it, and his knee is about the size of this huge football. Then he won't be able to go anywhere with me. When I want to go to the shops or to my friend's, he tells me I have to ride my bike because he can't drive, because his ankle's sore, or whatever. That's a pain in the neck. If he's not going to pretreat, he'll get more infections. AIDS is annoying because I see that he has to worry about little infections and stuff. I see AIDS as more annoying than traumatic. I guess AIDS is worse, because I don't like annoying!